

**UNITED NATIONS
CONVENTION ON THE RIGHTS OF
PERSONS WITH DISABILITIES**

KEY ISSUES IN INDIA

Prepared by

DEOC

for

**National Centre for Promotion of
Employment for Disabled People (NCPEDP)**

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Introduction

About India

India, officially the **Republic of India**, is a country in South Asia. It is the seventh-largest country by geographical area, the second-most populous country, with over 1.2 billion people, and the most populous democracy in the world. India is one of the fastest-growing economies in the world. Economic growth rates are projected at around 7.5%-8% for the financial year 2011-2012¹.

India became an independent nation in 1947 after a struggle for independence which was marked by non-violent resistance and led by Mahatma Gandhi. On 26 January 1950, India became a republic and a new constitution came into effect under which India was established as a secular and a democratic State.

The uniqueness of India lies in its diversity. There are people of various regions, religions, socio-economic background, castes and tribes living in the country.

India is a federal union of states, comprising of 28 States and seven Union Territories (UTs). The States and UTs are further subdivided into districts and so on. As per Census 2011, there are 640 Districts, 5924 Sub-districts, 7,935 Towns and 6,40,867 Villages in India².

There are 22 different languages that have been recognised by the Constitution of India. Article 343(3) empowered Parliament to provide by law for the continued use of English for official purposes.

The Population of India

The census of the population is conducted every ten years in India. According to the provisional data available for the Census 2011, the total population of the country is about 1.2 billion, with 600 million men and 580 million women. The density of population is 382 persons per square kilometer. The sex ratio is dismal at 940 females per 1000 males. Percentage of the population in the age group 0-6 years to the total population is 13.12%. The literacy rate is 74.04%, with 82.14% men and 65.46% literate women.³

There are no authentic data on number of people with disabilities in the country. The Census 2011 data on disability has not been announced yet. According to Census 2001, 21 .9 million people have disability in the country, which is about 2.13% of the population. The Government of India has admitted that this is

¹ Accessed at http://en.wikipedia.org/wiki/Economy_of_India on 5th December, 2011.

² Accessed at <http://censusindia.gov.in/> on 5th December, 2011.

³ 'Provisional Population Totals: India: Census 2011', accessed at <http://censusindia.gov.in/2011-prov-results/indiaatglance.html> on 12th November 2011.

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hugely underestimated and that persons with disabilities constitute anywhere between 5 to 6% of our total population.⁴

The Government of India

The President of India is the Head of the State. The Prime Minister is the Head of the Government and runs office with the support of the Council of Ministers who form the Cabinet Ministry. The Indian Legislature comprises of the Lok Sabha (House of the People) and the Rajya Sabha (Council of States) forming both the Houses of the Parliament.

Every State has a Legislative Assembly. Certain States have an Upper House called State Legislative Council. There is a Governor for each State who is appointed by the President. The Governor is the Head of the State and the executive power of the State is vested in him. The Council of Ministers with the Chief Minister as its head, advises the Governor in the discharge of executive functions. The Council of the Ministers of a State is collectively responsible to the Legislative Assembly of the State.

The Constitution distributes legislative powers between Parliament and State legislatures as per the lists of entries in the Seventh Schedule to the Constitution. The residuary powers vest in the Parliament. The centrally administered territories are called Union Territories.

Elections in India

India has a federal Government, with elected officials at the federal (national), state and local levels. On a national level, the head of Government, the Prime Minister, is elected directly by the people, through a general election. All members of the federal legislature, the Parliament, are directly elected. Elections in India take place every five years by universal adult suffrage. Elections in India are conducted by the Election Commission of India, the authority created under the Constitution.

The Planning Process

The Planning Commission of India plans every five years, for various Schemes and Policies, which is termed as the Five Year Plan, for overall development of the people of India. There are also State plans and annual plans and budgets.

The Legal System

The Supreme Court of India is the apex body of the Indian legal system, followed by other High Courts and subordinate Courts. There is National Human Rights Commission and State Human Rights Commissions. There are also specific commissions for women, children, minorities etc. There is an Office of Chief Commissioner and State Commissioners for Disabilities.

⁴ Page 130, Chapter 6, Social Justice, Eleventh Five Year Plan.

Context of the Study

India ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) on 1st October, 2007. It has been over three years since the ratification. Article 35 (1) of the CRPD mandates State Parties to submit a comprehensive report to the Committee within two years after the entry into force of the Convention. It is almost a year past the deadline and India has still not submitted the Report. National Centre for Promotion of Employment for Disabled People (NCPEDP) has been trying to get information regarding the timelines and the process involved in the preparation of the report. No reliable answer was available.

NCPEDP was in dilemma whether to start the work on the Alternate/Parallel Report. After a lot of consideration and consultation, NCPEDP felt that it may be useful to undertake an evaluation exercise with respect to the rights mentioned in the CRPD. Hence, a simple Study, including a National Survey, was commissioned to assess the satisfaction level of persons with disabilities, the progress so far and the concerns vis-a-vis the implementation of various Articles of the CRPD in India. The purpose was mainly to highlight the key issues concerning persons with disabilities in India under each Article of the CRPD.

It is hoped that the Study would provide some background for India's Alternate/Parallel Report when it is prepared.

Objective of the Study

The objectives of the Study are the following:

- a) To measure and analyse the satisfaction level of persons with disabilities vis-a-vis the Government's efforts in implementing the rights mentioned in the CRPD;
- b) To compile information about laws/policies, progress and concerns about the implementation of various Articles of the CRPD; and
- c) To provide some broad recommendations for more effective implementation of the Articles of the CRPD.

Methodology of the Study

a) National Survey

For preparing the Survey tool, existing Questionnaires on evaluation of implementation of the CRPD were studied. The International Disability Alliance (IDA) Guidance document, 'Effective Use of International Human Rights Monitoring Mechanisms to Protect the Rights of Persons with Disabilities', was found to be very comprehensive and useful. However, keeping in mind the Indian context and diverse educational backgrounds, a fresh objective type Questionnaire was prepared so as to make it simple and easy to answer. The Questionnaire is given in Annexure 2. In Part A of the Questionnaire, the respondents were required to rate their satisfaction level on the implementation of various Articles of the CRPD on a scale of 1 to 4 (from extremely dissatisfied to extremely satisfied). In Part B of the Questionnaire, the respondents were

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given space to share experiences and concerns on various issues and was optional.

The next step was to prepare a list of select persons with disabilities and parents of persons with intellectual impairment. The Sample was well represented with respect to region, gender and disability. It consisted of persons who are generally seen as having a wider view of disability and the concerns of persons with disabilities.

The Sample comprised a total of 124 persons.

The contact details of all the participants were compiled. The Questionnaire was then sent to these 124 people via e-mail or courier or registered post. The following three options were given for the participants to fill the questionnaire:

- 1) Fill and submit the form online.
- 2) Fill the form in the word format attached with the e-mail and send a mail.
- 3) Fill the Questionnaire manually by taking a printout of the Questionnaire and courier it.

After an initial follow-up to ensure that everyone got the Questionnaire, a rigorous and continuous follow-up via e-mails and telephone was done to ensure maximum number of responses. The data was continuously compiled. Out of the 124 persons contacted, 87 persons responded to the Survey. The gender break-up of the respondents was 58 men and 29 women. The list of Respondents is given in Annexure 1.

The responses of the satisfaction level of persons with disabilities vis-à-vis the efforts of the Government in implementing the various Articles of the CRPD have been compiled and given under each Article of this document.

b) Qualitative and Secondary Data

In order to understand the scores given by persons with disabilities regarding their perception of the Government's efforts to implement the CRPD, qualitative data was collected from various sources. People with disabilities, parents, experts/professionals in the field were asked to share their experiences. Latest available Annual Reports of various Ministries of Government of India were studied. Newspaper articles, websites of NGOs, publications etc. were studied to understand the status of the progress made by the Government.

Structure of the Report

This report is an analyses of the progress made in India on each CRPD Article since its ratification in October 2007.

One Chapter is dedicated to each Article. However, certain Articles have been combined together. Articles 1 to 5 and 33 are interlinked and are applicable to all the Articles and hence, combined in this Report. Similarly, Articles 15 and 16 are dealt with in one chapter.

Some of the Articles (Article 34, Articles 36 to 48 and Article 50) are not meant

specifically for countries to implement and are more about the monitoring of the CRPD at an international level. These have not been covered in this Report.

Each Article contains various sections. First, the text of the CRPD Article is given. Next, the results of the survey on the CRPD, where a brief analysis of the ratings is given vis-a-vis the satisfaction level of Government's efforts to implement the Article. The next section contains an analysis of the existing disability laws with reference to the Article plus a mention of the other relevant laws and policies. The progress and concerns under each Article is discussed at length next; the initiatives taken by the Government; and the impact as may be evident from the data or from what persons with disabilities have to say about the right in the Article. Each Article concludes with a list of recommendations.

Limitations of the Study

The limitations of Part A (Survey) were as follows:

- a) India being a large country, the Sample size of 87 may be considered as small. However, all efforts were made to include persons representing various regions, rural areas, different disabilities and gender. Many people were leaders who represented larger sections of the society and gave their ratings on behalf of the community they were representing. The Sample was also limited because we were looking only at persons who had a larger perspective of disability in India and would have some awareness of the rights of persons with disabilities. However, even within the Sample also, there were a few people with disabilities who shared that they were not aware of the CRPD.
- b) Reaching rural areas where the language is not English was another limitation. However, an effort was made to reach many of them through organisations working in rural areas.
- c) Getting responses from persons with intellectual impairment was difficult. Some persons with intellectual impairment regretted that they were not able to understand the questions.
- d) The Questionnaire was lengthy as it had to cover all the relevant Articles of the CRPD.
- e) The Questionnaire was sent in the month of May, which was holiday season for many. As some participants were travelling, they regretted that they would not be able to participate in the Survey.
- f) The percentages of the respondents in the Survey Findings have been rounded off to the nearest whole numbers. As a result, some of the percentage figures may not add to 100.

The general limitations of the Study were the following:

- a) One major limitation of the Study was the lack of data and documentation - both qualitative and quantitative - regarding persons with disabilities.
- b) Due to limitation of time and resources, an in depth work in collecting information from various sources could not be done. The purpose was to put together the basic available data and highlight the major issues, which could form a baseline for further data collection when doing the Alternate/Parallel Report.

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- c) Only the latest available Annual Reports of the Ministries were studied. Hence, comparative analyses of the progress with respect to previous years could not be done.
- d) The Budgets of the various Ministries has not been analysed due to lack of time and resources.
- e) The amounts and figures in this document are in Indian Number System (in lakhs and crores). 1 lakh = 0.1 million and 1 crore = 10 million.

Articles 1-5 and 33: Purpose; Definition; General Principles; General Obligations; Equality and Non-discrimination of People with Disabilities; and National Implementation and Monitoring

Articles 1 to 5 and 33 are general Articles, which are also closely interlinked with each other and form the basis for all other Articles. Hence, these have been clubbed together in one chapter.

Survey Findings

The survey results for the above Articles are given below. Three questions were asked. The first was on achieving the objectives of the CRPD, the next on impact on the lives of persons with disabilities and the last, on the involvement of persons with disabilities in implementing the CRPD.

1. The findings of the survey with respect to the efforts made by the Government to **achieve the purpose and the objectives** of the CRPD are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	46%
Dissatisfied	44%
Satisfied	10%
Extremely satisfied	0%
Do not know much about the issue	0%

2. The findings with respect to the **impact on the lives of persons with disabilities** with India's ratification of the CRPD are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	41%
Dissatisfied	46%
Satisfied	11%
Extremely satisfied	1%
Do not know much about the issue	0%

3. The findings with respect to the **involvement of persons with disabilities in the implementation and monitoring** of the CRPD are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	45%
Dissatisfied	37%
Satisfied	18%
Extremely satisfied	0%
Do not know much about the issue	0%

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There are a few respondents (10% to 18%) who have expressed satisfaction with respect to Government's effort to implement the CRPD. India's ratification of CRPD was a significant milestone. The Government agreeing to the sector's demand to draft a new disability law was another major step forward. The involvement of leaders with disabilities in drafting the new law is also being seen as a positive change, even though they had to fight to get included in the drafting committee. However, an overwhelmingly large majority (82% to 90%) of the respondents have expressed dissatisfaction, indicating clearly that the above steps taken by the Government are being perceived as not enough. It has been four years since the ratification of the CRPD and there has been no progress at all on the implementation front. There is NO change at the ground level brought about by the CRPD. The involvement of persons with disabilities in drafting the new law is also being seen as nothing more than tokenism, for their opinions were not seriously heard.

Some of the responses received from the respondents of the CRPD Survey

"Four years after it ratified the CRPD, the Government of India has failed to enact requisite legislation to bring domestic laws in harmony with international legal obligations. This is tantamount to a clear violation of international law and therefore ought to be a matter of concern for any accountable Government. Small wonder that, in the absence of a suitable law, every single commitment to millions of disabled people in India under the Convention remains unfulfilled. It is hence that I have unhesitatingly (not blindly) ticked option one in almost every single question, much to my own agony, shame and embarrassment.

My negative responses should not be construed as an attempt to ignore any advances made in the provision of public facilities. On the contrary, such advances are ad hoc, representing exemptions to the rule of patent absence of legal guarantees."

-Dr. Garimella Subramaniam

"Whatever little progress has been made on the CRPD front is due to civil society initiative, not the State's."

- Vaishnavi Jayakumar

"While Government has taken some initiative to form a committee to draft the new disability law in line with the CRPD, beyond that nothing much has happened.'

-Dr. Meenu Bhambhani

"The issues of persons with disabilities and the Office of the Commissioner Disabilities (Centre/State) continue to be under the Ministry of Social Justice and Empowerment. The Ministry has not made any significant change in their policies, programmes and practices since the ratification of the CRPD."

-Praveen Kumar

"Ratification of CRPD by India has not made any significant change till date in the lives of persons with disabilities. Therefore all my ratings for the different questions have been rated as 1 - Extremely dissatisfied."

-Mahesh C

"Is there a rating less than '1', say 'minus 1'?"

-Bhargavi Davar's query on phone, when she received the CRPD questionnaire.

Article 1: Purpose

The text of Article 1 in the CRPD is given below.

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

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.

Progress and Concerns

The Purpose of the CRPD is to promote, protect and ensure human rights of persons with disabilities. The terms '**promote**', '**protect**' and '**ensure**' have been explained below.

- Promote/Respect: States through their actions have to support the upholding of rights and to should not interfere with the exercise and enjoyment of the rights of persons with disabilities.
- Protect: States have to protect people with disabilities against discrimination/abuses by non State actors (individuals and private organisations/enterprise).
- Ensure/Fulfil: States to pro-actively facilitate, promote and provide to ensure progressive realisation of the rights of persons with disabilities.

The following sections analyse the overall current status with respect to India's effort in promoting, protecting and fulfilling the human rights of persons with disabilities. A more in-depth analysis is given in subsequent chapters dealing with each Article.

1. Promoting/Respecting the Human Rights of Persons with Disabilities

Historically, disability was seen as a charity or a welfare issue in India. Rights of people with disabilities were not even considered. However, with the emergence of the cross disability rights movement in the country in early 90's, there was a demand for a rights-based legislation. In 1995 (almost 50 years since Indian Independence) that a legislation on rights of persons with disabilities, 'The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act', henceforth referred to as **The Disability Act, 1995**, was enacted. It was a significant milestone in promoting the rights of persons with disabilities in India.

The Act covers some of the rights, such as right to education, accessibility, non-discrimination, affirmative action etc. For Government employees with disabilities, there is some amount of reasonable accommodation (though not

mentioned by that term in the law) such as, relaxation in upper age limit for applying for jobs, transport allowance, non-handicapping environment in workplaces etc. There are also certain provisions in the law for affirmative action such as reservation in jobs, preferential allotment of land etc.

However, there are many other rights that have not been mentioned in the Act, such as right to life, integrity, liberty, justice, respect for home and family, equality before the law etc.

Even within the realm of socio-economic rights, there are several gaps. For instance, the law on accessibility covers the built environment and transport but not communication and information. 'Non-discrimination' has been mentioned, but it is not comprehensive and does not apply to all aspects of life of all persons with disabilities. It does not mention 'reasonable accommodation' which is crucial to promote equality of opportunity and non-discrimination. Moreover, most of the clauses have the phrase, "within the economic capacity and development", which makes the rights non absolute. Therefore, **the law does not cover all rights mentioned in CRPD.**

The law also does not cover all people with disabilities. For example, the law leaves out people with autism, learning difficulties etc. (This has been detailed in the subsequent section on 'Definitions'). Further, many of the provisions mentioned in the Act are applicable only to certain disabilities. For example, reservation in employment is applicable to only three out of the seven disabilities recognised in the legislation!

India also has three other laws on Disability - The National Trust Act, 1999 Mental Health Act, 1987 and Rehabilitation Council of India Act, 1992.

The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 henceforth referred to as **The National Trust Act, 1999**, mentions in its objectives a few aspects of CRPD, like enabling and empowering persons with disability to live as independently and as fully as possible within and as close to the community to which they belong; strengthening facilities to provide support to persons with disability to live within their own families; to deal with problems of persons with disability who do not have family support; to facilitate the realisation of equal opportunities, protection of right and full participation of persons with disability. **However, a large part of the Act is devoted to 'guardianship', which is contradictory to the CRPD, which mentions full legal capacity. Moreover, the Act does not cover all disabilities and all rights. It is not a rights-based legislation.**

The **Mental Health Act, 1987** mainly covers aspects of treatment, procedures for admission, residential detention, reception orders, etc. It is not a rights-based legalisation. It does have a small section entitled, "Protection of human rights of mentally ill persons". It mentions that "no mentally ill person shall be subjected during treatment to any indignity (whether physical or mental) or cruelty" and "no mentally ill person under treatment shall be used for purposes of research". It does not talk about right to liberty, integrity, privacy, equality, non-discrimination, participation and inclusion, freedom to make one's own choices, independence, respect for difference and acceptance as part of

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human diversity and humanity etc. and hence, many of these rights are violated for mentally ill persons quite blatantly. It also does not talk about any other way of rehabilitation, like community based, etc. **Moreover, the Act allows for involuntary detention, which is contrary to legal capacity of people with disabilities.**

The Rehabilitation Council of India Act (RCI), 1992, regulates and monitors services given to persons with disabilities. Its mandate is also to standardise syllabi and to maintain a Central Rehabilitation Register of all qualified professionals and personnel working in the field of Rehabilitation and Special Education. It looks into manpower training, which would have a direct effect on the quality of services available to persons with disabilities.

RCI runs training courses for regular school teachers on inclusion. However, it would take time to cover all school teachers across the country. In the meantime, unqualified teachers in schools who are teaching children with disabilities are doing a bit of 'special education', speech therapy, counselling and are playing multiple roles. Many rehabilitation services are being set up by family members or persons with disabilities themselves, who may not have prescribed qualifications. Employers are also doing trainings for persons with disabilities. The Act makes it mandatory for everyone who is providing rehabilitation services to people with disabilities to register with RCI or they will be 'imprisoned' and/or fined. This is **restricting the mainstreaming of persons with disability. The other limitation of the RCI Act is that it does not cater to all disabilities and it is not a rights based legislation.** In a country where there is an acute lack of professionals, this can be seen as a discouragement for people like volunteers, personal helpers, teachers, product designers, family members, friends, employers, social workers etc. to work with persons with disabilities.

Most courses in rehabilitation are based on the medical model of disability. The RCI has to work towards demystifying disability and to cater to the changing need for mainstreaming and inclusion.

Another very important milestone towards promoting the rights of persons with disabilities is the Ratification of the CRPD. This was a result of advocacy by the disability rights movement in the country. India had signed the acceptance on the very first day the CRPD was opened for signature on 30th March 2007 but did not ratify it. The Government took a position that it would amend the disability legislations first and then ratify it. National Centre for Promotion of Employment for Disabled People (NCPEDP) and Disabled Rights Group (DRG) protested very strongly against this decision of the Government. The debate was taken up at a national consultation organised by NCPEDP in July 2007. The argument for ratification was that in India the International Conventions add to the rights of the citizens and can be immediately enforced in Indian Courts without local legislations. This provided the much-needed clarity that the ratified Convention is a law and can be enforced even without amending the domestic laws. Hence, the conviction became stronger that the ratification should be done first. DRG then advocated very strongly in the campaign mode for the speedy ratification of the CRPD. **Finally, on 1st October 2007, India ratified the CRPD.**

The Indian Constitution and several other legislations provide various rights to citizens of India. **However, most of them do not explicitly mention human rights and non-discrimination of persons with disabilities.** While, some laws clearly exclude (example, people with 'unsound mind' or 'deaf and mute' people cannot stand for elections), some others treat people with disabilities as objects of charity requiring only welfare measures (example, they are treated like minors who may not be able to make decision for themselves). Examples of laws discriminating against persons with disabilities are given in the chapter on Article 5, 'Equality and Non-Discrimination'.

2. Protecting the Human Rights of Persons with Disabilities – Current Scenario

The Purpose of the CRPD is also to 'protect' all human rights of persons with disabilities. This essentially means that the State has to take all appropriate measures to eliminate discrimination on the basis of disability by any person, organisation or private enterprise, as per Article 4(e). The Government has not taken any specific measure to implement this Article.

The private sector, institutions and individuals are seldom governed by the disability laws in India. There are no laws to prevent discrimination against persons with disabilities in the private sector. The term 'reasonable accommodation' is almost non-existent. The redress mechanism set up by the Government is often seen only for public and Government Sector companies. The Government sometimes provides guidelines for the private sector. No real action is taken against those discriminating against persons with disabilities.

However, there have been some positive actions on the part of the State to promote equal opportunities in the private sector. For example, Clause 41 of The Disability Act, 1995, provides for **incentives to private sector** to promote employment opportunities for persons with disabilities. This is the only place in the Act where the private sector has been mentioned by name.

With regard to accessibility, the Ministry of Urban Development has included disability in the **Building Bylaws**, which has been adopted by a few States, but its implementation and monitoring has been very poor. Many commercial complexes, restaurants, even hospitals and schools blatantly violate this law.

The **Director General of Civil Aviation (DGCA) issued Guidelines for "Carriage by Air of Persons with Disability and/or Persons with Reduced Mobility"** on 1st May 2008. The Guidelines are applicable to private airlines also. It clearly states that no airlines should refuse carrying persons with disabilities, aids, assistive devices, guide dogs etc. It also states that airlines should provide necessary support to passengers with disabilities. It further details various aspects including availability of wheelchair, ambulift, sensitisation of staff, boarding, seating procedures, complaint procedure etc.

The **Ministry of Tourism came out with new Guidelines for classification of hotels**, which also include making all hotels disabled-friendly by September,

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2010. This not only includes 4 and 5 star hotels which were already accessible to an extent, but also 1, 2 and 3 star hotels⁵.

With increasing privatisation, the role of State to protect people with disabilities from discrimination by individuals and private organisations becomes very crucial. **There are several incidents of blatant discrimination by the non State actors**, which are given below in the box.

"I live in a reasonably good locality in Bengaluru. In the last two years or so, several new departmental stores, restaurants, nursing homes, dental clinics, bakeries and parlours have come up. None of these are accessible to persons with disabilities. Yes, certain big malls are accessible in Bengaluru. The places that we use on a daily basis remain terribly inaccessible. Who do we go and complain to?"

-Seetha Chari, a wheelchair user.

"A very famous Saloon in Delhi refused to do haircutting for my daughter with Autism.

-Shared by a parent of a person with disability.

"Auto rickshaw drivers generally refuse taking me, as I am on wheelchair. If they do, they want to charge double the amount."

-Person with disability

"Buses in our village are run by private operators. Firstly, they are not accessible and secondly, they refuse to take wheelchair in."

-Shared by a person with disability.

"I am a well qualified person and am doing extremely well in my academics. I cleared all the selection rounds for a job in a well known company, which had come to our campus for placements. I was not given the offer letter because of my disability. I have written several mails to them. They are not answering."

-Shared by a person with disability.

"When I go alone or with another blind friend to a good restaurant to dine, they generally assume that we do not have money and refuse entry and sometimes even make fun of us."

-Shared by a person with disability.

(These provide a glimpse into the daily experiences of individuals as shared with the authors of this document).

⁵ DNIS News Network, India, August 15, 2009, accessed at http://www.dnis.org/news.php?issue_id=5&volume_id=6&news_id=885&i=5 On September, 2011.

3. Fulfilling the Human Rights of Persons with Disabilities

Though the CRPD is a law in the country, it remains unimplemented. Even the very first step of setting up a **Focal Point for implementation and monitoring has not been done**. No concrete step has been taken by the Government to undertake any measures stated as 'General Obligations' in Article 4.

On the positive side, the **Indian Judiciary has started referring to the CRPD to provide favourable judgments to persons with disabilities**. For instance, the Supreme Court allowed a woman with intellectual impairment to continue with her pregnancy, taking into account her wishes, and thus, upheld personal autonomy and freedom of choice (Articles 3 and 23 of CRPD)⁶. Similarly, in another case, the Bombay High Court upheld the Government's obligation to provide assistive technologies as reasonable accommodation for employees with disabilities working with the Government (Articles 4 and 27 of CRPD)⁷.

Having a few rights already mentioned in the legislation (The Disability Act, 1995) has enabled some persons with disabilities to get some rights by approaching the Courts. Some progress has been made by the Government in implementing the rights mentioned in the Act. For example, for implementing the right to education, there is a focussed programme on inclusion in the Sarva Shiksha Abhiyan or Universalisation of Education. Similarly, some work on accessibility (though not to the desired extent) can be seen in metropolitan cities, like the metro rail. A few Government websites have been made accessible. A few places of historical/tourist importance have been made accessible. There are some affirmative programmes, such as 3% reservation in Government jobs and poverty alleviation schemes, which have resulted in securing livelihood for some people with disabilities.

When one sees these few positive changes in the perspective of the large country that India is, these steps seem few and far in-between. The gaps in fulfilment are many.

The **existing implementing authorities** and monitoring mechanisms of current domestic legislations are weak. The Ministry of Social Justice and Empowerment works for the welfare of many disadvantaged groups, disability being just one of them. The hierarchy of Central and State Commissioners Offices (in-charge of implementing The Disability Act) is such that they do not have the necessary power to implement it through coordination with various other Ministries. The mechanisms for penalties and redress are weak. There is no autonomous independent body with necessary powers to address complaints and violations.

⁶ Supreme Court, CA No. 5845 of 2009 with SLA No. 17985/2009 Suchita Srivastava & anr. V. Chandigarh Administration.

⁷ Bombay High Court Gadgets Matter; WP 3294 of 2010 Nileema Anant Surve V. State of Maharashtra & ors.

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Disability is a **cross-cutting** issue. Various concerned Ministries have a role to play to ensure the various rights of persons with disabilities. However, none of the Ministries have a specific disability policy or an action plan, even though the XI Five Year Plan (2007-11) had mandated it.

There is negligible **fund allocation**. There is an allocation of 3% budget for disability in all the relevant Ministries according to the XI Five Year Plan (2007-11). However, this has not been implemented. The fund allocation within the Ministry of Social Justice and Empowerment on disability too is negligible when one sees it in relation to the number of persons with disabilities in the country. Even though it has been over three years since the ratification of the CRPD, no budget allocation has been made to implement it in particular. Hence, many of the rights mentioned in the CRPD are just on paper. NGOs too are always struggling for funds due to minimum support from the Government. Though some NGOs and DPOs are working towards creating awareness regarding the CRPD, translating it in local languages; having conferences and debates on it; the funds for the same are largely coming from international organisations.

Over Rs. 136 crore wasted by MSJE's Disability Division in the financial year 2010-2011

The financial year 2010-2011 is over and here is the 'Report Card' of our beloved Ministry of Social Justice and Empowerment (MSJE). The total budget of MSJE (both, for Plan and Non-Plan Schemes) was Rs. 4574 crore. Out of this, Rs. 489 crore was the budget for the Disability Division as per Budget Estimates 2010-2011. Roughly, 10% to 11% only. If one analyses the Programmes and Schemes of the Disability Division, the following picture emerges:

All the usual suspects have done well.

1. National Institutes: Rs. 60 crore allocated; Rs 57.84 spent
2. National Handicapped Finance Development Corporation (NHFDCC): Rs.50 crore allocated; full Rs. 50 crore spent.
3. Rehabilitation Council of India: Rs. 3 crore allocated; Rs 2.99 crore spent.
4. Indian Spinal Injury Centre: Rs.1 crore allocated; full amount spent.

The ones who didn't do so well are as follows:

1. Chief Commissioner for Persons with Disabilities (CCPD) had an allocation of Rs. 2 crore and 3 lakh. They could spend only 1 crore and 36 lakh. In other words, a fair sized amount of 67 lakh was wasted and not utilised.
2. Aids and Appliances Scheme: Only Rs. 69.68 crore could be utilised out of Rs. 100 crores. In other words, over Rs. 30 crore were wasted.
3. Deendayal Disabled Rehabilitation Scheme: Only Rs. 82.27 crore spent out of Rs. 120 crore allocated. A clear waste of over Rs. 37 crore.
4. Has ALIMCO (Artificial Limbs Manufacturing Corporation of India) been shut down? Rs. 3 crore was allocated for them but not a penny has been utilised.

Now comes the real heartbreaking news:

1. Scheme for Implementation of the Persons with Disabilities Act 1995: Rs. 100 crore allocated. Only Rs. 50.41 crore utilised. In other words, almost half the money, nearly Rs. 50 crore wasted.
2. Employment of Physically Disabled People: Rs. 8 crore allocated but not one paisa spent in the whole financial year.
3. Financial Assistance to Women with Disabilities: Rs. 5 crore allocated. Again, not one naya paisa spent!
4. Indian Institute of Sign Language: Remain a dream on paper. No movement forward. No expense therefore.
5. Centre of Universal Design and Barrier Free Environment: Again, remains only a dream on paper.
6. Rajiv Gandhi National Fellowship for People with Disabilities: Nothing happened this year. However, an allocation of Rs. 11.98 crore has been made for the current financial year, i.e. 2011-2012.

To sum it all up, out of the Rs. 489 crore that were allocated, as much as Rs. 136 crore and 48 lakh were left unutilised. **In other words, almost 28% of the budget was simply wasted!**

-E-Mail from Disability News and Information Service (DNIS), dated 24th May 2011.

The **procedures for getting benefits** from Government initiatives are complicated and beyond the reach of the common people. The basic document, the disability certificate, is difficult to get due to lack of information; difficult procedure; distance to the authorised hospital; and corruption throughout the system. The well-meaning welfare schemes often do not reach the people who need them the most, due to the same reasons. In some schemes/programmes there is a number target, such as 3% reservation. However, there is no mention of accessibility and reasonable accommodation, due to which, these number targets seldom get met. For instance, a person with disability may have a job, thanks to reservation, but is unable to work, because she/he was not given any reasonable accommodation to perform the job. **There is a huge gap between the ground reality and the vision provided by the CRPD.**

Even the disability organisations are struggling to understand the paradigm shift offered by the CRPD and the way forward.

The Struggle to Understand the Paradigm Shift

"Would special schools be closed down and not strengthened or expanded? Given the present non-friendly environment in the regular schools, would a child with deafness not be at a disadvantage there? We understand inclusion is the way forward but it is going to take a long time to ensure facilities in the regular school. Till then, what? Do we compromise the present for the future?"
– A deaf person

"Shouldn't homes for wandering men and women with mental illness be in every State? In fact there should be more than one."

- A common man who helped an elderly lady living on the street near his home to get admission into a old age home on a cold winter day.

"Well you really don't know the kind of life I live due to my son's disability. I get bruised, I get kicked, I get slapped, my hairline is fast receding as my son pulls at it whenever he has a behavioural tantrum. I am refused movement out of my bedroom because my son fears I might go out on a drive in the car...Please don't think that he hates me. Actually, he loves me unconditionally but he doesn't understand that now he is strong and his physical pressure or grip hurts me....you know why I bear this day in and day out ..???? BECAUSE I am his mother, the only Caretaker he will have, who will love him always. He cannot communicate and so his comprehension is very lowTell me ,... do you think he can ever stand up and ask for his RIGHTS and quote from The Disability Act when his rights are impinged upon ???And why do you forget that I am not just one isolated case. Most of the low functioning persons on the Autism Spectrum Disorder would never be able to demand for their so called RIGHTS. And we the Parents or the CAREGIVER are their mouthpiece....we are in fact doubly disabled because we have to sacrifice most of our RIGHTS."

-E-Mail from a mother of person with Autism to Yahoo Group, 1st April 2011).

"Those of us who have spent decades working for the mentally ill know that involuntary admissions and forced treatments are required in some cases when the predominant lack of insight leads to denial of illness in the patient which could result in harm to him/her or the family members. No law can be oblivious to this and the right to treatment in these cases is equally important."

-Dr. Thara, Discussion Paper, Persons with Disabilities Act, 2011 (Working Draft compiled by Amrit Kumar Bakhshy, E-mail sent to Mental health community Yahoo group on 23rd February 2011)

There are no easy answers to many of the questions raised. Disability rights activists are of the firm view that the rights should come first. **Just because there are practical difficulties, one cannot make it easier by removing certain human rights.** There should be a process and a road map to progressively realise the vision of a society, which is truly respectful and inclusive with people having full legal capacity and full participation with the support that may be required!

4. Definition of Disability

Article 1 states "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."

CRPD provides for a broad definition of disability. However, the definitions in the Indian disability laws are restrictive and do not cover all disabilities.

According to **The Disability Act, 1995**, "disability" means,

- (i) blindness
- (ii) low vision
- (iii) leprosy-cured
- (iv) hearing impairment
- (v) locomotor disability
- (vi) mental retardation
- (vii) mental illness

"Person with disability" means a person suffering from not less than forty per cent of any disability as certified by a medical authority. This definition also applies to the Rehabilitation Council of India Act, 1992 as per the Amendment in 2000 and is the definition used throughout the country for various purposes.

The provisions of **The National Trust Act, 1999**, are for persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities.

According to **The Mental Health Act, 1987**, "Mentally ill person" means a person who is in need of treatment by person of any mental disorder other than mental retardation.

The definitions used in various disability laws in India are medical-model based. These talk of specific impairments. Many impairments have been left out like persons with learning disabilities, disabling medical conditions. Certain disabilities covered under one law are left out in the other, like persons with Autism are in The National Trust Act, 1999 and not in The Disability Act, 1995. A person is considered disabled only if she/he has an impairment above a certain percentage, which is decided after assessments by doctors/professionals. The terminologies used are archaic, like 'handicapped' and 'suffering from'.

One of the major issues that is being debated in the country while formulating the new law is definition of disability. And as the basis of the new law is going to be the CRPD, one can hope for a more appropriate and broader definition of disability. However, there is a stiff resistance from certain sections of the disability sector to go for a social model definition, as they feel that there would be too many takers of the limited resources available.

Some viewpoints from persons with disability and others are mentioned below.

"There are a number of impairments which are long-term. Multiple Sclerosis, Muscular Dystrophy, Hemophilia, Thalessemia, Alzheimers, Parkinsons, Seizure disorders, Stroke, Lysosomal Storage Disorders (LSD) and Mucopolysaccharidosis (MPS) are some impairments, which are not recognised by Indian laws. Persons with such conditions require long term medication, rehabilitation, counselling, vocational training, care givers and other support systems to ensure their rights to good maintenance, development, non-discrimination, equal participation and dignified way of living."
-Smitha.S.S, Assistant Coordinator, Disability Legislation Unit South, 18th May 2011.

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"I am highly dissatisfied that haemophilia is not considered as disability. Haemophilia is a hidden disability in Blood. Person with haemophilia faces difficulties in day to day life. Because it is incurable, repeated bleeds, usually untreated (very expensive treatment) leads to physical disability. It is irony that Government waits till a person with haemophilia becomes disabled and only severe physical disability makes him eligible to get the recognition under Disability Act."

-Dr. Suresh Hanagavadi, Haemophilia Federation

Article 2: Definitions

The text of Article 2 in the CRPD is given below.

For the purposes of the present Convention:

"Communication" includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology;

"Language" includes spoken and signed languages and other forms of non spoken languages;

"Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation;

"Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;

"Universal design" means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

Progress and Concerns

These definitions are yet to be incorporated in the Indian laws. Words like reasonable accommodation and universal design are relatively new to persons with disabilities and to the sector in general and their understanding is limited. These terms are seldom used in disability discourse, especially in the Government Sector. Moreover, translation of these terms into the different official languages is important to ensure that it is understood correctly across India. Once these terminologies are incorporated into the legislations, there would be more discussions around the concepts and a better understanding will develop.

Article 3: The General Principles

The text of Article 3 in the CRPD is given below.

The principles of the present Convention shall be:

- 1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;*
- 2. Non-discrimination;*
- 3. Full and effective participation and inclusion in society;*
- 4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;*
- 5. Equality of opportunity;*
- 6. Accessibility;*
- 7. Equality between men and women;*
- 8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.*

Progress and Concerns

The 'General Principles' form the basis for legislation, policy and practice. Each one forms a corner stone of the mosaic that ensures that persons with disabilities are equal and meaningful participants in the mainstream. The General Principles are closely connected or inter-linked to each other and, overall, to every provision in the Convention⁸.

The law upholds certain aspects of General Principles, violates a few and is silent about certain others. Accessibility, non-discrimination, equality of opportunity and participation are covered to some extent. However, respect for inherent dignity, freedom of choice, individual autonomy, respect for differences and evolving capacity have not been taken into account. There is no specific mention of the rights of women and children with disabilities.

Some examples of violation of certain General Principles are given in the box below. In the chapters on each Article there are more examples.

Violation of Respect for Dignity

"I recently applied for an ID card (for persons with disability) from the office of one of the District Commissioners of Delhi. I am locomotively disabled. My left leg has been amputated below the knee. I was told by the office that unless I sent a photograph clearly indicating my disability, I would not be issued an ID

⁸ 'Understanding the UN Convention on the Rights of Persons with Disabilities: A Handbook on the Human Rights of Persons with Disabilities', by Marianne Schulze, edited by Handicap International, September 2009.

card. I informed the Chief Commissioner for Disabilities (CCD) that this was a demand that attacked my dignity and this was not in order. It was only after the CCD intervened that I was issued with the ID card with a standard passport photograph.”

-Major General Ian Cardozo, AVSM, SM, Response to CRPD Questionnaire

Violation of the Right to Individual Autonomy

“Over a hundred civil laws in the country, including the Constitution, deprive persons with “unsound” mind of their rights and legal status. People with certain disabilities cannot open a bank account, take loans, enter into Contract, be married, own properties, decide on having children, choose the kind of medical treatment they want, etc. People of “unsound” mind are not allowed to represent themselves, give evidence or bear witness before a Court of law. Such a person accused of a crime remain in prison for inordinately long periods of time without having access to justice.”

-NAAJMI

Violation of Freedom of Choice and Equality of Opportunity

“The realisation of right to education on an equal basis is far from reality in India. We have experienced a regular denial of this right for students with vision impairment at various level of higher education. A range of educational services are barred to visually impaired persons on the basis of their disability – Medicine, various streams of science education where practical examinations are involved are all denied to the visually impaired.”

-Dr. Sam Taraporevala, Response to the CRPD questionnaire

Violation of the Right to Full and Effective Participation

“Nomination of a Candidature for the upcoming elections (2011) was rejected on the ground that she is deaf!”

-Tamil Nadu Handicapped Federation Charitable Trust.

Article 4: General Obligations

The text of Article 4 in the CRPD is given below.

1. *States Parties undertake to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:*
 - a) *To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;*
 - b) *To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;*
 - c) *To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;*
 - d) *To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;*
 - e) *To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;*
 - f) *To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;*
 - g) *To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;*
 - h) *To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;*
 - i) *To promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights.*

2. *With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.*
3. *In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.*
4. *Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of persons with disabilities and which may be contained in the law of a State Party or international law in force for that State. There shall be no restriction upon or derogation from any of the human rights and fundamental freedoms recognized or existing in any State Party to the present Convention pursuant to law, conventions, regulation or custom on the pretext that the present Convention does not recognize such rights or freedoms or that it recognizes them to a lesser extent.*
5. *The provisions of the present Convention shall extend to all parts of federal States without any limitations or exceptions.*

Progress and Concerns

The General Obligations mentioned in Article 4 are the measures that State Parties have to undertake to promote, protect and ensure full realisation of human rights.

Article 4(a) mandates the State to adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognised in the present Convention.

Indian Government has done very little to adopt any measures to implement the rights in the CRPD. As a result of advocacy from the disability sector, the Government has started working on the **formulation of a new disability law consistent with the CRPD.**

Formulation of New Law on Disability – Progress so far

In 2009, Ministry of Social Justice and Empowerment (MSJE) had put up the proposed amendments on the website of the Ministry to seek inputs. NCPEDP and Disabled Rights Group (DRG) formed a Core Group to review the proposed amendments and found that they were not aligned to the CRPD. The Core Group felt that, given the paradigm shift in the thinking about the rights of

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persons with disability as outlined in the CRPD, the changes are so substantive that it may be useful to write a new law rather than just amend the present one. In order to take the debate further and to build a consensus on the issue, NCPEDP and DRG organised a National Consultation in New Delhi, followed by four Zonal Consultations in the North (Delhi), South (Chennai), West (Mumbai) and North East (Guwahati). There was an overwhelming response in favour of the new law. The Minister of Social Justice and Empowerment finally announced that the Government would be finalising a new law for persons with disabilities that would replace the existing one.

On 30th April 2010, Ministry of Social Justice and Empowerment finally constituted a Committee to draft a new disability law based on the CRPD. The 27-member Committee had only three people with disabilities! Finally, after a candle light vigil and a hunger strike, a few more disabled leaders were added.

The larger demand of the sector is to go in for a comprehensive disability law, which will include the National Trust, the Rehabilitation Council and the rights of persons with psychosocial disabilities and people living with mental illness. This would enhance not only the resources but also the powers of the National Trust and RCI and would help them function better. Also, the multiplicity of authorities which exists today because of multiple laws would go away and people at the grassroots will have an easy, single window access to all their rights.

However, the Committee totally brushed aside that idea. Four Committee members (three of them were persons with disabilities) resigned from the Committee. No efforts were made to bring back the Members who had resigned. The Committee finalised the draft in July 2011 and has handed it over to the Minister of Social Justice and Empowerment⁹.

Many disability activists are not very happy with the draft. There are still many unresolved issues. It is a long way to go for the new law to be formulated and to be passed in the Parliament. The decision to formulate a new law was an effort in the right direction. However, the approach that is being followed has been non participatory, which is a violation of General Principles of the CRPD.

“The voices of persons with disabilities from the rural areas continue to be completely ignored during the formulations of new laws/policies. For example, the demand for rural consultations regarding the New Law on the Rights of Persons with Disabilities was not part of the initial design of the Government”
-Praveen Kumar, Response to the CRPD questionnaire.

The Government is also reviewing other disability laws like The National Trust Act, 1999, The Mental Health Act, 1987, and The Rehabilitation Council of India Act.

The various laws, concerning marriage and divorce, formation of partnership, associations, contracts, participating and standing for elections, holding public

⁹ Disability News and Information Service (DNIS), managed by NCPEDP, Volume 8 Issue 1, January 01, 2011.

office, etc. have certain aspects which are not in line with the CRPD. (More information about the laws in India with respect to the CRPD has been detailed in chapters on various Articles). **There has been very little effort on the part of the State to review the various laws as mandated by the CRPD.**

The obligations of the State Parties - to modify/abolish laws, regulations, customs and practices that constitute discrimination against persons with disabilities; to undertake research and development of universally designed goods and services; provide accessible information about aids and technologies and support services, to promote training of professionals and staff in the rights recognised in the Convention and to achieve progressive realisation and involving persons and children with disabilities - **none of these have been undertaken in the last four years since the ratification of CRPD.** These obligations have been looked at more closely in the later chapters where each Article has been analysed.

Article 5: Equality and Non-discrimination

The text of Article 5 in the CRPD is given below.

1. *States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.*
2. *States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.*
3. *In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.*
4. *Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.*

Progress and Concerns

Article 5 on Equality and Non-discrimination mandates equality to be achieved through ensuring non-discrimination and reasonable accommodation, including certain positive measures/affirmative action to compensate for past exclusion.

There has been no effort by the Government towards implementation of any of the clauses in this Article. Many laws continue to discriminate against people with certain disabilities. Even the disability law discriminates against people with certain disabilities.

Certain blatant discriminations in the Indian laws against persons with disabilities have been mentioned below.

According to **Article 326 of Constitution** of India and Representation of Peoples' Act, some persons with disabilities (people with so-called "unsoundness of mind"¹⁰) are not allowed to vote, stand for elections or hold public office.

The Disability Act, 1995, provides for 3% reservation in employment in Government and Public Sector, only to those persons belonging to three categories of disabilities, namely, locomotor, visual and hearing and not for people with any other disabilities, like the mental/intellectual impairment. This is clearly not in line with the CRPD.

The Hindu Marriage Act, 1955 allows for divorce if a person has been incurably of unsound mind, or has been suffering continuously or intermittently from mental disorder of such a kind and to such an extent that the petitioner

¹⁰ "Unsoundness of mind" is a very vague term. People with intellectual, psychosocial, autism, multiple impairments/communication difficulties are denied opportunities citing this term.

cannot reasonably be expected to live with the respondent; or has been suffering from a virulent and incurable form of leprosy.

Orissa Municipal Act 1950 states: "No person shall be qualified for election as a councillor of a municipality if such person has been adjudged by a competent court to be of unsound mind or is a leprosy or a tuberculosis patient." Further, the Act says: "Subject to the provisions of the section, a councillor shall cease to hold his office if he becomes of unsound mind, a leprosy or a tuberculosis patient." (Source: Laws in India criminalise leprosy; Extracted from an article written by *Alok Prakash Putul* published in *One World South Asia*, , 23 June 2008)

The Right to Education Act which was enacted post ratification has not taken into account any provisions given in the Article 24 of the CRPD. It has based its provisions on The Disability Act 1995 which is very restrictive in terms of coverage of all disabilities and the provisions.

"People affected by leprosy and others gave a Petition to the Petition Committee of Rajya Sabha. The Petition was for amendment of laws which stand as a barrier for normal living of persons cured of leprosy. In spite of these developments, the recommendations are not implemented."
-Dr P K Gopal, In response to the CRPD Questionnaire.

Article 33: National Implementation and Monitoring

The text of Article 33 in the CRPD is given below.

- 1. States Parties, in accordance with their system of organization, shall designate one or more focal points within Government for matters relating to the implementation of the present Convention, and shall give due Consideration to the establishment or designation of a coordination mechanism within Government to facilitate related action in different sectors and at different levels.*
- 2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.*
- 3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.*

Progress and Concerns

1. Focal Point and Framework

Article 33(1) and (2) of the CRPD obligates State Parties to designate one or more Focal Points and to establish a framework and independent mechanism for implementing the Convention. India has neither designated a Focal Point nor formulated a framework. Without these basic mechanisms, the Convention remains unimplemented.

2. Involvement of DPOs

Article 33 (3) mandates persons with disabilities and DPOs should be involved in the monitoring process. No monitoring process/mechanism has been put in place by the Government yet. Hence, there is no question of persons with disabilities or their organisations participating in it.

However, the civil society has been active. A few organisations have prepared alterative reports on the CRPD.

The participation of persons with disabilities and DPOs in the implementation and monitoring of the existing legislations is also very limited. For example, the Central Coordination Committee and State Coordination Committees require "five persons as far as practicable, being persons with disabilities, to represent Non-Governmental organisations or associations which are concerned with disabilities, to be nominated by the Central Government..." In addition, it

discriminates by stating that “No person shall be a Member of the Central Coordination Committee, who is of unsound mind and stands so declared by a competent court.”

Recommendations for Articles 1-5 and 33

- 1) The Government needs to review all disability and other laws in line with the CRPD and amend them in a time bound manner.
- 2) Any new law being formulated in the country needs to be in line with the CRPD.
- 3) Information dissemination, awareness raising, debates, discussions on CRPD to spread the message widely and to develop a better understanding of the Convention is needed.
- 4) An autonomous body with the adequate power and resources to be established as Focal Point for implementing and monitoring of the CRPD.
- 5) The Government needs to ensure active involvement of persons with disabilities in various decision making, implementation and monitoring bodies.
- 6) A road-map requires to be formulated, keeping India’s realities in mind, towards progressive realisation of rights provided in CRPD.
- 7) Disability Definition should be modified as per the CRPD.
- 8) All relevant laws, policies and programmes should have provision for reasonable accommodation with requisite mechanism and funds to implement it, to ensure the right to equality and non-discrimination.

Article 6: Women with Disabilities

The text of Article 6 in the CRPD article is given below.

- 1. States Parties recognise that women and girls with disabilities are subject to multiple discrimination and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.*
- 2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.*

Survey Findings

- The following are the findings of the survey with respect to the efforts made by the Government for ensuring equality of rights and opportunities of women with disabilities when compared with women without disabilities.

Rating	Percentage of Respondents
Extremely dissatisfied	70%
Dissatisfied	18%
Satisfied	6%
Extremely satisfied	0%
Do not know much about the issue	6%

The majority, that is 88% of respondents, said they were 'dissatisfied' with the efforts made by the Government for ensuring equality of rights and opportunities of women with disabilities. The gender aspect is seldom included in the disability programmes and disability aspect is hardly taken into account in the programmes for women. Disability being seen as a welfare issue and a responsibility of Ministry of Social Justice and Empowerment (MSJE), disability aspects are not addressed effectively by the Ministry of Women and Child Development. Like all other developmental issues, there is no dialogue between the concerned Ministries. Disability is seen as a separate issue rather than part of other issues. Even in MSJE, there are no focused programmes on issues of women with disabilities.

Laws and Policies

The **Indian Constitution** prohibits discrimination against women; provides for equal pay, accommodations such as humane working conditions and maternity leave and affirmative action. It also states quite emphatically to "renounce the

practices derogatory to the dignity of women.” It does not state anything specifically for women with disabilities.

In **The Disability Act, 1995** there are no specific provisions for non-discrimination or reasonable accommodation or affirmative action for women with disabilities. However, it provides that the Secretary, Department of Woman and Child Development should serve as a member in the Central and State Coordination Committees. It also mandates that the Central Executive Committee, the State Coordination Committee and the State Executive Committee should all also have at least one woman with disability.

The National Trust Act, 1999 also provides that one of the members of the Board should be from Ministry of Women and Child Development and she/he should not be below the rank of Joint Secretary. In addition, it states in Clause 11(3), “while earmarking funds for the purpose of clause (c) of sub-section (2), (i.e., setting up of residential hostels and residential homes for persons with disability), preference shall be given to woman with disability.”

The Mental Health Act, 1987 on “Judicial Inquisition Regarding Alleged Mentally Ill Person Possessing Property, Custody of His Person and Management of His Property”, states, “if the alleged mentally ill person is a woman, who according to the custom prevailing in the area where she resides or according to the religion, to which she belongs, ought not to be compelled to appear in public, the District Court may cause her to examine by issuing a commission as provided in the code of civil procedure, 1908”.¹¹ That apart, the Act does not have any specific clause or provision for women with disabilities.

There are several **other legislations**, related to women’s rights, which automatically also apply to women with disabilities (even though there may not be specific mention about disability). For example, the Immoral Traffic (Prevention Act); the Dowry Prohibition Act, the Indecent Representation of Women (Prohibition) Act; the Commission of Sati (Prevention) Act, Protection of Women from Domestic Violence Act, 2005, etc. These Acts have to be suitably amended to include issues of women with disabilities. In the meantime, effort should be made to ensure accessibility of all existing services, such as shelter homes, counselling, etc. for persons with disabilities. Authorities and people in charge of providing these services (protection officers, police officers, shelter home in-charge, counsellors, lawyers, social workers, etc.) need to be sensitised to provide the necessary support to women with disabilities.

The XI Five Year Plan has a paragraph on Women with Disability. The Chapter, ‘Towards Women’s Agency and Child Rights’ under the section Women with Disability, states that “Although a rights-based approach today defines the disability rights movement, the specific concerns of women with disabilities have to be adequately reflected in the planning process. Reproductive and Child Health (RCH) programmes will pay attention to reproductive health needs of women with disabilities. Violation of their reproductive rights through forced sterilisation, contraception and abortion especially in institutions will be dealt with severely. In the Eleventh Plan, women with disabilities will be specifically

¹¹ Accessed at <http://nhrc.nic.in/Publications/Disability/annexure3.html> on August, 2011.

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included in gender equity programmes, both as beneficiaries and as project workers. The sensitisation programmes of Government departments, police, and health care personnel will include sensitisation to the needs of women with disabilities. Laws will be strictly enforced in cases of discrimination.”¹² However, no progress has been made to implement any of the points mentioned in the Plan.

Progress and Concerns

1. Status of Women with Disabilities

Census 2001 has revealed that over 21.9 million people in India have one or the other kind of disability. This is equivalent to 2.1% of the population. About 58% of persons with disabilities were males while only 42% were females. According to National Sample Survey Organisation (NSSO) 2002, about 42% of girls with disabilities are enrolled in 'ordinary' schools, compared to 48.6% boys with disabilities. There is a major gender difference in employment rates between men and women. Only 10.4% of women with disabilities are employed compared to 36.4% men with disabilities. About 31% women with disabilities reported their marital status as "currently married" compared to 45% men with disabilities.¹³ It would also be important to mention here that these statistics are not very authentic, as most people with disabilities didn't get counted in these Surveys.

2. Ministry and Apex Organisations Dealing with Women's Issues

The **Ministry of Women and Child Development** seeks to promote the social and economic empowerment of women through policies and programmes cutting across sectors, mainstreaming gender concerns, creating awareness about their rights and facilitating institutional and legislative support for enabling them to develop to their full potential. The Ministry looks into subjects like trafficking, orphanages, pre-school education, nutrition and overall welfare of family. It is also in-charge of implementing various women and child related Acts.

National Commission for Women (NCW), an apex national level organisation of India has been mandated to protect and promote the interests of women. It is interesting to note that about 18 research studies were sponsored by the NCW for the financial year 2010-2011 but none were on women with disabilities.¹⁴

The **National Mission for Empowerment of Women** (launched in March 2010), aims to empower women socially, economically and educationally by securing convergence of schemes/programmes of different Ministries/

¹² Accessed at

http://planningcommission.nic.in/plans/planrel/fiveyr/11th/11_v2/11th_vol2.pdf on 5th October 2011.

¹³ NSS 58th Round, 2002, accessed at

http://punarbhava.in/index.php?option=com_content&task=view&id=734&Itemid=540 on 5th October 2011.

¹⁴ Accessed at <http://ncw.nic.in/PDFFiles/TopicsReserchStudy.pdf> on 5th October 2011.

Departments of Government of India as well as State Governments. The National Mission Authority (NMA) is headed by the Prime Minister and has Chief Ministers of the two States of Andhra Pradesh and Bihar and five Civil Society Organisations as Members. The Mission is yet to receive the approval of the Planning Commission as a Centrally Sponsored Scheme.

Based on the information given in the websites and Annual Reports, **disability is not a focus area in any of these organisations or initiatives for women**. Persons with disability are mentioned only cursorily in one or two places and even there, the provisions are restricted! For example, the 'Swadhar: A Scheme for Women in Difficult Circumstances' has the objective of providing primary need of shelter, food, clothing and care to the marginalised women/girls living in difficult circumstances who are without any social and economic support. The scheme provides economical, clinical and legal aid to women and girls in need. One of the beneficiary or target groups of the scheme include "mentally challenged women (except for the Psychotic categories who are without any support of family or relatives)".¹⁵

All concerned Central Ministries were requested by Ministry of Social Justice and Empowerment to implement the provisions of the CRPD in so far as these relate to them. The need for focus on women and children was also emphasised. The Ministries were also requested to identify statutes and orders that require amendment in the light of the Convention and to initiate the process of amendment.¹⁶

Another interesting fact that is mentioned in the Annual Report of the Ministry of Women and Child Development is that "No Person with Disability has been appointed in NIPCCD, NCW, NCPCR, CSWB and CARA"¹⁷ (which are institutions under the Ministry of Women and Child Development).

There are other related Ministries, like the Ministry of Health and Family Welfare, Ministry of Human Resource Development, Ministry of Rural Development, Ministry of Labour etc., which have a few focussed programmes for women but do not have any information or specific initiatives for women with disabilities in particular. The nodal Ministry of disability, Ministry of Social Justice and Empowerment has no focused initiative on women with disabilities.

3. Right to Health

Article 25 of the CRPD highlights the need for gender-sensitive health services. Some of the issues would be nutrition, insurance, subsidised and free health services close to their homes, respect for privacy and consent for treatment.

Major initiatives of Ministry of Women and Child Development focusing on health and nutrition of adolescent girls and women do not mention the needs of women with disabilities in specific terms. The Rajiv Gandhi Scheme for Empowerment of Adolescent Girls and Janani Suraksha Yojana do

¹⁵ Page 27, Annual Report of Ministry of Women and Child Development, 2010-11.

¹⁶ Page 106, Annual Report, Ministry of Social Justice and Empowerment, 2009-10.

¹⁷ Page 308, Annual Report of Ministry of Women and Child Development, 2010-11.

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not mention disability. **The flagship programme, National Rural Health Mission (NRHM), which aims to achieve access to health services in the rural areas has no mention of disability.**

The XI Five Year Plan states that the Reproductive and Child Health (RCH) will pay attention to reproductive health needs of women with disabilities. In addition, sensitisation programmes will be conducted for Government departments, police, and health care personnel which would include sensitisation to the needs of women with disabilities.¹⁸ None of these provisions are reflected in any of the programmes of the Ministry.

4. Freedom from exploitation, violence and abuse

Article 16 of the CRPD is on Freedom from Exploitation and Abuse.

The status of women in general is a cause of concern. The decreasing sex ratio, cases of infanticide, dowry deaths, trafficking, rape, unemployment, poverty, lack of social security etc. are all areas of concern. **And when girls/women have disability, the problem only further compounds.** Many of the cases of discrimination and abuse go unreported. Infanticide happens with the support and advice of the doctors; violence and abuse happen within closed doors of families and institutions. There are hardly any support systems available for women with disabilities. The support systems available for women in general remain inaccessible for girls and women with disabilities.

There are several Acts and Programmes of the Government and civil society to protect women from exploitation, violence and abuse. **There are redress mechanisms; legal service etc. for women. However, there are no provisions for accessibility or for addressing and supporting specific needs of persons with disabilities. There is no data on the number of women with disabilities accessing these services.**

Research indicates that violence against children with disabilities is at least 1.7 times greater than for their peers without disabilities.¹⁹

Mathura Sekhri (name changed) was denied her right to healthy childhood and property! Mathura was born to a very well to do business family in 1992 in a prestigious nursing home in Kolkata. She was the second daughter to Manju and Manav Sekhri (names changed). When the second daughter was born and the family found that she had Downs Syndrome, she was not accepted as a part of family. Torture on her mother began in many forms and attempts to throw away the mother and this daughter began since her birth.

¹⁸ Accessed at

http://planningcommission.nic.in/plans/planrel/fiveyr/11th/11_v2/11th_vol2.pdf on 5th October 2011.

¹⁹ Disabled World, World Facts and Statistics on Disabilities and Disability Issues accessed at <http://www.disabled-world.com/disability/statistics/> on 5th October 2011.

Manju, unable to bear the torture, filed a case against her husband and in-laws with the police. Her in-laws were extremely rich and influential people and it was difficult for her to get justice. Finally she took help of National Commission for Women as well as State Commission for Women. When pressurised by both these bodies and after fact-finding teams visited her family, the Sekhri family agreed to pay Mrs. Manju Rs. 1,60,00,000/- (Rupees One Crore Sixty Lakhs only) to vacate their house and to withdraw the police case. This deed of Agreement was signed by both NCW and State Women's Commission representatives on 16th June 2006.

The deed states that "The younger daughter Mathura shall stay with her mother. The elder daughter Vasudha (elder daughter of the Sekhris) will stay with her father and her maintenance, education, marriage and final settlement in life will be fully taken care by her father." Not a single line on who will take care of education, day-to-day living or rehabilitation of the girl with disability was mentioned.

It is very clear from this document that the Sekhris were not even interested in accepting responsibility of Mathura – they considered her as a non entity as she is mentally disabled. Mathura has no brother, so the question arises who has the right to inherit properties of her great grandfather, grandfather as well as father? Is her sister the only heir of father's property? Can her father write her off from Family Trust Property because she is a mentally disabled girl? Does he not have any responsibility towards making arrangements for her day to day living, education, medical and future rehabilitation programmes? Mathura's mother is afraid that after her death, Mathura will be without a shelter and will have no house to live even though her family possesses a number of houses in different cities of India.

-Shampa Sengupta, Sruti Disability Rights Centre, Kolkata, through email exchange dated 20th September 2011.

This issue has been covered at length in the chapter on Article 16 of the CRPD.

5. Right to Education, Employment and Social Security

Articles 24, 27 and 28 of the CRPD deal with Education, Employment and Social Security respectively.

Apart from the barriers faced by most persons with disabilities in education and employment, women with disabilities face increased negative attitudinal barriers. **Education and employment opportunities for girls/women with disabilities are much lower compared to boys/men with disabilities.** Beneficiaries with disabilities are generally considered as one category and hence, gender segregated data is not collected or maintained.

- The Sarva Shiksha Abhiyan (SSA) for Universal Education has a special focus on girls with disabilities. However, gender segregated data on number of beneficiaries or budget allocation was not available on the SSA website.

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- Total placements by all Employment Exchanges across the country in the year 2008 were merely 3700, out of which women were only 800 (21.6%)! Total number of registrations was 54,900, out of which only 10,200 thousand were women.²⁰
- A rebate of 1% on interest is given to women with disabilities in all Schemes of National Handicapped Finance and Development Corporation (NHFDC). Out of the total beneficiaries of loan assistance from NHFDC during 2009-10, only 20% were women!²¹
- The Vocational Rehabilitation Centre (VRC) at Vadodara is the only VRC which is exclusively for women with disabilities.²² Gender segregated data on number of people trained in the 20 VRCs of the country is not available.
- There is a National Social Security Scheme called 'Indira Gandhi National Disability Pension'. Gender-segregated data for the same was unavailable in the relevant website and Annual Reports.

6. Right to Home and Family

Article 23 is on Respect for Home and the Family. There are no visible measures taken by the Government to protect the rights of persons with disabilities to live in their homes and with the family. **There seems to be little support system from the Government to help girls/women with disabilities to lead a life of dignity with family at home. The Government has done little towards changing the mindset of the society.**

Moreover, in a society that views girls as 'liability', a girl with disability is considered 'unworthy'. This mindset leads to abandonment; or they are sent to hostels or they are kept hidden within homes. Girls/women with disabilities are also not encouraged to talk about their feelings and their needs. There are examples of quite a few women with disabilities in India, who have managed to come up, inspite of the challenges, by their own efforts or support from their families, however, they are very few in number. **Majority of them are still struggling for their survival.**

"Only in Kolkata city we have more than 750 mentally disabled women who are forced to live in shelter homes as their families do not accept them."

-Shampa Sengupta, Sruti Disability Rights Centre, Kolkata through email exchange dated 20th September 2011.

"I am a woman with disability. I have not been able to find a suitable alliance due to my disability. Even men with disability do not want to marry a girl with disability. They think I may not be able to do household chores, like cooking, washing clothes, dishes etc. They think I may not be able to bear or take care of children. I am over 40 years and am unmarried. I am now thinking of

²⁰ Page 44, Table 16, Employment Exchange Statistics, 2010, Ministry of Labour and Employment.

²¹ NHFDC Annual Report, 2009 -10.

²² Page 155, Annual Report, Ministry of Social Justice and Empowerment, 2009-10.

adopting a child. I am well educated and well employed. At the same time, I am also single, a woman and disabled! I am not sure if I will be allowed to adopt!”

-Kalpana (name changed), a person with physical impairment.

“For ages, the champions of women’s right and liberation have fought to discard traditional roles of women and define themselves anew. On the other hand, the fight of women with disabilities has been, to be heard and be accepted as a woman, spouse, mother, etc.”

-Priya Varadan, Researcher, a person with disability

7. Awareness

Article 8 of the CRPD is on Awareness. While it is an accepted fact that information and awareness are tools for empowerment, the Government seems to have done little in this area. None of the relevant Ministries have initiated awareness programmes on rights of women with disabilities. There seems lack of awareness on the CRPD and rights of girls and women with disabilities among policy makers and others functionaries of the Government.

Divya’s (name changed) story is an example of ‘Insensitivity exhibited by people who work with women with disabilities.’

Divya is a young woman of 24 years with mild intellectual disability. She studied in mainstream school till Class VII. She could not cope up with the studies and dropped out. She started going to a Vocational Training Centre (VTC) for young adults with mental retardation run by a Parents’ Group.

From the da she joined the VTC, she showed signs of flustered adolescent behaviour – trying to be too close with male teachers who taught them specific skills as well as openly saying that she longs to visit Rabindra Sadan (a place frequently visited by young couples of Kolkata) with male friends. She also demanded to know why these opportunities were not given to her.

The training centre where she goes, did not try to impart life skills or sexuality training to her. The special educators scolded her and at made jokes about her. Her family was also clueless about how to deal with this. However, they found a match for her. In the year 2010, Divya got married to the man chosen by her parents. The mother says she explained the situation to the man’s family and they accepted.

However the VTC management was not ready to cater to a married woman. So Divya had no choice – she had to opt for either marriage or work.”
-Shampa Sen Gupta, Sruti Disability Rights Centre, Kolkata.

8. Participation in Decision Making and Monitoring Bodies

Participation of women with disabilities in the decision making and monitoring bodies, be it the Government, Private Sector or the NGOs, is very limited. In general, people with disabilities are not in top positions, but in the recent times, there have been a few men with disabilities holding the top post in the Government, like the Chairman of Rehabilitation Council of India. However, there are no examples of women with disabilities in top positions. **The Government formed a Committee to draft a new law on disability based on the CRPD and out of 34 Committee Members, only 2 were women with disabilities!**

Recommendations

- 1) Disability laws and women related laws need to be reviewed in the light of various relevant Articles of the CRPD.
- 2) The Government should have focused programmes for women/girls with disabilities and inclusion of women with disabilities in all programmes of the various relevant Ministries.
- 3) Gender-segregated disability data of beneficiaries of various schemes needs to be maintained and made available to facilitate monitoring and evaluation.
- 4) The Government needs to have a policy on including women with disabilities in decision making, implementing and monitoring bodies.
- 5) Special focus on the rights of women with disabilities is needed by Ministry of Information and Broadcasting, Ministry of Women and Child Development, Ministry of Social Justice and Empowerment, Ministry of Human Resource Development etc.

Article 7: Children with Disabilities

The text of Article 7 in the CRPD is given below.

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Survey Findings

1. The following are the findings of the survey with respect to the efforts made by the Government for ensuring equality of rights and opportunities of children with disabilities.

Rating	Percentage
Extremely dissatisfied	57%
Dissatisfied	32%
Satisfied	10%
Extremely satisfied	0%
Do not know much about the issue	0%

The above data shows that 10% of the respondents were satisfied with the implementation of the Article on child rights. About 89% were dissatisfied. This is indicative of the fact that the rights to be enjoyed by children with disabilities are not very satisfactory. The implementation of laws and policies for ensuring the rights of children with disabilities need attention so that they can enjoy full equality of rights.

Laws and Policies

The **Constitution of India** guarantees some rights to children. Some that are specifically meant for children include²³:

- Right to free and compulsory elementary education for all children in the 6-14 year age group (Article 21 A).

²³ HAQ Centre for Child Rights, Constitution of India, accessed at <http://www.haqcrc.org/constitution-india> on 6th October 2011.

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- Right to be protected from any hazardous employment till the age of 14 years (Article 24).
- Right to be protected from being abused and forced by economic necessity to enter occupations unsuited to their age or strength (Article 39(e)).
- Right to equal opportunities and facilities to develop in a healthy manner and in conditions of freedom and dignity and guaranteed protection of childhood and youth against exploitation and against moral and material abandonment (Article 39 (f)).
- Right to early childhood care and education to all children until they complete the age of six years (Article 45).

Besides, children also have rights as equal citizens of India, just as any other adult person. These are:

- Right to equality (Article 14).
- Right against discrimination (Article 15).
- Right to personal liberty and due process of law (Article 21).
- Right to being protected from being trafficked and forced into bonded labour (Article 23).
- Right of minorities for protection of their interests (Article 29).
- Right of weaker sections of the people to be protected from social injustice and all forms of exploitation (Article 46).
- Right to nutrition and standard of living and improved public health (Article 47).

The Disability Act, 1995 includes early detection of 'at risk' children and the right to education of children. It supports it through measures like free books, assistive aids, transport etc. The law also states that the Central Coordination Committee and the State Coordination Committees need to have members of Ministry of Women and Child Development.

The National Trust Act, 1999, does not have any mention of rights of children with disabilities. The **Rehabilitation Council of India** recognises various courses for rehabilitation professionals, teachers and doctors and ensures that it includes the concerns of children with disabilities. **The Mental Health Act, 1987**, provides for treatment of mental health issues of minors, who can be admitted for hospital care through a guardian and is then considered voluntary admission. The minor can also be discharged when the guardian so desires. It does not have any provision for rights of children.

Other than the above, India is also a signatory to the **United Nations Convention on the Rights of the Child** (UNCRC). The UNCRC for the first time addressed protection against discrimination on the ground of disability. Article 2(1) provides right to every child without discrimination irrespective of child's disability. Article 23 of the UNCRC, 1989, refers in particular to the rights of children with disabilities: "a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self reliance and facilitate the child's active participation in the community." It also provides for assistance free of charge, access to education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities, cultural and spiritual development.

The **Right to Children to Free and Compulsory Education Act (RTE) 2009** mentions right to free and compulsory education in accordance with The Disability Act 1995. It does not include persons with disabilities under the "disadvantaged group". As a result of advocacy from the disability sector amendments to the RTE Act have been tabled (not passed yet) in the Parliament to include the following – (1) children with disability will be in 'children belonging to disadvantaged group', and thus being entitled for the 25% reservation in neighbourhood schools. (2) The provisions would be extended to children with disabilities as defined by both The Disability Act, 1995 and The National Trust Act, 1999.

There are also some other child **related laws** like:

- The Juvenile Justice Act 2000 and Juvenile Justice Act Amendment 2006.
- The National Commission for Protection of Child Rights Act, 2005 and Amendment 2006.
- The Immoral Traffic Prevention Act 1956.

These need to be reviewed in the light of the CRPD.

The **National Commission for Protection of Child Rights (NCPCR)** was set up in March 2007 as a statutory body under the Commission for Protection of Child Rights Act, 2005. It was set up to protect, promote and defend child rights in the country. Though children with disabilities have not been specifically mentioned in the chapter on functions and powers of the Commission, one of the functions mentioned is to look into the matters relating to children in need of special care and protection, including children in distress, marginalised and disadvantaged children, children in conflict with law, juveniles, children without family and children of prisoners and recommend appropriate remedial measures. The NCPCR is beginning to look into children with disabilities as part of their work. Chapter 4 on State Commission for Protection of Child Rights states that out of the six members of the State Commission, one could be also a person having experience of working with children with disabilities.²⁴

Progress and Concerns

Out of the rights mentioned above, there has been comparatively more focus on right to education for children with disabilities and on prevention and early identification of children with disabilities in India.

1. Right to Life, Health and Habilitation

Article 10 provides Right to Life; Article 25 deals with Right to Health and Article 26 is about Habilitation and Rehabilitation. All these rights apply to children with disabilities too.

²⁴ See the website of NCPCR, <http://www.ncpcr.gov.in/childrenwithdisability.htm> accessed on 6th October 2011.

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According to a study, hardly fifty per cent of children with disabilities reach adulthood, and no more than twenty per cent survive to cross the fourth decade of life.²⁵

Government has not taken any proactive measures to protect the right to life, survival and development of infants with disabilities. In India, children with disabilities are often seen as a liability. When they are born with an evident disability, there is an unsaid policy at a premier hospital in the capital city, Delhi, to wait and not give any treatment for a fortnight or so. There are no guidelines for doctors/health workers and other medical professionals about what needs to be done if an infant is identified as having a disability. Though there is emphasis on early detection in the disability legislation, there is no system to ensure early rehabilitation. Many a times, the doctor may not know any rehabilitation NGO for referral.

There are quite a few cases of children having mental health concerns. These are brought out by teachers to parents as “problems” in schools and many a times result in expulsion from school or the child dropping out of school.

All the above aspects are discussed in further detail under the respective Articles of this document.

2. Right to Name and Nationality

Children with disabilities who are not registered at birth are at greater risk of neglect, institutionalisation, and even death.²⁶ This aspect has been covered in greater detail in Article 18, ‘Liberty of Movement and Nationality’. India has a clear mandate for registering all births in the country. **There is no data with respect to registration status of children with disabilities.** However, one can logically assume that the chances of children with disabilities not getting registered are high due to many reasons. When a child with disability is born, the family may be in a state of shock/confusion and registering may not even come to their mind. There are many street children with disabilities; some children are abandoned at birth, hidden from the society etc.

3. Right to Protection from Abuse, Exploitation and Neglect

Article 16 highlights the need for child-focused legislation, measures, rehabilitation and awareness against exploitation, abuse and violence. Children with disabilities are more prone to violence and abuse. Many international studies too have found that children with disabilities are at a greater risk than their non-disabled peers to sexual abuse in families, in institutions, in schools and other situations. In India, there are many beggars who have disability. Either they are made to beg by their families or sometimes, the beggars’ mafia

²⁵ Dr (Brig) M L Kataria, ‘War against disability-Fighting for the right of the child’, 29 May 2002, accessed at www.tribuneindia.com on 10th October 2011.

²⁶ Para 36, General comment 9, The rights of children with disabilities, page 62, ‘Understanding the Convention on the Rights of Persons with Disabilities’, Marianne Shulze, referred to CRC.

make children disabled in order for them to earn more. **Most cases of violence and abuse against children with disabilities are unreported/under reported and sometimes even supported by community, justifying the difficulties and stress of taking care of children with disabilities.**

"A group of 16 girls had all been sexually abused/assaulted in school hostels and had not been able to talk about it to any one or even knew that what was being done was illegal or wrong."

-Arun Rao, Deaf Way.

"I was about 13 years old. My father took me to a market place. He asked me to sit under a tree and said he would go and buy a dress for me. He never returned! I was taken from one police station to the other and abused....."

-a girl with disability.

"My caretaker had a lot of power on me. He would take advantage of my condition. I was totally dependent on him. He would also sexually abuse me. When I tried to talk about it to others, they felt I was just seeking attention and hushed up the matter!"

-a boy with disability.

"I face verbal abuses every day in the family for my disability. I do not get taken anywhere..."

-a girl with disability.

"My child was routinely being beaten up in the school by his teacher for not studying and for misbehaving. I finally had to remove him from the school."

-Parent of a child with learning disability.

There have been quite a few instances of **sexual abuse and rape** that have been reported in the media from time to time. There would be many more instances which may not get reported.

A 12 year old mentally challenged, hearing and speech impaired girl was raped by CRPF constables. The inhuman incident took place at the Sai Vikas Home and School for Mentally Retarded at Bhimaram in Andhra Pradesh. The CRPF camp was located near the institution.

-Email from Kanti Ganguly, Convenor and Muralidharan, National Platform for the Rights of the Disabled (NPRD)

Many of the **redress mechanisms/help-lines for children do not adequately cater to children with disabilities.** Children with disabilities do

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not know whom to talk to about their feelings, about abuse, about their fears. There are no guidelines by the State for schools and other organisations on how to handle situations/complaints of abuse against children with disabilities. There is also hardly any information available regarding cases where the issues have been brought to their notice or resolved or where the accused have been punished.

Though the National Commission for Protection of Child Rights (NCPCR) has disability on their agenda, there isn't much information on their website regarding any initiatives particularly in the area of protecting them from violence and abuse.

"I have been working in the field of child rights. I have hardly seen any child with disability using any of the systems established for child rights. The only time these systems are used are when they are found abandoned on the streets and they are taken to the magistrate before admitting them to children's homes."

-Disability activist working in the area of Child Rights

"State run children's homes have nothing much to offer to children with disabilities. Sometimes they shift children with disabilities to homes run by NGOs, but most NGOs do not take children with moderate/severe disabilities. They remain in the children's home till the age of 18 and then are shifted to adult homes later."

-Lawyer working in the area of child rights.

Sex education and awareness about abuse is often not part of curriculum in many regular and special and mainstream schools. The assumption is made that children with disabilities do not need it or it may unnecessarily "increase their desires"!

4. Right to Family and Home

Article 23, Right to Home and Family, mentions that the State should ensure that children with disabilities have equal rights with respect to family life and take measures to prevent concealment, abandonment, neglect and segregation of children with disabilities. It also requires States Parties to provide early and comprehensive information, services and support to children with disabilities and their families. It also states that persons with disabilities, including children, retain their fertility on an equal basis with others.

Due to factors like ignorance, lack of acceptance by society, lack of facilities like social security provisions, families are demoralised and are compelled sometimes to abandon children with disabilities. Further, being abandoned, they are not considered for adoption, more so by Indian citizens, for the reasons cited above. The Government has not recognised the

enormity of the issue. There are no proactive measures taken by the State to ensure children with disabilities are not deserted in the first place.

"30 per cent of the male children received from child reception centres all over the State have some kind of disability. We have almost 150 couples that are waiting to adopt children from here. But, all of them want only normal children," - V.S Gandhinathan, Senior Adoption Coordinator of Families for Children and a member of the Child Welfare Committee at Coimbatore.²⁷

As per data available between 2007-2008 with Child Line Lucknow, out of the 27 new born abandoned children, 21 were females and had disability. While out of 19 boys abandoned, 10 had disability and out of the total of 50 found abandoned in one year, 31 were disabled and females.²⁸

Retaining fertility as a right is not granted to many persons with disabilities. The convenience of the caretaker is often the priority in such instances.

Human rights activists are up in arms against a recent decision by the Maharashtra State Government. The Government proposes to perform hysterectomy operations on mentally challenged women. The reason it gives is that 'mentally retarded adolescent girls or adult women during menstruation have no sense of hygiene.'²⁹

5. Right to Education, Equal Access in Play, Recreation, Leisure and Sports

Article 24 is on Right of Education. The Government is making some efforts in this area. The Sarva Shiksha Abhiyan (SSA) policy ensures that every child with special needs, irrespective of the category and degree of disability, is provided meaningful and quality education. SSA has a zero rejection policy. This means that no child having special needs should be deprived of the right to education and taught in an environment, which is best suited to her/his learning needs. However, **there are several issues related to implementation**, which have been discussed in the Chapter on Right to Education in this document.

Article 30 provides for States to take steps to ensure "children with disabilities have equal access with other children to participation in play, recreation and

²⁷ 'Adoption: disabled children are shunned, Anasuya Menon', The Hindu, Aug 15, 2006, accessed at <http://www.hindu.com/2006/08/15/stories/2006081510130100.htm> on 10th October 2011.

²⁸ 'Children of a lesser God? Abandoned and Stricken too!', By Anjali Singh, NI Wire, February 10, 2009, accessed at <http://www.newstrackindia.com/newsdetails/66829> on 10th October 2011.

²⁹ 'Maharashtra Government Recommends Hysterectomy to the Mentally Challenged', Mental Health News, January 30, 2008, accessed at <http://www.medindia.net/news/Maharashtra-Government-Recommends-Hysterectomy-to-the-Mentally-Challenged-32420-1.htm> on 10th October 2011.

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leisure and sporting activities, including those activities in the school system. Some special schools regularly organise extra-curricular activities for their students. However, no information was available in the Annual Reports of the Ministry of Human Resource Development and the Ministry of Social Justice and Empowerment regarding how extra-curricular activities/sports are being encouraged in regular schools for children with disabilities.

6. Awareness and Participation

The need to raise awareness and foster among children respect for the rights and dignity of persons with disabilities, particularly within the education system, is covered in Article 8.

There is no evidence of any systematic work being done in this area to include disability awareness in the school education.

Article 4 provides for **consultation with children with disabilities** in the development and implementation of legislation and policies implementing the Convention. Government has not taken any measures to consult children with disabilities. The New Law on disability is currently being framed in the country. **There has been no effort on the part of the drafting committee to consult children with disabilities.**

7. Dialogue between Different Ministries

Disability comes under Ministry of Social Justice and Empowerment. Child Rights is under Ministry of Women and Child Development. **There is no active dialogue or collaboration between the two Ministries to implement the various child rights programmes.** Children's concerns being a cross cutting issue, several other Ministries, like the Ministry of Health, Ministry of Human Resource Development, Ministry of Youth and Sports Affairs have to come together to work on various aspects. This aspect of convergence seems to be completely missing when it comes to dealing with children with disabilities in the country.

Recommendations

- 1) Make necessary amendments in existing laws need to not only include children with disabilities but also ensure accessibility and accommodation for all services and support.
- 2) Disability laws should have stringent provisions to ensure right to protection from abuse, exploitation and neglect of children with disabilities.
- 3) Children with disabilities need to be included in all relevant provisions and programmes initiated by various Ministries. Data on beneficiaries with disabilities needs to be maintained. Budget allocation for children with disabilities needs to be part of each of these programmes.
- 4) Children with disabilities should be included during consultations with respect to child rights. When preparing disability laws and policies, children should be included as one of the key stakeholders.

- 5) Coordination between different relevant Ministries needs to be established.
- 6) Curriculum of disability professionals, health professionals, mental health professionals, social workers and even teachers need to include concerns of children and adolescents with disabilities. Government needs to support NGOs and schools working with children to include children with disabilities in their programmes.
- 7) Child friendly and disabled-friendly redress mechanism to be established at various levels by the Government, private and NGO sectors.
- 8) Programmes for raising awareness amongst children, parents, teachers, community workers, professionals, etc. on rights of children with disabilities needs to be initiated at local, District, State and National levels by Ministry of Information and Broadcasting through various mediums.

Article 8: Awareness Raising

The text of Article 8 in the CRPD is given below.

1. States Parties undertake to adopt immediate, effective and appropriate measures:
 - a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
 - b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
 - c) To promote awareness of the capabilities and contributions of persons with disabilities.
2. Measures to this end include:
 - a) Initiating and maintaining effective public awareness campaigns designed:
 - To nurture receptiveness to the rights of persons with disabilities;
 - To promote positive perceptions and greater social awareness towards persons with disabilities;
 - To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;
 - b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;
 - c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;
 - d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.

Survey Findings

Two questions were asked in the survey regarding Article 8. The first was on whether the Government had put enough effort into creating awareness amongst persons with disability regarding their rights and the other was on whether the officials within the Government itself were made aware of these rights.

1. The results with respect to the efforts made by the Government to create awareness amongst persons with disabilities, their families and the society at large about disability rights, as per the CRPD are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	48%
Dissatisfied	40%
Satisfied	10%
Extremely satisfied	0%
Do not know much about the issue	1%

About 88% respondents have expressed dissatisfaction with respect to the efforts made by the Government to create awareness amongst persons with disabilities, their families and the society at large about disability rights. About 10% have expressed satisfaction. There have been some efforts in creating awareness, which has largely been undertaken by NGOs and to some extent by the Government. But the majority of respondents have expressed dissatisfaction with the Government's efforts. Most of the campaigns of the Government focus on prevention of disability and portray images of persons with disabilities as objects of pity and charity.

2. The results with respect to the efforts made by the Government to create awareness amongst Government officials (central and local) are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	60%
Dissatisfied	26%
Satisfied	7%
Extremely satisfied	0%
Do not know much about the issue	7%

About 86% respondents have expressed dissatisfaction with respect to the efforts made by the Government to create awareness amongst Government officials (central and local). Only about 7% have expressed satisfaction. About 7% have mentioned that they do not know about the issue. When persons with disabilities interact with Government officials for various provisions/entitlements, continue to face a lot of difficulties, including rude behaviour, harassment and abuse. The behaviour of the officials reflects their perception that they are doing a favour/providing charity.

Laws and Policies

None of the disability laws make a specific mention of awareness creation, as mentioned in the CRPD. **The Disability Act, 1995**, mentions awareness creation, campaigns and information dissemination only in relation to prevention and early detection of disabilities! This is a major gap in the disability laws of the country.

The Central Board of Film Certification (CBFC) is a regulatory body under

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the Ministry of Information and Broadcasting, Government of India. The Censor Board of India basically censors and reviews movies, television programmes, television advertisements or any sort of promotional materials.

The Cinematograph Act, 1952, Cinematograph (Certification) Rules promulgated in the year 1983 and the guidelines issued on December 6, 1991 under Section 5B of the Cinematograph Act guides the Censor Board in the censorship of films. The Cinematograph Act, 1952 does not specifically mention 'portrayal of persons with disability' as a criteria for deciding the certification of the film for public viewing.³⁰ However, the detailed Guidelines for Certification of Films, issued in 1991, states that a film shall not be certified for public exhibition, if, in the opinion of the authority competent to grant the certificate, the film or any part of it is "showing abuse or ridicule of physically and mentally handicapped persons".³¹

A redress body, **Broadcast Content Complaints Council (BCCC)**, has been established to self-regulate the content of all non-news TV channels in India on 1st June 2011. It will regulate the 550 Indian general entertainment television channels, children's television and special interest channels, to prevent the broadcast of vulgar or offensive content, and provide a mechanism of redress for public complaints. The guidelines now divide India's broadcast content into two categories. 'G' stands for content suitable for unrestricted viewing or under parental guidance, while the second category, 'R' is for restricted content to be aired after 11pm and before 5am.³² This puts the onus on the viewers to file a complaint. It is a relatively new initiative of the Government and it would largely depend on the advocacy of persons with disabilities to use this redress mechanism effectively.

Progress and Concerns

1. Public Awareness Campaigns and Information Dissemination

Most of the discrimination that happens against persons with disabilities can be attributed to lack of awareness/correct understanding of disability (from a human rights point of view). Hence, awareness is extremely crucial to achieve equality.

The Ministry of Social Justice & Empowerment (MSJE), the nodal Ministry for Disability, organises awareness programmes to create awareness, particularly to disseminate information about their various schemes. According to the Annual Report of MSJE (2009-10), under the '**Scheme for Implementation of Persons with Disabilities Act**', funds were allocated for creation of awareness. State level workshops were organised by National Handicapped Finance Development Corporation (NHFDC), National Institutes and District

³⁰ 'Harmonizing Laws with the UNCRPD – Human Rights Law Network, Deaf Way and NAD', Edited by Dr. Amita Dhanda and Rajive Raturi, May 2010.

³¹ Accessed at

http://www.indianetzone.com/8/central_board_film_certification_%28cbfc%29.htm on 10th October 2011.

³² Accessed at <http://www.rapidtvnews.com/index.php/2011050811965/june-2011-launch-for-indias-broadcast-complaints-council.html> on 20th October 2011.

Disability Rehabilitation Centres to create awareness and to promote their schemes and services.

The National Trust organised 1084 training programmes in different States. **National Trust's, 'Badhte Kadam** – Mobile Disability Awareness Expedition', covered 14 States of India in four different routes, covering 60 NGOs of National Trust. They created awareness on the rights of persons with autism, cerebral palsy, mental retardation and multiple disabilities. They also have a helpline, 'Abiline', for answering queries and counselling support for people with disabilities and their families.³³

The Rehabilitation Council of India (RCI), in collaboration with the Media Lab Asia, has developed a comprehensive **national web portal, namely, 'www.punarbhava.in' on disability**. The portal is designed to provide all related information regarding different disability issues at one platform. This will help persons with disabilities, professionals, policy makers, students, parents, community workers, and other stakeholders to access information relating to disability sector on a regular basis.³⁴

The **Education Satellite Channel 'NAVSHIKHAR'** has been set up at RCI Office in collaboration with Indian Space & Research Organization (ISRO) and Media Lab Asia (MLA). More than 500 study centres/institutions have been connected through this station for the benefits of the students, trainees and parents of the persons with disabilities. Live telecast/re-telecast of recorded programme/teleconferencing is done on regular basis.³⁵

According to the Annual Report of Ministry of Information and Broadcasting, the Ministry, one of whose main role is information dissemination, launched a campaign based on the advisories received from the MSJE, regarding implementation of the provisions of the CRPD. The Report states, "**Programme, highlighting provisions covered under Articles 8, 9, 21, 27 and 30 of the CRPD were broadcast creating social awareness on the issues of persons with disabilities**".³⁶

Under the **University Grants Commission's** (which comes under the Ministry of Human Resource Development) scheme for 'Higher Education for Persons with Special Needs', **one of the components in the funding is the establishment of enabling units for "differently-abled"** persons to inter-alia provide guidance and counselling and create awareness about the needs persons with disabilities.³⁷

The Office of the Registrar General and Census Commissioner, under the Ministry of Home Affairs, **organised trainings on the disability question in Population Census 2011, to the enumerators and their trainers**. It was a collaborative effort between the disability sector and the Census Commission. NCPEDP developed the Training Module and trained the National Trainers, Census Officials and select NGOs, who then trained the Trainers at the State

³³ Annual Report, Ministry of Social Justice and Empowerment, 2009-10.

³⁴ Page 149, Annual Report, Ministry of Social Justice and Empowerment, 2009-10.

³⁵ Page 148, Annual Report, Ministry of Social Justice and Empowerment, 2009-10.

³⁶ Page 142, Annual Report of Ministry of Information and Broadcasting, 2010-11.

³⁷ Page 150, Annual Report, MSJE, 2009-10.

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level and the enumerators. NGOs and DPOs, particularly people with disabilities, were actively involved in the training at the National, State and District level in many States. The training at District and Village levels were conducted in the local language.

The training was done in a cascade manner, covering 90 National Trainer, 725 Master Trainer Facilitators, 54000 Master Trainers and 27 lakh enumerators and supervisors. People involved in the Census were mostly school teachers and public servants. Hence, this training helped in sensitisation and awareness creation on disability issues in general throughout the country. Posters and TV spots to highlight the importance of disability question in the Census were also brought out by the Census Commission and aired on national channels during the Census enumeration period.

The larger scale awareness campaigns of the Government are on prevention of disability or to disseminate information about their schemes, by having large hoardings or newspaper advertisements, which are not very effective in terms of communication and mostly not seen by the larger public. The Government has reported that they have undertaken awareness campaigns on the CRPD.³⁸ However, **very few people in the country are aware of the CRPD, including those involved in the sector.**

"I am a District Committee Member of the National Trust and have been attending the meetings regularly since the past 8 years, never has anyone mentioned/discussed anything about UNCRPD. My region has been totally neglected of the same."

- Rajni Bala, Himachal Pradesh, In response to the UNCRPD Questionnaire.

"A Minister in charge of Education had recently said in the public that children with disabilities should study only in special schools. One other Minister spoke at length in a disability conference about how all blind people are great singers. If that is the awareness at the Ministerial level, you can very well imagine the kind of awareness that exists at various other levels in the Government."

-A disability activist

"I am not sure if awareness has increased in the society. My family still does not take me to any social functions because they have to face a lot of questions from our relatives. I am of marriageable age and I don't think they are thinking about my marriage. They are more worried that my sister and my brother would have difficulty finding a life partner because of my disability."

-Geetha (name changed) from Tamil Nadu.

³⁸ Page 142, Annual Report, Ministry of Information and Broadcasting, 2010-2011.

"I have Bipolar disorder from the year 1992. Till date, I do not know about any provisions, which regards psychiatric illness/condition as a disability! Therefore, I have never accessed any Governmental support regarding the same."

-Response to the CRPD Questionnaire

There have been several NGO initiatives in creating awareness among various stakeholders such as Government officers, judiciary, medical fraternity, architects, school teachers and students, employers and general public. NGOs also organise awareness campaigns, like film festivals, cultural shows and walkathons.

Some NGOs have a focussed programme for creating awareness about the CRPD, particularly among people with disabilities. They have translated the CRPD in local languages. They have organised training workshops for people with disabilities to develop better understanding of the rights and have brought out posters. Most of these initiatives are either locally funded or supported by international agencies.

The World Disability Day has been promoted in a major way by the disability sector to create awareness amongst larger public. Disability Rights Movement uses this opportunity to not only bring disability to the centre stage but also to showcase solidarity and the strength of the growing cross disability rights movement in the country. A few corporates that have a focussed programme for disability are using the 1st week of December to celebrate diversity and create organisation-wide awareness. Media also gives disability good prominence by having a dedicated supplement or special features or discussions/interviews etc. on the issue.

"It is the duty of the Government to translate the CRPD in all regional languages of India so that it could reach the grass root level. Government has failed in its duty and not adopted necessary measures. The well aware NGOs have themselves translated the CRPD into various regional languages. The National Association for the Blind, (India) had translated the CRPD in Marathi with the able support of NCPEDP and distributed the copies of this Marathi translation in all parts of the State of Maharashtra.

-Suhas Karnik, National Association for the Blind (India)

The Bethany Society in Meghalaya is implementing a three year project entitled, 'Disability Rights Movement in Meghalaya'. A major focus of the project is to have a vibrant DPO in every Block of Meghalaya. The Bethany Society is using the UNCRPD as the basic document to create awareness about rights of persons with disabilities. The Society through its Legal Awareness Cell has organised consultations and focussed group discussions at various levels. They are also working towards preparing a shadow report on CRPD.

-Response to the CRPD Questionnaire

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However, the campaigns of NGO do not have a very wide reach. Their campaigns are targeted to cover a small area or a few Districts or at the maximum a State. For most NGOs, resources are a major constraint and hence, their coverage is limited.

2. Education System and Trainings

Article 8(2)(b) of the CRPD talks about fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities. **There has been no discussion or debate regarding incorporating rights of persons with disability in the curriculum of any subject in school education.** However, a few schools have sensitisation programmes for students and parents on disability, which can be traced to a local NGO/DPO initiative which would be working in that area towards inclusive education.

The Sarva Shiksha Abhiyan has a component of inclusive education and has developed **booklets for guiding teachers and parents.**³⁹

The **Lal Bahadur Shastri National Academy of Administration**, which trains Civil Service Officers of the Indian Administrative Service, Indian Police Service, Indian Foreign Service, Indian Forest Service, Indian Revenue Service, Indian Audits and Accounts Service, Indian Railway Traffic Service, and other Government agencies, **has included disability as part of their training programme.** No other information could be found on any other systematic/structured training that is being given to any other public officials, customer support people, including people working directly with people with disabilities, like the placement officers, medical officers issuing disability certificates, or officers in-charge of pension, bus passes etc.

Disability Studies has been recently introduced as a Masters level course in a few Universities. Disability forms a very small component of a few subjects like Architecture and Teachers Training. Under other subjects of higher education or specialisation that are closely related to disability like Management, Administration, Development Studies, Human Rights, Media Studies, etc. disability is not part of the curriculum.

3. Media

Media plays a crucial role in creating images and perceptions, which have a lasting effect on people's mind. Media also can influence the thinking of policy makers and can help in building public opinions on issues.

A few Indian films, particularly in the recent past, have portrayed persons with disability in a positive manner, which reflects the changing mindset of the society. However, **majority of the films portray persons with disability in a negative way** - as evil characters, reinforcing the theory of karma and disability

³⁹ Accessed at http://ssa.nic.in/page_portletlinks?foldername=inclusive-education on 12th October 2011.

being a curse; or to add a comic factor, or to arouse feeling of sympathy, by showing dependency or helplessness.

"On behalf of people who stammer, we, The Indian Stammering Association, wish to lodge a strong protest with the Central Board of Film Certification (popularly known as the Censor Board of India), with respect to the movie "Golmaal-3". This movie has been cleared for screening in India by the Censor Board. The movie features a character with a stammer (played by Shreyas Talpade), and clearly portrays the character as an object of ridicule. The movie repeatedly makes fun of people who stammer, and by doing so, humiliates them, and portrays a disability in a negative light, in the name of cheap humour. It promotes the stereotype that persons who stammer are mentally deficient and are incompetent. This thoughtless depiction would adversely impact the millions of Indians with a speech impediment, and would only increase bullying of stammerers in schools, propagate negative perceptions of stammerers during interviews and at the workplace, and would make ours a society where it is acceptable to poke fun of people who stammer."

-Extract from a Petition filed by Dr Satyendra Srivastava (Coordinator), for The Indian Stammering Association to the Censor Board.⁴⁰

Television and Radio are very powerful mediums to reach the masses but remains largely unutilised by the Government. Even local language programmes on the TV/radio fail to create awareness on disability. Sometimes there are specific programmes on disability like a 'phone-in' programme, a panel discussion, but these are very rare and the viewers/listeners are limited. Disability does not figure in the general programmes, thus, the reach becomes restricted. **The persons with disability in television serials are portrayed in a stereotypical way. In general, the content of these serials is not well researched and can be misleading.**

Print Media, though reducing in its popularity, continues to play a role particularly in influencing policy makers through editorials, feature stories etc. The priority given to social issues including disability is quite low. Only events organised by NGOs, or politicians distributing aids and appliances get reported. **Very rarely, one comes across issue-based coverage or editorials.** Most organisations are busy with providing services and are media shy. Only in the last decade or so, disability sector has used media effectively to raise issues.

A lot of credit can be given to media for playing a very crucial role in many of advocacy campaigns taken by the disability rights movement of the country, particularly in Delhi and to some extent in other parts of the country where disability activists are media savvy.

With privatisation of media, social and public awareness is not a priority for radio, print or visual media. Many newspapers/channels openly refuse to do stories on social issues saying it does not have readership/viewership. Moreover, the cost of airing a **TV spot or radio advertisement or advertisement in**

⁴⁰ Accessed at http://www.petitiononline.com/mod_perl/signed.cgi?TISA0001 on 12th October 2011.

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newspaper is so high, that it is beyond the reach of any NGO or DPO. Many of the films/spots made by NGOs/DPOs gather dust in the shelves because they do not have resources to air them.

Social Networking sites, like Facebook, Twitter etc. are gaining a lot of popularity with the urban middle class. This medium is yet to be effectively tapped for disability awareness.

Education and training of media professionals is crucial for them to become passionate about the cause of disability. Some NGOs have played a role in sensitising film makers, theatre personalities and journalists. People with disabilities are beginning to take up media as their profession but there are barriers and mindsets which make it quite difficult.

Recommendations

- 1) Disability laws should mandate relevant stakeholders, including the private sector, to undertake awareness programmes on disability etiquette, issues and rights.
- 2) Stronger legislation for Censor Board to ensure that negative, stereotypical and misleading information about disability is not given by the films.
- 3) Each concerned Ministry should allocate a part of their Budget for awareness creation for disability related information dissemination.
- 4) Awareness programmes should be planned and budgets allocated at Village, District, State and National levels, so that persons with disabilities are aware of their rights and know where to go in case of complaints.
- 5) Relevant bodies that make curriculum for school education should include age appropriate information about disability, which could include stories of successful people with disabilities, information about rights, etc.
- 6) Curriculum of professional courses and services should include disability issues (for journalists, doctors, architects, film makers, Government officers, social workers, customer support, security guards, etc.)
- 7) Disability studies should be introduced as a separate course in various Universities.
- 8) People with disabilities should use media to spread awareness on various issues that concern them. Leadership training programmes for persons with disabilities can include this aspect in the trainings.

Article 9: Accessibility

The text of Article 9 in the CRPD is given below.

1. *To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:*
 - a) *Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;*
 - b) *Information, communications and other services, including electronic services and emergency services.*
2. *States Parties shall also take appropriate measures:*
 - c) *To develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;*
 - d) *To ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;*
 - e) *To provide training for stakeholders on accessibility issues facing persons with disabilities;*
 - f) *To provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;*
 - g) *To provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;*
 - h) *To promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;*
 - i) *To promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;*
 - j) *To promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.*

Survey Findings

Seven questions were asked in the survey regarding Article 9. Given below are the responses.

1. The findings with respect to the efforts made by the Government to promote **accessibility of built environment** are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	56%
Dissatisfied	39%
Satisfied	4%
Extremely satisfied	0%
Do not know much about the issue	1%

2. The findings with respect to the efforts made to promote **accessibility of transport** are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	61%
Dissatisfied	30%
Satisfied	9%
Extremely satisfied	0%
Do not know much about the issue	0%

3. The findings with respect to the efforts made to promote **accessibility of services (health, banking, etc.)** are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	56%
Dissatisfied	37%
Satisfied	7%
Extremely satisfied	0%
Do not know much about the issue	0%

4. The findings with respect to the efforts made to promote **accessibility of information** are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	54%
Dissatisfied	40%
Satisfied	6%
Extremely satisfied	0%
Do not know much about the issue	0%

5. The findings with respect to the efforts made to promote **accessibility of consumer goods** are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	74%
Dissatisfied	18%
Satisfied	5%
Extremely satisfied	0%
Do not know much about the issue	3%

6. The findings with respect to the efforts made to promote **accessibility of Information Communication Technology (ICT)** are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	41%
Dissatisfied	38%
Satisfied	15%
Extremely satisfied	0%
Do not know much about the issue	6%

7. The findings with respect to the efforts made to promote **availability of assistive devices** are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	56%
Dissatisfied	29%
Satisfied	10%
Extremely satisfied	1%
Do not know much about the issue	3%

The satisfaction of respondents on various aspects of accessibility ranges from 4% - 15%. The number of respondents who have expressed satisfaction for accessibility to Information, Communication and Technology (ICT) is comparatively higher (15%). This could be because of the Government's policy decision to adopt Web Accessibility Standards and for its commitment to make Indian Government websites compliant to the Standards. These actions are being seen as concrete steps towards promoting accessibility. The overall dissatisfaction rate is quite high across all aspects of accessibility ranging from 79% to 95%. The dissatisfaction level is highest for built environment (95%) as most roads, footpaths and buildings remain inaccessible in the country. Accessibility is very crucial for people with disabilities to participate in the society with dignity on equal basis with others. The high level of dissatisfaction is because people are facing issues on a daily basis; whether they have to travel, visit a public place, access a public service or use the Internet. The changes are very few and restricted to certain high end products/services/big malls etc. and are not impacting the common people much. Accessibility is still an afterthought and not included in the planning or design stage of any development programmes.

Laws and Policies

The Disability Act, 1995, (Clause 44 - 46) provides for non-discrimination in transport, roads and in the built environment. In the Chapter on Education, it provides for removal of architectural barriers from schools, colleges or other institutions imparting vocational and professional training (Clause 30). Though it mentions provision of books for children attending school, it does not specify books in Braille or any other accessible format. In the Chapter on 'Coordination Committee', it mentions that the Central and State Coordination Committees should take steps to ensure a barrier-free environment in public places, workplaces, public utilities, schools and other institutions.

The National Trust Act, 1999, and **The Mental Health Act, 1987**, has no mention about Accessibility

The Ministry of Urban Development has formulated the **Guidelines and Space Standards for Barrier-Free Built Environment for Disabled and Elderly Persons**, 1998. The Ministry has also framed model building bylaws which includes accessibility of facilities for persons with disabilities.

The National Building Code 2005, in Annexure D, has 'Special Requirements for Planning of Public Buildings Meant for Use of Physically Challenged'.

The **Ministry of Information Technology has adopted Web Content Accessibility Guidelines 2.0** and has made a commitment for making all its websites disabled-friendly. (2009).

Other legislations like The Aircraft Act, 1934, The Airports Authority of India Act, 1994, The Ancient Monuments and Archaeological Sites and Remains Act, 1958, The Cantonments Act, 1924, Contract Labour (Abolition & Regulation) Act, 1970, The Factories Act, 1948, The Government Buildings Act, 1899, Mines Act, 1952, Motor Vehicles Act, 1988, Plantations Labour Act, 1951, Representation of Peoples Act, The Bombay Lifts Act 1939 (As applicable to Delhi) and Delhi Lift Rules 1942, need to be reviewed and amended suitably.⁴¹

The Copyright Act of 1957, Delivery of Books & Newspaper (Public Libraries) Act, 1954, all e-governance standards, IT policies and procurements policies, etc. need to be reviewed and amended to include accessibility for persons with disabilities, as per the CRPD.

Progress and Concerns

With the clear mandate of accessibility in The Disability Act 1995, there has been some development in this area. The disability rights movement has also been very active in advocating about accessibility issues in the last 10 years or so. As a result, some initiatives have been taken up by the Government in the areas of physical environment, transportation, information and communication. However, the impact has not been much. The following sections analyse the current

⁴¹ 'Harmonizing Laws with the UNCRPD', Human Rights Law Network, The Deaf Way Foundation, National Association of the Deaf, Edited by Dr. Amita Dhanda and Rajive Raturi, May, 2010.

scenario and the gaps with respect to the various provisions given in Article 9 of the CRPD.

1. Physical Environment

With respect to the physical environment, according to the Ministry of Urban Development, **Model Building Bylaws** have been framed which have been adapted by 28 States/Union Territories. All State Governments have been requested to appoint a **Nodal Officer in each District** to bring non-compliance to the notice of the concerned authorities. Governments of Goa and Lakshadweep have appointed such Nodal Officers. The Ministry has also framed an **action plan for promotion of barrier-free built environments** which focuses on the pursuit of amendments of building bylaws with States, review of guidelines for barrier-free built environment, access audits of buildings, awareness generation, capacity building and monitoring. The **Ministry has undertaken access audits of 40 buildings located in Delhi/New Delhi so far**. These reports were reviewed and passed on to the concerned departments and central public works for action. The Ministry also organised capacity building and awareness generation workshops for the concerned departments.⁴²

There has been some effort on the part of the Central Government in terms of framing guidelines, developing model bylaws and writing to States to appoint Nodal Officers. It has been over 15 years since the passage of the Act which clearly mandates accessibility of public buildings. **Seven States/UTs have still not adopted the Model Bylaws. Only 2 States have appointed Nodal Officers!** The Ministry mentioning that only **40 buildings have been audited even in the capital city is again indicative of very slow progress**. Information on the development in other States/UTs was not available. In spite of adopting the bylaws by most States/UTs, there are hardly any changes at the ground level.

As mentioned in the chapter on Article 24, 7.27 lakh (58.02%) schools have been made barrier-free (Annual Report of Ministry of Human Resource Development (MHRD) (2010-11). The term 'barrier-free' used in **Sarva Shiksha Abhiyan (SSA) seems to be very restrictive to include only ramps and handrails, as evident from the SSA Manual**. There seems to be no standards specified. Another issue is the **pathway to schools** which seem to have not been addressed at all. For example, a child in the rural area may find it extremely difficult to go through a field to go to school even though the school may not be very "far".

There has also been no effort on the part of the Government to ensure that buildings used for public service and owned by the **private sector** are accessible. Apart from a few large malls located in metropolitan cities, most buildings (shopping centres, clinics, restaurants, banks, etc.) remain inaccessible.

The **Jawaharlal Nehru National Urban Renewal Mission (JNNURM)** was launched in 2005 with the objective of reforms driven and fast track

⁴² Response to RTI filed by NCPEDP, October 2011.

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development of cities across the country. The focus of the mission is on bringing about efficiency in urban infrastructure, service delivery mechanisms, community participation and accountability of urban local bodies and Parastatal agencies towards citizens.⁴³ About 63 cities are covered under the programme. Disability does not seem to be included in the agenda of JNNURM. While modernisation is on fast track in India, it leaves behind the needs of persons with disabilities.

There are also programmes like the '**Provision of Urban Amenities in Rural Areas (PURA)** and the '**Pradhan Mantri Gram Sadak Yojna (PMGSY)**. However, in **rural areas** there has been little effort on making roads, transport and buildings like the community halls, panchayat ghars, shops, marriage halls, places of worship accessible for persons with disabilities.

'**Housing**' is an important aspect for leading a life with protection, safety, security and dignity. There are two issues to this. One is access to housing/shelter and the other is accessibility within the house.

There is reservation for persons with disabilities in Government housing schemes. Housing is a State subject and implementation varies from State to State. Some States are providing 3% reservation for persons with disabilities, some are providing 1% and some are providing none. Some States provide reservation to people with only certain disabilities. The Ministry of Rural Development has a housing scheme, '**Indira Awaas Yojana (IAY)**' under which the total number of Dwelling Units completed during the period 2010-11 (up to December 2010) was 26,86,117 out of which 33,118 (1.23%) houses were allotted in the name of persons with disabilities.⁴⁴ This is way below the 3% which is mandated by the law. The Government has initiated the '**Rajiv Awaas Yojana (RAY)**' which aims at providing support to States that are willing to provide property rights to slum dwellers. The proposal of the scheme has been submitted for consideration to the Cabinet Committee on Economic Affairs as on 10th February 2011.⁴⁵ Nothing specific has been mentioned about disability in the scheme.

The '**Night Shelters, public toilets and drink water outlets**' are also inaccessible to most people with disabilities. Issues related to Housing/Shelters are also covered in chapters on Articles 19 and 28.

2. Transportation System

India's transport sector is large and diverse. Road transportation is the dominant mode of transportation in India today. They carry almost 90 per cent of the country's passenger traffic. Indian Railways has 7,083 stations and carries over

⁴³ Page 20, Annual Report of Ministry of Urban Development 2010-11.

⁴⁴ Annual Report of Ministry of Rural Development 2010-11.

⁴⁵ Page 36, Annual Report, Ministry of Housing and Urban Poverty Alleviation, 2010-11.

30 million passengers. India has 12 major and 187 minor and intermediate ports and 125 airports, including 11 international airports.⁴⁶

Transportation includes bus stops, all road vehicles (urban and rural), railway coaches and stations, airplanes and airports, sea vessels and sea ports, and also the systems that are required for the smooth running of these, like pedestrian safety, traffic management, parking rules, ticketing systems and so on.

There have been some developments in the area of making transportation accessible. These can again be attributed to the clear mandate of the Disability Act and advocacy by the disability sector.

The **National Urban Transport Policy** dwells on all issues related to urban transport but does not address the issue of accessible transport to disabled people and elderly people.⁴⁷

2.1 Roads, Footpaths and Road Transport

Accessibility of roads and footpaths is important because it affects access to health services, education, employment, leisure activities, tourism etc. **Most Indian roads are not only inaccessible for persons with disabilities but are also unsafe. There is massive encroachment of footpaths (where they exist) by parking of vehicles, street hawkers etc.** The surface is usually uneven and sometimes even dug up and broken. People in fact prefer to walk on the side of the road instead of on the footpath due to these reasons, which is also dangerous due to speeding vehicles. In New Delhi, some footpaths have guide blocks which have not been laid properly.

“The pavements in Delhi are been refurbished and most with tactile guidance and ramps at the beginning and end. The amazing part is that the guidance breaks whenever there is an obstacle in the path like trees, poles etc., hence ensuring people with blindness bang into them and majority of the ramps are blocked by bollards, through which a wheelchair cannot pass.”
-Shivani Gupta, AccessAbility.

For the preparation of Commonwealth Games held in New Delhi, an effort was made to make roads and pavements accessible by procuring **disabled-friendly buses** (with ramps etc.) and to make bus stops disabled-friendly. Though the effort was in the right direction, **the voices and suggestions of persons with disabilities were not taken into account.**

Alok Sikka (35) has waited in his wheelchair at bus stops for hours on an end, but most of the time buses have sped past without stopping for him. One of

⁴⁶ Report of Sub-group on Accessibility, Mobility, Research and Innovation for XII Fiver Year Plan (2012-17), e-mail sent by Shivani Gupta to DEOC on 8th November, 2011.

⁴⁷ Accessed at <http://urbanindia.nic.in/moud/programme/ut/TransportPolicy.pdf> on 10th September 2011.

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biggest problems that disabled people face, he says, is commuting. This confines them to their homes for most of their lives.

-Campaign to create awareness about rights for disabled people, The Times of India, Delhi, 4th November, 2011.⁴⁸

Ironically, all bus stands flaunt the accessibility symbol — a person in a wheelchair. "That symbol on these bus stands is a joke," said Shivani Gupta, director of AccessAbility. "Built at a cost of Rs. 25 lakh each, the bus stands have two major problems. One, the ramps on both ends are merged with the pavements, and two, one end of the stop has a huge steel advertisement board which blocks the so-called ramp." Javed Abidi, Director of NCPEDP, agrees. "Practically, there is no ramp to get onto the bus stand. And to get into the new low-floor buses, a person on wheelchair has to be on the bus stand," he said.

"We told DTC several times that bus stands coming up in the city are not disabled-friendly. The advertisement board near the ramp is a big hurdle for a wheelchair-bound person," said Anjee Agarwal, executive director and accessibility consultant at Samarthyam. DTC chairman Naresh Kumar said, "I agree bus stands are not completely disabled-friendly, but we cannot do anything about it as pavements are built by land-owning agencies. If they merge the pavement with ramps, we cannot help it."

-For Disabled on Capital Roads Hurdles Remain, Risha Chitlangia, The Times of India, 31st July, 2010.⁴⁹

"Just yesterday, I went out on my wheelchair and thought of crossing to the other side from the overhead foot bridges that have been built all over Delhi. The bridge is about seven meters high with a ramp 89 meters long of 1:12 gradient to get onto the bridge and the same ramp on the opposite side. In India, most people will say "There is a ramp to get on and off the bridge and that too of 1:12 gradient, then what more do you want?" What they fail to see is that a wheelchair user will need to wheel two hundred meters, that too up and down a ramp to cross just a 10 meter wide road. So its 10 meters verses 200 meters"

- Shivani Gupta, AccessAbility.

Delhi has at least made some efforts in creating accessibility. **However, none of the other cities have taken any such initiatives.** In the IT Capital of India, Bengaluru, several buses are being procured - low floor and semi low floor

⁴⁸ Accessed at http://articles.timesofindia.indiatimes.com/2011-11-04/delhi/30359360_1_disabled-people-disabled-children-ability-development on 24th October, 2011.

⁴⁹ Accessed at http://articles.timesofindia.indiatimes.com/2010-07-31/india/28277965_1_disabled-friendly-wheelchair-bound-person-javed-abidi on 24th October, 2011.

buses – but none of them have disabled-friendly features, like built in ramp etc. and none of the bus stops are disabled-friendly.

“There is nothing like access anywhere. Rajiv was denied a place in the bus going to Madurai because he has a wheelchair. In addition, you need to carry different certificates for getting the concession for travel, like the disability certificate, railway concession and bus concession. Why can't we have just one document/ID card?”

-Dipti Bhatia, Response to the CRPD Questionnaire.

In **rural** areas, apart from the physical infrastructure, the distances and lack of appropriate transport are barriers.

In most States, **Government buses do not ply in the interior areas - districts and villages**. It has been given to private operators. In general, they do not follow any rules and when it comes to people with disabilities, most of them are just not cooperative. They refuse carrying them, they do not stop the bus when they see a person with disability in the bus stop or charge extra money from them and are abusive.

The buses are inaccessible, the restrooms at bus stations are inaccessible, signages and maps are absent, the people at ticket counters are often insensitive and impatient, 'May I help you' or 'Information' counters often do not have anyone to man them. The barriers are innumerable

Bullock carts, horse carts, camel carts, “jugadu” or the indigenously made auto-rickshaws, manual rickshaws, tractors are used in rural areas but are not accessible. Many rural areas in plains, hills, deserts, sea-sides, do not have proper roads and people have to make do with '*kutcha*' roads/pathways on which assistive devices like wheelchairs or tricycles are not of any use, especially during the rainy season.

To travel by a bus, a person with disability, firstly, has to reach the bus stand from his/her house. In most cases, the road leading to the stand would be a mud one and not asphalted. So even if she/he has a wheelchair, they need somebody to push them till the stand. In rainy season with mud puddles and slippery ground the road would be more difficult to navigate.

Once they reach the bus stand, the next problem is to enter the bus shelter, (*if there is one*) which usually has 2-3 steps leading to it with no ramp. Thus, they would end up waiting for the bus to arrive in the heat or under a nearby tree. The waiting time depending on the location of the village and bus service could be anywhere between 5 minutes to 1 hour. On the arrival of the bus, there is a mad rush to get inside and the disabled person is more likely to be pushed around. Then arrives the moment of truth: 'the wheelchair cannot fit into the bus doorway' and there is no ramp for the wheelchair to be pushed in, which effectively means the disabled person has to get out of the chair and be either physically lifted or crawl into the bus. The wheelchair if foldable would be allowed into the bus.

The problems faced by other disabled people – those with visual, speech and hearing impairment are even worse, with no signages or zebra crossings to help them. The only other alternative for a disabled person is to hire private transport like - *rickshaws*, bullock carts, etc to travel. Although, none of these systems have accessible features and are expensive compared to government transport, they nevertheless offer the convenience of home pick-up and drop. -Vardhani Ratnala, 'It is not disability but the system which makes a person disabled'.⁵⁰

The private high end vehicles such as cars and taxis are also not accessible in India. **Vehicle Manufacturers do not make fully disabled-friendly vehicles and modifications are required to make them disabled-friendly.** There are no accessible taxi services in the country, except one or two which are run by NGOs and have very few vehicles. The taxi service is extremely expensive. One positive thing is that there is excise duty and road tax exemption for people with disabilities on purchase of cars.

A major issue is that people with disabilities are often denied driving license due to prevailing misconceptions. **A landmark judgment was passed by the Delhi High Court in 2011 which opened doors for deaf people to take driving test to get driving licence.** The issue is covered in detail in Chapter on Article 20, Personal Mobility.

2.2 Airlines

Indian Airlines faced the very first litigation in 1997⁵¹ on the basis of the Disability Act, 1995. As a result, ambulift and aisle chairs were introduced in certain airports. However, with many private sector flights operating in the last few years, there were many issues faced by persons with disabilities. As a result of the pressure from the disability sector, **Directorate General of Civil Aviation (DGCA) issued a Civil Aviation Requirement (CAR) Section 3, Air Transport, Series M, Part 1 dated 1st May 2008 regarding carriage by air of persons with disabilities and/or persons with reduced mobility.** (Response to RTI by NCPEDP dated 11th October 2011).

These are certainly positive developments but at the ground level, people with disabilities continue to face problems, due to insensitivity and lack of awareness on the part of staff/officials and lack of systems to provide the necessary support. The airports have certain accessibility features like elevators, washrooms etc. However, there seems to be a lack of any standards that is being followed. Even the new airports of Delhi and Bengaluru have a lot of barriers. There has hardly been any change in the design of the aircraft itself to make it accessible for persons with disabilities.

⁵⁰ Accessed at http://www.ifrtd.org/new/issues/op_disability2.php on 1st November, 2011.

⁵¹ NCPEDP website <http://www.ncpedp.org/policy/judg-ac01.htm>; Javed Abidi vs Union of India & Others, accessed on 1st August 2011

"I boarded the Kingfisher flight from Ahmedabad and reached Mumbai, from where I was supposed to take a connecting flight to Goa. I had barely taken a seat in the connecting flight around 12.30 pm when a crew member came and asked me to follow him. He also asked me to take my cabin baggage and kids with me. Initially, I thought that he must be changing my seat, but realised something was amiss when he took me to some stairs. I asked him why he was making me get off the plane but he refused to answer. When my kids and I got off, they closed the aircraft's doors and took off, leaving us standing there."

-Shabnam Mansuri⁵²

"Jet and Kingfisher airlines have stated to me that without service animal no blind (person) is allowed to fly overseas with them"

-Girish Sethi⁵³

2.3 Railways

Based on the information given in the Sub Group Report on Accessibility for the XII Plan, Indian Railways has so far manufactured 2100 specially designed non air conditioned coaches having accommodation for persons with disabilities. Also it is mentioned that 58 A1 class, 284 A class and 138 B class stations have been made accessible. These may seem positive steps. **However, there are a lot of issues that people with disabilities are facing while travelling by railways, particularly in the so-called "disabled-friendly" coaches.** It is an unreserved coach, which is not useful for passengers who may like to make bookings in advance. Few months ago the Government converted that coach to reserved compartment, which left many people with disabilities, particularly from lower socio-economic backgrounds who travel in unreserved compartments, stranded. Persons with disabilities protested and wanted it to be converted back to unreserved. Therefore, persons with disabilities should have both options of reserved and unreserved. The coach also has several other issues. It is located at the fag end of the train, there is no vestibule connecting it to the other coaches, pantry services are unavailable, no railway officials are present to handle the crowd which becomes unwieldy and causes a lot of discomfort to passengers with disabilities and the toilets remain dirty.

Only about 6.8% of the stations have been made accessible. There is no information if these have been audited or verified in terms of its compliance to accessibility standards. Then the question of what standards are being followed. Have concerns of all disabilities been included in that?

⁵² 'Kingfisher crew offloads blind woman with kids' By Vedika Chaubey, 21st May 2011, Mid Day Mumbai, accessed at <http://www.mid-day.com/news/2011/may/210511-Shabnam-Mansuri-Kingfisher-crew-blind-woman-disembark-Airline-mumbai.htm> on 12th November 2011.

⁵³ E-mail to Access India Group; 3rd December 2010.

Some experiences of passengers

"There is always confusion regarding whether a particular train has an accessible coach and if yes, where it is exactly located, whether in the front or at back. This requires disabled passengers to run helter-skelter for locating it, defeating the very purpose of such a coach. Besides, the location of the coach at the fag end or beginning of the track, makes it difficult to board due to absence of overhead shade and even platform floor many a times towards the extremities. Further, more often than not, it is occupied by non disabled unauthorised passengers and is not vestibuled rendering seeking any assistance by disabled passengers from Railway Police Force or ticket checking staff extremely difficult."

-Extracted from the letter to Minister of Railways, on behalf of the blind community and disability community for consideration in the Railway Budget, 11th February 2010, Access India.⁵⁴

"I was in Jamshedpur last week and had to go by train from Kolkata. There was no wheelchair available at the station. At Howrah Junction, there was only one wheelchair - rusted and completely broken (risking both life and safety of person with disability)".

-Dr. Meenu Bhambhani, Response to the CRPD Questionnaire

"There is no uniformity in the format of the railway concession certificate to be produced at the time of booking tickets and it is subject to frequent changes, sometimes at the whims of booking officials. Concession tickets are issued only to completely blind individuals leading to undue discrimination to those with residual sight. Reservation forms required to be filled at the time of reserving berths cannot be independently filled by a blind traveller. Many accidents are caused by blind persons falling to the tracks from the platform. There is general lack of information, not only to disabled passengers but also to all passengers about approaching station, time of arrival there etc. There is virtually no or little support from railway staff for blind/disabled passengers while at the station or in the train, barring at a few stations. The "may I help you" counter is more often than not, non-functional, and is hardly equipped or informed to deal with specific needs for the disabled passengers.

-Extracted from the letter to Minister of Railways, on behalf of the blind community and disability community at large for consideration in the railway budget. 11th February 2010 Access India.⁵⁵

Apart from the Indian Railways, **the metro system is operational in a few cities for travelling within the city.** It is fully operational in New Delhi and

⁵⁴ Accessed at <http://draindiarail.blogspot.com/search?updated-min=2010-01-01T00:00:00-08:00&updated-max=2011-01-01T00:00:00-08:00&max-results=6> on 20th November 2011.

⁵⁵ Accessed at <http://draindiarail.blogspot.com/search?updated-min=2010-01-01T00:00:00-08:00&updated-max=2011-01-01T00:00:00-08:00&max-results=6> on 20th November 2011.

National Capital Region.⁵⁶ The first phase of Bengaluru Metro, “Namma Metro” became operational recently. The effort was made to make the Metro disabled-friendly from the planning stage itself. As a result several accessibility aspects have been included, lifts ramps, guide blocks, voice announcement, information scrolls, wheelchair accessible gates etc.

The users of Delhi Metro have mixed opinions about its disabled-friendliness, particularly the fact that not all Entry Points to the stations are accessible to persons with disabilities.

Experiences of the Metro Rail System

“The Metro has changed my life. I go from one place to the other on the metro on my motorised wheelchair without much problem. Earlier I could not use public transport.”

-Muthu, a person with disability living in New Delhi

“In all the swanky planning of Delhi Metro, planning for disabled is at the lowest. Just putting a couple of elevators and ramps and some unusable accessible toilets and not to mention the strangely laid guiding pavings in no way make it 'accessible'. I feel so angry.....and some in the disability sector applaud the metro. Considering we cannot travel alone and need to travel with at least two attendants to help negotiate inaccessibility, the Government needs to start giving us travelling allowance to pay for all this additional help.”

-Shivani Gupta, a wheelchair user and an accessibility consultant, AccessAbility, Open Group in Facebook, 26th June 2011.

It was a rare occasion. For 12-differently-abled persons, it was a Saturday date with Namma Metro. Of the group, Ajith, Nilesh, Deepa and Sunil, all physically-challenged, arrived at the station with Satish Subramanian, a friend who had worked with them in the past. The others, speech-and-hearing-impaired, had come of their own for a ride. They had a hassle-free ride but it was not so for the wheelchair users. The trouble began outside the station itself. "There was no parking space on MG Road. I wanted to take a ride from MG Road to Baiyappanahalli and back. But due to lack of space, I had to park my vehicle at Baiyappanahalli and then take my car back to MG Road," said Ajith KS, who works in a private firm.

-From 'Metro Ride not that Friendly', Times of India, 13th November 2011.⁵⁷

3. Information and Communication

Access to information can be through print media, television, cinema and radio and for this effective communication is critical. However it is one of the biggest

⁵⁶ The National Capital Region (NCR) is a name for the metropolitan area which encompasses the entire National Capital Territory of Delhi as well as urban areas ringing it in neighbouring States (from Wikipedia).

⁵⁷ Accessed at <http://timesofindia.indiatimes.com/city/bangalore/Metro-ride-not-that-friendly/articleshow/10710800.cms> on 29th November, 2011.

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barriers faced by persons, particularly those with sensory impairment. For example, a deaf person may not be able to hear the announcement at the railway station, a blind student may not get class books in accessible formats, a person with speech impairment may not be able to participate in a discussion, a person with intellectual impairment may not get instructions in plain, simple and short sentences.

Deaf people in India have been advocating for the **recognition and development of Sign Language**. One of the first steps taken in this direction by the Government has been the announcement for setting up the Indian Sign Language Research & Training Centre (ISLRTC) in 2011. In a recent order of the High Court, the Ministry of Social Justice and Empowerment has been asked to appoint sign language interpreters in all public places.

A Delhi High Court Order is likely to make life easier for the speech and hearing impaired people. Public places like railway stations, airports, bus depots, hospitals, police stations, educational institutions and Government offices may soon have sign language interpreters to facilitate basic communication for the speech and hearing impaired. Delivering a time-bound set of directives for the Ministry of Social Justice and Empowerment, a division bench of Acting Chief Justice A. K. Sikri and Justice Rajiv Sahai Endlaw described the provision of sign language interpreters at such places as an extension of the right to life under the Constitution.

-From 'Need interpreters for hearing impaired at public places: HC', 26th November, 2011, Indian Express.⁵⁸

On World Disability Day, 3rd December 2011, reminding that the High Court in a recent ruling had ordered that a survey must be undertaken in public buildings, hospitals, airports, railway stations that require sign language interpreters, NCPEDP Director Javed Abidi said, "In this country, we have 18 million hearing impaired people but only 250 certified interpreters by a conservative estimate. If we are having dearth of sign language interpreters, then how would we deploy them at public places?"

-From 'Official Language Status for Sign Language Demanded', The Hindu, 4th December 2011.⁵⁹

The Ministry of Social Justice and Empowerment has mentioned in their Status Report that "a **National Captioning Centre** was to be set up to provide subtitling and captioning services. There was no financial provision for the intervention in the XI Five Year Plan!" It is also mentioned in the Report that 'Doordarshan' has taken several measures for providing captioning and sign languages in a number of programmes.⁶⁰

⁵⁸ Accessed at <http://www.indianexpress.com/news/need-interpreters-for-hearing-impaired-at-public-places-hc/880608/> on 6th December, 2011.

⁵⁹ See the website <http://www.thehindu.com/news/national/article2684848.ece>. accessed on 6th December 2011.

⁶⁰ Status Paper, Working Group on Empowerment of Persons with Disabilities for formulation of XII Plan (2012-17), 2011.

Currently, most **Indian films and television programmes do not have captions and audio descriptions**. International channels like Start World, HBO, Zee Studio have open captioning and is therefore accessible. **The television sets in India do not have decoders which would give the option of starting or closing the captioning.**

The Bollywood industry produces the largest number of films globally and is known for producing song and dance visual extravaganzas. RNIB has undertaken the Bollywood Audio Description Project to enable audio description provision in both India and UK.⁶¹ One or two (exact numbers are not available) Indian films have Audio Descriptions, which is available on DVDs. However, most people with visual impairment are not aware of it and none of the theatres have a system to play these.

Television and Films should include Captioning and Audio Description. The Ministry of Information and Broadcasting should play a crucial role to create the necessary capacity to provide closed captioning and audio descriptions. Accessible television sets and necessary infrastructure should be made available to provide the necessary support to access captions and audio descriptions in television and cinema halls.

Another media for communication and information for persons with disabilities is the **Internet**, which is being extensively used in India now and the number is increasing by the minute. In 2009, the Government adopted the Web Content Accessibility Guidelines (WCAG 2.0) as the standard for making all Government websites accessible. As given in the 'Guidelines for Indian Government Websites' some of the websites of the Government that have been made compliant are the National Portal of India, Department of IT, Ministry of Finance, Government of India Web Directory, National Advisory Council, Ministry of Social Justice and Empowerment, Cabinet Secretariat, Central Information Commission Online, Rajbhavan Uttarakhand website, Chief Minister's Office Uttarakhand website, State Election Commission Uttarakhand website, Information Technology Development Agency Uttarakhand website, High Court of Uttarakhand, District Courts of Uttarakhand.⁶²

NASSCOM, which is the premier organisation that represents and sets the tone for public policy for the Indian software industry has also taken up Accessibility of applications and software. They have written to all their members regarding the Accessibility Guidelines and urging them to make their Internet, Intranet and other applications accessible to persons with disabilities. A few NGOs have also made their websites accessible, but the number is negligible.

Several websites/applications have been developed in the last one/two decades, which are already up and running, which have not taken into account the accessibility needs of persons with disabilities. There is comparatively greater awareness now on need to make the applications

⁶¹ RNIB website accessed at <http://www.rnib.org.uk/livingwithsightloss/tvradiofilm/film/Pages/bollywood.aspx> on 7th December, 2011.

⁶²Guidelines for Indian Government Websites, Compliant websites, accessed at <http://web.guidelines.gov.in/compliantwebsites.php> on 3rd December 2011.

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accessible but not much information on how to carry out this humongous task in existing applications, without disrupting the service that the application is currently providing. Lack of accessible software applications is a huge barrier for persons with disabilities in employment.

A lot of time and money is going into computerisation of different systems within the Government and private sectors, with an effort to reach the rural areas too, for a range of purposes - for information dissemination, maintenance of data, livelihood, education, transactions, banking, marketing, purchasing and various other services.

The issues are that the Web Accessibility Guidelines are still not known to most people and since these are **not mandatory**, most developers do not take these guidelines seriously. Secondly, for the implementation of these Guidelines, there are very few **technical personnel** with knowledge of accessibility in the country who can provide the expertise required for making existing web/software applications accessible. Thirdly, there are no **monitoring mechanisms** in place to ensure that Government, private and NGO sector adheres to these Guidelines in a time-bound manner. The Rehabilitation Council of India, which initiates and standardises courses to meet the various needs emerging in the disability sector for different personnel is yet to wake up to this need for trained professionals who can make websites accessible.

Though Internet is becoming popular, physical **books** are still very much being used and will continue to be used. The school and college education still is book based. Higher Education requires going through reference materials, journals etc. Reading in general not only enhances knowledge but also develops a person's personality. There are wide range of books - fiction, non-fiction, self improvement, management, cookery, health, spiritual and many other books. This huge wealth of knowledge is not available to persons who may have print impairment. **Only about 0.5% of books are available in accessible formats in the country.** Children with visual impairment are to be provided Braille Books. However, most of the time, these books are not available on time. There are no scanners in most of the colleges and schools to convert books into soft copies. Most people have to depend on family members to read out books for them.

Copyright obstacle for Braille, audio books

For the 12 lakh or so visually-challenged and dyslexic persons in the State, access to good Indian literature in Braille or audio format is a challenge. Obtaining copyright to convert books into special format is the biggest hindrance, say activists working for disability rights. "Even the National Library does not have any Braille or audio books. Authorities argue that the number of such special books is too less to create full-fledged sections," said Shampa Sengupta of Sruti. When it comes to the audio-version, the scenario is worse, says Lina Bardhan from Noble Mission that works with the mentally challenged.

City Braille publishers say legal formalities prove to be an obstacle."We believe that as a humanitarian gesture, the Copyright Act of 1957 should be relaxed

for books meant for the differently-abled," said Amiyo Biswas of Blind Persons' Association, one of the three Braille publishers in the city.⁶³

4. Consumer Products and Services

There are several barriers for people with disabilities for using the various **consumer goods** available in the market. For example, visually impaired persons have difficulty operating an oven or a washing machine; a person with hand function impairment finds it difficult to open a door latch; a person with hearing impairment has difficulty knowing when the door bell/alarm system is ringing; a person with orthopaedic impairment find it difficult to access a vehicle. There are a few products that are available like talking watches, calculators etc. **The Ministry of Consumer Affairs, under which is the Bureau of Indian Standards, has not done much in the area of promoting the concept of universal design in designing goods.** All the consumer products should not only be easy to use but also safe for all users, including those with disabilities.

"India used to have accessible coins and currency however, over time, with modernisation, India now has undistinguishable coins making them inaccessible to persons with disabilities."

-Kanchan Pamnani, Lawyer

There are also several services - banking, health, emergency, library, travel/tourism related, entertainment, beauty, information, legal etc. - most of these remain inaccessible to persons with disabilities. **The attitude of the service provider can also pose a huge barrier for people with disabilities in accessing the various services.**

Reserve Bank of India, India's Central Bank, issued a Circular on 4th June 2008 titled 'Banking facility to visually challenged'.⁶⁴ It states, "Banks are advised to ensure that all the banking facilities such as cheque book facility including third party cheques, ATM facility, Net banking facility, locker facility, retail loans, credit cards etc. are invariably offered to the visually challenged without any discrimination. Banks may also advise their branches to render all possible assistance to the visually challenged for availing the various banking facilities." The circular is applicable to all Scheduled Commercial Banks (excluding Regional Rural Banks (RRBs)). Talking ATMs have been introduced in a few places in the country.

In spite of these very clear guidelines, **many bank officials continue to harass people with visual impairment and refuse many of the banking facilities to them giving various reasons or putting many conditions on**

⁶³ From Arpit Basu, 'Copyright obstacle for Braille, audio books', The Times of India, Kolkata, 7th November, 2009, accessed at http://articles.timesofindia.indiatimes.com/2009-11-07/kolkata/28081414_1_audio-books-publishers-cis on 5th September 2011.

⁶⁴ RBI / 2007-08 / 358 DBOD.No.Leg BC. 91 /09.07.005/2007-08.

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them. The number of ATMs are very few and there is no information on how many talking ATMs are there and their locations. One would prefer that all ATMs are accessible or at least all the new ones should be and that is not happening. There seems to be lack of monitoring of the implementation of the RBI Guidelines.

"Banking is one area where there is a lot of discrimination against persons with visual impairment. Opening an account itself isn't any easier, but once you open an account, getting the common banking facilities like ATM cards and cheque book is an absolute nightmare. I've an account with the Punjab National Bank, and I had the struggle of my life to get my ATM card issued. It took me a good seven months for the same to be done. The struggle for the cheque book was also on similar lines, and although I've got the cheque book, it has come with a lot of conditions."

- Mahesh Panicker, 'Difficulties in Banking', 23rd May 2010, E-Mail to Access India E Group.

There is a circular that allows **Legal Guardians to open and operate bank account on behalf of persons with disabilities**, which are mentioned in the National Trust Act and Mental Health Act. This has helped a few people, particularly those with intellectual impairment, who were not allowed to open an account earlier, to now be able to do it with the help of their Guardians. However, this is also being seen as discriminatory to people who may not want to appoint a Guardian for operating their account. It denies legal capacity of persons with certain disabilities.

Rajiv Rajan, activist, has been in a running battle with his bank for over a year now. He has cerebral palsy and is a wheelchair user. Banks are inaccessible but he is required to be present to withdraw money; an ATM card was denied to him; he is constantly told on getting a joint signatory, witness, etc.

-Vaishnavi Jayakumar, E Mail to Access India, 26th May, 2010, Subject: 'Faced difficulties opening bank accounts.'

People with disabilities also **face discrimination/harassment while applying for passport.**

"When applying for passport, if we are affixing thumb, we have to get it attested by a notary. The authorities insisted me for a gazetted attestation on the prescribed performa and further insisted me to sign an illiterate declaration along with it. Notary authorisation is compulsion"

-Srikanth Kanuri, E-mail to Access India, 12th October, 2010, Subject: 'Special Formalities for passport?'

Accessibility is a cross cutting issue and has been covered in almost all Articles of the CRPD. To access all the rights given in the CRPD the redress

mechanism should be also accessible. Some of the Articles which mention accessibility/reasonable accommodation/non-discrimination are given below.

- Article 2 - Definitions
- Article 3 - General principles
- Article 4 - General obligations
- Article 5 - Equality and non-discrimination
- Article 6 - Women with disabilities
- Article 7 - Children with disabilities
- Article 8 – Awareness-raising
- Article 9 - Accessibility
- Article 11 - Situations of risk and humanitarian emergencies
- Article 12 - Equal recognition before the law
- Article 13 - Access to justice
- Article 15 - Freedom of torture or cruel, inhuman or degrading treatment or punishment
- Article 16 - Freedom from exploitation, violence and abuse
- Article 18 - Liberty of movement and nationality
- Article 19 - Living independently and being included in the community
- Article 20 - Personal mobility
- Article 21 - Freedom of expression and opinion, and access to information
- Article 23 - Respect for home and the family
- Article 24 - Education
- Article 25 - Health
- Article 27 - Work and employment
- Article 28 - Adequate standard of living and social protection
- Article 29 - Participation in political and public life
- Article 30 - Participation in cultural life, recreation, leisure and sport
- Article 49 - Accessible format

Recommendations

- 1) All disability laws should clearly mention accessibility of physical environments, transportation, information, communication, technology, consumer goods and services. Universal design should be promoted in a major way to ensure all products are designed in a manner that the maximum number of people are able to use them.
- 2) There should be clear time frame mentioned in the laws to make all existing buildings, information and services accessible for persons with disabilities. This should apply to the places owned by the Government, private and non-profit organisations and services which are for public.
- 3) All other laws related to travel, various services, information and technology, procurement, copyright, etc. should be reviewed and amended to ensure non-discrimination of persons with disabilities. Any denial of entry to a public place/transport or service should be taken up very seriously and there should be penalty imposed on the owners/service providers.
- 4) The Ministries of Urban Development, Rural Development, Consumer Affairs, should have a cell on Disability. All Flagship programmes for urban and rural development should include disability.

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- 5) Existing courses in Architecture, Engineering, Designing, Web development, Computer Applications etc. should ensure inclusion of concept of universal design and accessibility.
- 6) Training should be conducted on Accessibility to architects, designers, web developers, civil engineers and Government officials to ensure they have the necessary technical expertise on the subject.
- 7) Professionals should be developed to provide necessary support, for example, sign language interpreters, tactile interpreters, transcribers, readers, scribes, personal assistants etc. - and these services should be provided by the Government as reasonable accommodation at no extra cost.
- 8) Monitoring mechanism should be put in place to ensure proper implementation of accessibility provisions.
- 9) All Tenders inviting proposals for any construction, provision of service or purchase of products should ensure accessibility for persons with disabilities as a mandatory requirement.
- 10) Research should be undertaken on accessibility and universal design.
- 11) All Service Providers should undergo training in not only customer support with respect to persons with disabilities but also the laws and guidelines in order to ensure non-discrimination. Any complaints of misbehaviour or misinformation should be taken up seriously.
- 12) Each service provider should mention clearly on their website regarding facilities for persons with disabilities and whom to contact for support.

Article 10: Right to Life

The text of Article 10 in the CRPD is given below.

States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

Survey Findings

1. The findings of the survey with respect to the efforts made by the Government to promote right to life of persons with disabilities are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	54%
Dissatisfied	33%
Satisfied	8%
Extremely satisfied	0%
Do not know much about the issue	5%

About 8% of the respondents have expressed satisfaction. There is some indication of a positive trend, with somewhat greater awareness, particularly after The Disability Act, accessibility to some extent, right to education, employment opportunities, etc. There have been a few individual instances where people with disabilities have felt a change in the way the “worth of their life” is perceived by the society. However, these are still exceptions compared to the size of the population in the country. About 87% of the respondents were dissatisfied with the efforts of the Government to ensure the right to life of persons with disabilities. The awareness about this right is very low in the country in general, particularly for persons with disabilities. People with disabilities are often seen as liabilities to the families. Moreover, the support from the Government and the society is negligible. As we will see below, though the Indian Constitution enshrines this right, at the ground level, this is often not ensured by the society at large.

Laws and Policies

Article 21 of the **Indian Constitution** mentions right to life: “No person shall be deprived of his life or personal liberty except according to procedures established by law.”

The Disability Act, Mental Health Act, Rehabilitation Council of India Act and the National Trust Act do not mention about the right to life explicitly.

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There is the **Medical Ethics Regulation**⁶⁵, which clearly states that "No physician shall arbitrarily refuse treatment to a patient"; "The patient must not be neglected", etc. It also states that "practicing euthanasia shall constitute unethical conduct. However, on specific occasions, the question of withdrawing supporting devices to sustain cardio-pulmonary function even after brain death, shall be decided only by a team of doctors and not merely by the treating physician alone. A team of doctors shall declare withdrawal of support system. Such a team shall consist of the doctor in charge of the patient, Chief Medical Officer/Medical Officer in charge of the hospital and a doctor nominated by the in-charge of the hospital from the hospital staff or in accordance with the provisions of the Transplantation of Human Organ Act, 1994".⁶⁶

There have been certain **court judgments** on this issue, like the Aruna Shanbhag's case. Aruna Shanbhag is a nurse from Karnataka. In 1973, while working at King Edward Memorial Hospital, Mumbai, she was sexually assaulted and has been in a vegetative state since the assault. After she had been in this status for 37 years, the Supreme Court of India responded to the plea for euthanasia filed by Aruna's friend journalist Pinki Virani, by setting up a medical panel to examine her. The Court turned down the mercy killing petition in March 2011. However in its landmark judgment, it allowed passive euthanasia in India.⁶⁷

This was a **"landmark" judgement legalising passive euthanasia - or withdrawal of life-support systems** - for patients who are brain dead or in a permanent vegetative state, and whom doctors have lost hope of reviving even with the most advanced medical aid with safeguards including meeting the strict guidelines and a case by case review of medical condition by a team of court appointed doctors and prior approval of the High Court.⁶⁸ The judgement received widespread commendation as "brave", well researched and "path breaking". **However, there are others who have criticised the judgement stating that if killing is a good thing, let public opinion and the Parliament, not two judges, decide this.**⁶⁹

Progress and Concerns

There are laws which recognise the right to life. However, there are hardly any proactive measures on the part of the State to ensure its effective enjoyment by

⁶⁵ Code of Medical Ethics Regulations, 2002, Medical Council of India, accessed at <http://www.mciindia.org/RulesandRegulations/CodeofMedicalEthicsRegulations2002.aspx> on 6th September 2011.

⁶⁶ See Section 6.7. at <http://www.mciindia.org/RulesandRegulations/CodeofMedicalEthicsRegulations2002.aspx> accessed on 6th September 2011.

⁶⁷ The Hindu. 7 March 2011, accessed at <http://www.thehindu.com/news/national/article1516973.ece>. on 6th September 2011.

⁶⁸ The Times Of India, accessed at <http://timesofindia.indiatimes.com/india/Aruna-lives-but-others-can-die-with-dignity/articleshow/7651216.cms> on 8th September 2011.

⁶⁹ India Today, accessed at <http://indiatoday.intoday.in/story/questions-about-the-right-to-die/1/132338.html> on 8th September 2011.

persons with disabilities, as mentioned in the CRPD. Some of the concerns related to right to life of persons with disabilities have been listed below.

1. Infanticide of Children with Disabilities

Many cases of infanticide of children with disabilities are known in the community but not recorded or reported. People working in the field of disability often report of cases where the doctors/family members advise parents of a newborn child with disability to leave the child without care, feed, etc. as it is a lifelong liability of raising a person with disability. **In hospitals too, newborns with disabilities are left without treatment during the initial critical period, and only if she/he survives this critical period, surgeries and other treatments are started for her/him.** Most of these cases remain undisclosed and unrecorded and only very close relatives or parents would tell them to Community Based Rehabilitation (CBR) workers or professionals working in the field of disability at a much later stage.

In a newsletter, 'Health Rights - Work Group for People's Health and Rights', December 2005, David Werner writes... "In hands-on workshops I facilitate in Latin America there are always young children with severe cerebral palsy or multiple disability"... On not finding the children in India when he visits three community based rehabilitation projects, he asked and the answer everyone agreed on is that "severely disabled children are often allowed to die... especially those born disabled and especially girls."⁷⁰ The infant mortality rate (IMR) (< one year) at the national level is 50 per 1,000 live births.⁷¹ The data for infants with disabilities was not mentioned.

2. Refusal to Treat Persons with Disabilities

There have also been experiences where doctors refuse assessment and treatment for persons with disabilities. **Doctors express their inability to handle/communicate with people with disabilities,** even for minor ailments like viral infections, dental cavity, let alone major treatments and surgeries!

"We are not treated and are often told to be making things up when our physical symptoms could be something very serious. We are not given the right treatment and often always put back on psychiatric medications. I was having seizures. The doctor refused to treat saying I was making it up. Later I got to know I had a brain tumour and the seizures were due to that."
-A disability activist

"I have personally experienced this attitude of neurologists, "oh you got this, there is nothing much to do about it, you have to live like this, there is no hope in this case and let's move on to a case which has more scope" instead of

⁷⁰ 'Report on Children (specially with disability)', E-Mail sent by Radhika Alkazi, AARTH to DEOC, 7th February 2009.

⁷¹ Page 258, Annual Report, Ministry of Home Affairs, 2010-11.

considering me as an individual with all rights and freedoms until I live and entitled to quality medication and treatment.”
-A person with a disabling medical condition

There have been a few unreported cases of people with disabilities being discriminated against where they have required organ transplants stating that they will not understand the post operative care or even blatantly stating that “there may be other ‘more deserving’ non disabled people who may benefit more from the organs, given that there is a huge shortage of organs in the country.”

3. Organ Donations

Persons with disabilities are also easy targets as donors for organ transplants, within the family and outside it. The person with disability may not understand the implications of donating an organ and may agree easily. Moreover, who really asks for their agreement?

4. Mercy Killing Requested by Parents due to Poverty

Within a family and a society where there are limited resources, the education or health of a child/person with disability, more so if she is a girl, is the last amongst their priorities. Even when the person with disability is a priority within the family, the circumstances are sometimes just too difficult and unmanageable. Without adequate monetary and financial support, it becomes extremely difficult for the family.

There are many cases across India where parents or people with disabilities have written to the State for giving them permission for mercy killing/death.

A couple in Uttar Pradesh have written a letter to the President of India Pratibha Patil seeking mercy killing of their four physically-challenged sons. (August 2011).⁷²

In another case, a poor farmer in a village in Bihar asked the State Government to grant permission for mercy killing of two sons with muscular dystrophy. (March 2011)⁷³

In Andhra Pradesh, two brothers felt that their life is a “waste and a burden” and sought permission for mercy killing so that they can donate their organs and be of “some help”.(October 2010)⁷⁴

⁷² ‘UP: Parents seek mercy killing of 4 disabled sons’, OneIndia News, 11th August, 2011, accessed at <http://news.oneindia.in/2009/08/11/up-parents-seek-mercy-killing-of-4-disabled-sons.html> on 16th August 2011.

⁷³ ‘Bihar parents seek mercy killing for two sons’, NDTV, March 9, 2011, accessed at <http://www.ndtv.com/article/india/bihar-parents-seek-mercy-killing-for-two-sons-90358> on 10th August 2011.

There is no information on what happens to these applications for mercy killing. Does the Government provide any support to them? There may have been some help coming in from the Government or NGOs or individuals but what happens in the long run? There seems to be no systemic policy on dealing with such cases.

Recommendations

- 1) Review and include 'Right to Life' in all the disability and medical laws of the country.
- 2) Medical ethics should emphasise more explicitly on Right to Life of persons with disabilities.
- 3) Sensitisation is needed of the medical fraternity, judiciary and rehabilitation professionals on the rights of children and adults with disabilities to life.
- 4) Right to Life of persons with disabilities to be included in their course curriculum.
- 5) Strict action should be taken against those who deny the Right to Life, including denying treatment, denying food/water, denying life support or forcing medical interventions, and making persons with disabilities donate organs without their consent.
- 6) There is direct correlation between acts of violation of Right to Life by family and society with the lack of support services available. Hence, the focus should be on creating support services like early intervention, rehabilitation support and counselling within the hospitals or effective linkages and referral system.
- 7) Social security measures should be strengthened and people with high support needs or families with more than one person with disability should be given greater support including, monetary and physical support (care taking, household support, etc.) by the State/community. There should be a system to ensure that State identifies such families on a proactive basis and gives them benefit.
- 8) The Government needs to spread wide scale awareness in the society about Right to Life for persons with disabilities; highlight the support systems that are available in the community and positive role models leading a meaningful life and contributing to the society.

⁷⁴ 'Muscular dystrophy patients in AP seek mercy killing', The Hindu, October 1, 2010, accessed at <http://www.thehindu.com/news/states/andhra-pradesh/article806814.ece> on 10th August 2011.

Article 11: Situations of Risk and Humanitarian Emergencies

The text of Article 11 in the CRPD is given below.

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

Survey Findings

1. The following is the finding of the survey with respect to the efforts made by the Government to provide protection and safety to persons with disabilities in situations of risk and humanitarian emergencies.

Rating	Percentage of Respondents
Extremely dissatisfied	72%
Dissatisfied	23%
Satisfied	0%
Extremely satisfied	1%
Do not know much about the issue	3%

One can clearly see that the results of the survey indicate that almost all the respondents feel that nothing much was done by the Government of India to provide protection and safety to persons with disabilities in situations of risk and humanitarian emergencies. When it comes to emergencies, people with disabilities are often left behind by the Government and Civil Society Organisations. There seems to be no system for warnings or support for persons with disabilities.

Laws and Policies

The Disaster Management Act, 2005 is the main Act that is used to manage disasters throughout the country, both natural and man-made (except drought and epidemics). There is no reference in this Act to persons with disabilities, as far as rescue and rehabilitation is concerned.

The Disability Act, 1995, Chapter VI, Clause 38(1) on Employment talks about "health and safety measures and creation of a non-handicapping

environment in places where persons with disabilities are employed". No further elucidation appears to be given on how this is to be achieved in this Act.

The Rehabilitation Council of India Act, The National Trust Act and The Mental Health Act, do not make any specific reference about providing protection and safety to persons with disabilities in situations of risk and humanitarian emergencies.

The **National Policy on Disaster Management** (NPDM), which was issued based on the Disaster Management Act, 2005 covers all aspects of disaster management, including legal and financial arrangements as well as those related to prevention, preparedness, mitigation etc. It accords high priority to States/UTs developing their own disaster management capabilities for preparedness. It also discusses the need to *encourage* States/UTs to have training and mock drills so as to help in preparedness. It makes a cursory mention of persons with disability, under the Section 5.3.2 under the 'Community Based Disaster Preparedness'. It says, "Needs of the elderly, women, children and differently abled persons require special attention".

Thus, **laws and policies for ensuring safety and protection for persons with disabilities in situations of risk and emergencies are inadequate or non-existent.**

Progress and Concerns

Natural and man-made disasters, except droughts and epidemics, come under the purview of the Home Ministry of the Government of India. The key organisations involved are the National Disaster Management Authority (NDMA), which is under the chairpersonship of the Prime Minister, State Disaster Management Authorities (SDMAs) under the chairpersonship of the Chief Ministers and District Disaster Management Authorities (DDMAs) under the chairpersonship of Collectors, District Magistrates and Deputy Commissioners. The Annual Report of the Home Ministry, 2010-2011, says (page 177) that the approach to disaster management has changed from being relief centric to a more integrated approach which encompasses prevention, mitigation, preparedness, response, relief, reconstruction and rehabilitation.

1. Disaster Preparedness and Prevention

Disaster prevention and preparedness is the ability of both the Governing Bodies and the people to anticipate, plan for and so avoid or mitigate the effects of disasters, both natural and man-made. The Annual Report, 2010-2011 of the Home Ministry gives importance to these aspects of disaster management.

At the national level, the National Disaster Management Authority (NDMA) lays down policies on disaster management. It also lays down guidelines to be followed by the State Authorities in drawing up State Plans for the prevention of disasters, mitigation, preparedness and capacity building for dealing with any threatening disaster situation or disaster.

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There are certain **infrastructural norms** provided in local building bylaws, which vary from State to State. Plan sanctioning authority provides 'No Objection Certificate', based on various aspects in the bylaws, including, safety aspects - fire, earthquake, environmental hazards; water board clearance for hygiene and sanitation, for example, ventilation in toilets, etc. **Even though some bylaws specifically mention accessibility, it is usually one tick in the box.** Details like accessibility of emergency exits; steepness of the ramps, availability of continuous railings on both sides of the emergency staircase, colour contrasts, lighting, tactile maps and signages indicating these exits, visual alarm for hearing impaired people etc. are not taken into account.

Access to emergency services, such as ambulance, fire engines, police, child helpline, etc. for persons with disabilities have not been given due priority. Most of these services have to be accessed telephonically (100, 101, 102, 108, 1098, etc.) and **there are no alternative methods for persons with speech and hearing disabilities to contact these. These numbers are not known to majority of people and sometimes, these numbers vary from State to State.** Even if one wants to access these services in person, there are many **barriers - physical, communication and attitudinal.**

According to the Annual Report, NDMA has so far released **26 documents which are disaster specific** and which contain extensive guidelines only on how specific disasters, like chemical and nuclear disasters, earthquakes, floods etc. are to be managed. Some of these have been written in 2007 and not updated since. *The booklets also discuss the lacunae in disaster management that have prevented effective implementation.* **None of them appear to contain any reference as to how to deal specifically with persons with disabilities in the area of preparedness, prevention and access to basic services.** Even the document that deals with psychosocial support, '**Psychosocial Support and Mental Health Services in Disasters**', 2009, though discusses the importance of preparedness and prevention and mentions persons with disabilities as being vulnerable, does not include them as a concerned group that ought to be educated too.

As part of preparedness, mock drills, etc. are now being conducted by organisations, including the private sector. **Again, one could not find much evidence as to how the needs of persons with disabilities are being taken into account in terms of information, capacity building, evacuation, etc.**

NPDM, 2010-2011, only states that "Efficacy of plans and Standard Operating Procedures (SOPs) is tested and refined through training, seminars and mock drills. **The NDMA will assist the States/UTs in these areas and will also conduct mock drills in different parts of the country.**" **No mention of the need to include persons with disabilities has been made.**

"One of the large companies that conducts mock fire drill on a regular basis actually had a practice of telling one of their employees with disability prior to the drill that there is going to be a mock drill on a specific date and she can work from home on that day. This was basically done with an intention to "not

inconvenience" her! The fact is that they didn't know how to help persons on a wheelchair to evacuate from higher floors. One standard alternative that companies come up with is that all employees with disabilities should work on the ground floor near the exit!"

-Account of a disability consultant with private sector companies.

A lot of resources (financial and human) are being spent on preparedness and risk management in the country. **However, there is no information about disability related spending.** One could easily assume that there is negligible spending towards safety of persons with disabilities – for ensuring accessibility of infrastructure and services, purchase of equipments like evacuation chairs and training of officials involved in providing emergency services.

2. Rescue, Relief, Welfare and Rehabilitation

According to the Handbook 'Understanding the UN Convention on the Rights of Persons with Disabilities' by Marianne Schulze, welfare measures broadly encompass the right to food, the right to prevention and control of diseases, the right to water, and the right to education. In rehabilitation, one would include the right to accessible shelters, social safety, economic empowerment and so on.

The Annual Report of the Ministry of Home Affairs, 2010-2011, has this to state about National Policy on Disaster Management (NPDM). It states that (see page 181), "In terms of grant of relief and formulating measures for rehabilitation of the affected persons due to disasters, the issue of equity/inclusiveness has been accorded due consideration. It further, aims to bring in transparency and accountability in all aspects of disaster management through involvement of community, community based organisations, Panchayati Raj Institutions (PRIs), local bodies and civil society." The Annual Report also then goes on to say that "Financial assistance in the wake of natural calamities is towards relief and not for compensation of loss. The relief fund is provided to assist the affected persons to restore their economic activities."**There is no specific mention of any Procedures/Standards for persons with disability with respect to their safe evacuation, food, shelter, etc. in the various Guidelines of NPDM.** With respect to Relief and Rehabilitation it states that "Relief is no longer perceived only as gratuitous assistance or provision of emergency relief supplies on time. The relief needs to be prompt, adequate and of approved standards." One cannot see how this lofty principle could be met without taking into account the needs of persons with disability. **The Annual Report of the Ministry of Social Justice, 2009-2010, which is directly responsible for the welfare of persons with disability, is silent on the rehabilitation of persons with disability in the aftermath of a disaster. It mentions no schemes in such an eventuality.**

One of the recently released documents by the NDMA in July, 2010, is the **Incident Response System (IRS)**, which adopts a comprehensive set of guidelines for responses to disasters. **On the issue of disability however, this document only mentions payments to persons with disabilities and does not discuss how Government agencies would take into account the**

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needs of persons with disabilities in their response to disasters. The IRS also mentions the setting up of camps but does not specify anything about them being disabled-friendly. The document also discusses the role of community based organisations like NGOs, Self-Help Groups, Youth organisations, Civil Defence & Home Guard and so on as integral to the management of any disaster. It places these as part of the Operations Section and discusses the need to train and be part of the IRS.

Though a lot of policies and systems seem to have been put in place in general for disaster management in the country in the last few years, disability does not figure in them. In absence of any specific procedures or system with regard to support for persons with disabilities during the rescue and relief, their needs remain ignored and unmet.

Some of the common concerns of persons with disabilities in the rescue and relief have been highlighted below.

Regarding rescue attempts, in the 1999 Orissa cyclone, a quote says "It was found that the vulnerability of severely disabled people was two folds. On one hand, their families and community members left them behind and on the other hand, Government or Non-Government personnel could not evacuate them. They spent several weeks in isolation and a majority without food, shelter or a means of treatment. The fate and the loss of lives amongst this target group will never be known."

-From "Training Manual for Inclusion of Disability in Disaster Response", by Prof. Asha Hans and co, Shanta Memorial Rehabilitation Centre (SMRC), Bhubaneswar, Orissa, India, 2005.

"People affected by disasters are generally provided temporary shelters in schools, religious places, etc. or sometimes temporary shelters, like tents are provided. There are generally no provisions for people with disability, like accessibility, etc. in these places. The toilets are generally away from the shelter and the terrain also makes it very difficult. Most times, the relief camps do not even keep a count of people with disabilities and their needs."

-Disability Activist

"We visited only two relief camps in Port Blair. We made one announcement and 28 disabled people identified themselves in ITF Camp and 15 disabled people came forward in the HADO Telugu School. There were children, youth and adults with different disabilities. This finding was totally contradictory to the Director Social Welfare's claim that there were no disabled people in the relief camps."

-Report by NCPEDP, 2004.

Many people lose/leave behind their assistive devices and medicines and this further adds to their difficulty. In Annexure XIII (pg 116) of the IRS document,

there is a mention of providing suitable medical care to “differently-abled people” and psycho-social care to affected people.

Access to food is also a major difficulty. Most persons with disabilities depend on their family members to bring food for them and those who live independently have difficulty reaching the location where food is getting distributed. Sometimes, food is served on first come first served basis and people with disabilities get excluded in such methods.

The National Institute of Mental Health and Neurosciences (NIMHANS), Bengaluru has number of brochures dealing with the **psychological trauma suffered by those affected by disasters**.⁷⁵ These provide very clear detailed steps to those who are directly involved with affected people as to what to expect, what to avoid doing and what to do in different circumstances. Modelled on this, NIMHANS has also helped NDMA to produce the brochure, “Psycho-Social and Mental Health Care” which deals with the same topic of care for trauma afflicted victims of disasters.

Compensations (monetary and livelihood options) are provided to people who acquire disability. In most cases, it has been seen that the compensation is inadequate and there is also considerable delay in reaching the victims of the disasters. Many people are not aware as to what to expect as compensation.

The State announced a compensation of Rs. 3 lakh to families of those who have suffered a permanent disability due to the blasts and the Government will bear the complete medical cost of their treatment... Many victims with permanent injuries could be the sole bread winners of the family. Merely offering them compensation and bearing treatment cost will not suffice in such cases. They need to be rehabilitated, with suitable jobs to earn a respectful living.

-From “Govt turns to corporates for rehabilitation of injured in Mumbai blasts”, Sandeep Ashar, TNN Jul 18, 2011.⁷⁶

The victims of the twin blast in Hyderabad four years ago have received little help from the Government. For G Sadashiva Reddy, the incident turned his life upside down when he went to grab a bite with his friend on the fateful day. He lost his vision due to the blast and was comatose for 4 to 5 months. Though he is recovering gradually, the erstwhile senior designing engineer can hardly voice the trauma he has lived through. His brother, G Srinivas Reddy says, “Government had announced a compensation and a Government job for relatives of the victims of the blast. I have the Government job but we have not received any financial help so far. My brother was the sole bread-winner as my father has retired. He added that Badshah, Sadashiva’s friend, was also

⁷⁵ Accessed at http://www.nimhans.kar.nic.in/dis_man/default.htm on 12th November 2011.

⁷⁶ Accessed at http://articles.timesofindia.indiatimes.com/2011-07-18/mumbai/29786684_1_blast-victims-mumbai-blasts-compensation on 2nd November 2011.

promised a compensation of 15 lakh as he suffered spinal nerve injury. But even he hasn't received the money yet.

-From "Fourth anniversary of the twin blasts held", Indian Express, 28th August 2011.⁷⁷

3. Role of NGOs

Some NGOs play an important role in disaster management. The disability sector has been actively advocating for the needs of persons with disabilities in disaster management, particularly post Tsunami in 2004.

In fact, NDMA's set of guidelines to NGO's in disaster management,⁷⁸ discusses quite comprehensively what NGO's should do for persons with disabilities during the response phase of any disaster. It includes having suitable search operations, distribution of food and water, medical facilities, assistive devices, basic care and monitoring to prevent neglect and abuse. For instance, it emphatically says that "By involving Persons with Disabilities in risk mapping, the possible barriers they may face during an emergency situation can be understood and special measures can be designed to address such concerns through participatory and inclusive processes. For example, immediately after an earthquake, a person who is physically handicapped may not be able to negotiate over rubble to reach the temporary relief camp."

There are also some proactive initiatives on the part of NGOs in this area including training and research initiatives, focussed programmes, funds mobilisation, advocacy, etc.

Handicap International has initiated a project, the objectives of which is to reduce the vulnerability of Indian populations living in areas most affected by natural disasters, by increasing the awareness and the response capacities of local communities to potential and frequent natural disasters and to reduce the effects on the most vulnerable. In India, the project is being implemented in two states – West Bengal and Orissa, in collaboration with the Department of Disaster Management and the Office of the Commissioner, Persons with Disabilities.

The broad activities planned under the project are enhancing capacities of persons with disabilities by understanding their needs, providing assistive devices and linking them with mainstream development activities including community based disaster risk reduction activities. Simultaneously, activities such as sensitisation and training of the disability inclusive Village Disaster Management Committee and Task Force members, Panchayati Raj Institution members, Government and non Government actors are planned to enhance their capacities at different levels to mainstream disability in community based disaster risk reduction process. A major component of the program includes

⁷⁷ Accessed at <http://ibnlive.in.com/news/fourth-anniversary-of-the-twin-blasts-held/178684-60-121.html> on 12th November, 2011.

⁷⁸ 'Role of NGOs in Disaster Management', National Disaster Management Guidelines, September 2010, National Disaster Management Authority, Government of India.

hardware activities, such as modification of the shelters to make them accessible for all, including persons with disabilities. Each shelter, it is planned, will have basic equipments of search and rescue and first aid along with disability friendly equipments.

-From "Handicap International has started Disability Inclusive", Report by OrissaDiary.com correspondent, Bhubaneswar, 27th September 2011.⁷⁹

4. Information Dissemination

There are two aspects to information dissemination. The first is to ensure that the **relevant people involved in preparedness, rescue, relief etc. have a good understanding of needs of persons with disabilities** and the kind of support that needs to be provided. The second is related to the **dissemination of information to persons with disabilities to educate them as to how they could help themselves during emergencies.** This would include accessibility of information.

The NPDM document discusses the need to disseminate information and training to students, artisans and other groups like paramedics, social workers, plumbers, sanitary fitters and safety auditors in the field of disaster management. The plan is to have the Ministry of Human Resource Development introduce Disaster Management as part of the curriculum in Secondary Education Boards and State Education Boards for children and it says the course would cover disaster management in schools and possibly create a culture of preparedness and safety. Looking at the CBSE Curriculum for 2012⁸⁰ one does indeed see that Disaster Management is part of the Social Science curriculum but there is no reference to the needs of persons with disabilities there.

For the training of artisans, it is mentioned that the guidance of IITs, National Institutes of Technology would be taken with Industrial Training Institutes and other Central, Regional and State Vocational Training Institutes assisting in the implementation of the training. For the other groups, including artisans who are disabled, there is no mention of how disaster management training would be implemented nor is there any reference to the programmes that have been developed.

There is no information regarding accessibility of information. There are many audio-visuals, training modules, etc. that are being prepared on the issue. However, how these could reach persons with disabilities remains a question mark. It is important to have brochures in Braille, films with transcription and audio descriptions, instructions in sign language and pictorial information for those who may not be able to read. Targeted awareness programmes would also be very useful.

⁷⁹ Accessed at <http://www.orissadiary.com/Shownews.asp?id=29403> on 10th October 2011.

⁸⁰ Pages 121, 128 and 135 in the website http://cbse.nic.in/currisyllabus/SECONDARY_VOL_1_FINAL_1_JUNE_2010.pdf accessed on 10th October 2011.

5. Conflict Areas

Safety and security of people with disabilities in conflict areas needs special attention, as the difficulties are more and the support available is less. Disability is more in these regions compared to other non conflict areas. Conflict areas find that for every one child that is killed, three are injured and permanently disabled. Children with disabilities are at a 1.7 times greater risk of being subjected to some form of violence.⁸¹ It is not just physical disabilities but also mental disabilities due to trauma and stress caused by instability and violence. There are several reports indicating increase in the number of people who are affected by mental health issues in areas affected by conflict.

Some of the initiatives given in the Website and Annual Report of Ministry of Social Justice and Empowerment are:

- District Disability Rehabilitation Centres set up by the Ministry are also funded under this scheme after they have been run for a period of five years in respect of such centres set up in Jammu & Kashmir or North East and three years in the rest of the country and handed over to a prominent NGO in the District for its further continuance and maintenance.⁸²
- National Institutes, like NIRTAR, etc. is expanding their services, like organising camps etc. in remote localities including tribal areas in Orissa and Jammu & Kashmir.⁸³
- State level workshop was held in July, 2009 at Srinagar (in Jammu & Kashmir), on the schemes of NHFDC organised by the Jammu & Kashmir State Women Development Corporation (State Channelising Agency of NHFDC). (Page 136)

According to statistics released to mediapersons by a disability association here, the largest number of people with disabilities belong to the twin border districts of Kupwara and Baramulla in the valley which remained the worst affected because of the separatist violence during the last two decades here. "There are 38,530 physically challenged people in Kupwara district while their number is 39,421 in Baramulla district," said a member of the association.

The number of disabled people released on Monday does not include thousands of mentally challenged people who fall victim to depression, insomnia, behavioural disorders and mental trauma because of the disturbed situation in the state.

The physically disabled people on a hunger strike here demanded reservations in Government jobs, enhancement of monthly financial support from the existing Rs.400/- to Rs.1,500/-, introduction of the Braille system of education from nursery to the university levels in the State, subsidised loans, residential

⁸¹ Accessed at <http://www.childlineindia.org.in/children-with-disabilities.htm>.
On 18th October 2011.

⁸² Page 114, Annual Report, MSJE, 2009-10

⁸³ Page 126, Annual Report, MSJE, 2009-10

plots, free education for their children, provision of artificial limbs, diesel motorcycles instead of tricycles to disabled people.

-From "3.6 lakh disabled in Kashmir, many protest raw deal" Dailybhaskar.com; 25th May 2011.⁸⁴

The services - rehabilitation, educational and employment opportunities are not adequate in these regions. Many professionals have migrated to other parts of the country and professionals do not want to work in these regions. There are also not many NGOs (local, national and international) working in the field of disability in these regions.

The tribals of Chhattisgarh were denied the right to the enjoyment of the highest attainable standard of physical and mental health because of the lack of medical facilities including doctors. With a population of 70 lakhs, Dantewada district reportedly had only 12 MBBS doctors.

-From "Violations of the right to health", Issue-01, July to September 2010, India Human Rights Report Quarterly, Asian Centre for Human Rights.⁸⁵

Recommendations

- 1) The Disaster Management Act and the disability laws should specifically mention about the measures with respect to preparedness, relief, information dissemination in order to ensure people with disabilities are provided equal opportunities and support during disasters.
- 2) Adequate allocation of funds needs to be given to all relevant Ministries for providing training, grant-in-aid to NGOs and for providing relief and should reach the remotest of village panchayats and the youth groups.
- 3) Audit of all emergency services and equipments and a time bound Plan to make them inclusive is needed.
- 4) Emergency numbers need to be made the same all across India. These numbers need to be well publicised and need to be accessible for people with different disabilities.
- 5) Committees/Groups formed as part of disaster management, should include disability experts and people with disabilities.
- 6) The concerns of persons with disabilities need to be addressed in the rules and regulations made by the NDMA and governing the SDMA and DDMA.
- 7) Trainings of all relevant personnel in rural and urban areas should include concerns of persons with disabilities. The curriculum for professionals working with persons with disabilities should include a module on handling emergency situations.

⁸⁴ Accessed at <http://daily.bhaskar.com/article/J-AND-K-3-2133712.html> on 12th November 2011.

⁸⁵ Accessed from <http://www.achrweb.org/ihrdq/issue1/chhattisgarh.html> on 12th November 2011.

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- 8) Persons with disabilities should be trained in handling emergency situations in schools, institutions, camps, etc.
- 9) Warning and information systems should be in accessible formats for all persons with disabilities.
- 10) Temporary and permanent shelters made by the Government should be accessible.
- 11) Food and water distribution during disasters should reach out specifically to people with disabilities.
- 12) Emergency and essential medicines, rehabilitation aids and assistive devices should be part of the relief measures during emergencies and natural disasters.
- 13) The relief measures should include not only monetary help but also livelihood options for the person who has acquired disability.
- 14) Mock drills and trainings should be done on regular basis at Government buildings, NGOs, shopping centres, private offices, and must include evacuation of persons with disabilities etc.
- 15) Specific schemes for providing focused health and rehabilitation services should be started in areas of conflict.

Article 12: Equal Recognition Before the Law

The text of the article in the CRPD is given below.

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Survey Findings

1. The findings of the survey with respect to the efforts made by the Government to ensure that persons with disabilities are able to take decisions for themselves with necessary support and safeguards being made available, so as to ensure their full legal capacity as per UNCRPD are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	61%
Dissatisfied	28%
Satisfied	5%
Extremely satisfied	1%
Do not know much about the issue	6%

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About 89% of the respondents were dissatisfied with the efforts made by the Government to ensure that persons with disabilities are able to take decisions for themselves with necessary support and safeguards being made available, so as to ensure their full legal capacity as per the CRPD. Respondents seem to be aware of the lacunae in many of the Indian laws that discriminate against persons with disabilities, especially those with “unsound mind”. However, ‘legal capacity’ was a new concept for many of them and therefore about 6% felt that they do not understand the issue much.

Laws and Policies

None of the disability laws in the country specifically recognise persons with disabilities as having legal capacity on an equal basis with others in all aspects of life. On the contrary, there are laws that restrict legal capacity of persons with disabilities.

The Disability Act, 1995, has a provision that violates the legal capacity of persons with mental impairments. It states that, “No person shall be a Member of the Central Coordination Committee, who is of unsound mind and stands so declared by a competent court.”

Similarly, the Clause related to employment provides reservation in “identified posts”, thereby, excluding people with disabilities from employment in many other unidentified posts. This is a violation of legal capacity and autonomy, since it does not allow a person to make her/his decision to even applying for a job of her/his own choice.

The National Trust Act, 1999, has an elaborate system of guardianship and in fact is perceived as being almost synonymous with a mandate to provide legal guardianship for the four categories of disabilities under its ambit. In the light of UNCRPD, the entire chapter on guardianship must be removed as it is completely contradictory to the assertion of full legal capacity.⁸⁶

The Mental Health Act also contains a procedure by which a guardian for the person and a manager for the property can be appointed for those persons living with mental illness who cannot manage themselves or their property. Depending upon the extent of incompetence, the statute allows for both the appointment of a guardian and a manager or if the person living with mental illness can take care of self then only for the appointment of a manager. The MHA incorporates a plenary system of guardianship which means that during the subsistence of the guardianship, the person living with mental illness is not recognised by the law. It is the guardian who speaks and decides for the individual. Whilst the guardian is meant to perform his or her duties in the best interest of the person living with mental illness, there is no obligation to consult with the declared incompetent. Further any action taken or decision made by the person living with mental illness has no validity in the eyes of the law and such a system continues till the person living with mental illness is declared fit and the guardian

⁸⁶ Page 188, ‘Harmonizing Laws with the UNCRPD’, Edited by Dr. Amita Dhanda and Rajive Raturi, Human Rights Law Network, The Deaf Way Foundation, National Association of the Deaf, May 2010.

removed from office. Insofar as a person in plenary guardianship loses all authority to manage his or her life and to make the simplest of decisions, guardianship in a manner of speaking becomes equal to civil death.⁸⁷

Many of the **other laws** in the country also explicitly restrict the legal capacity of persons with certain disabilities who are considered incompetent by the law. Moreover, due to stereotype, myths and stigma surrounding disability, people with all disabilities face situations where they are perceived as incompetent or having 'incapacity'. The term that is extensively used is "people with unsound mind" referring to people with intellectual and mental impairment. A lot of other people, including people with psychosocial disabilities, multiple disabilities, etc. are sometimes labelled "unsound" and are excluded from equal legal capacity. People affected by leprosy also have restricted legal capacity, in many laws in the country.

Some of the Acts which are in violation of Article 12 of the CRPD are the Contract Act, 1872, The Government Savings Banks Act, 1873, The Government Savings Certificates Act, 1959, Hindu Minority and Guardianship Act, 1956, Hindu Succession Act, 1956, Transfer of Property Act, The Special Marriage Act-1954, The Hindu Marriage Act, 1955, The Dissolution of Muslim Marriages Act, 1939, Hindu Adoptions and Maintenance Act, 1956, The Indian Divorce Act, 1869 etc.⁸⁸

The National Trust Act, 1999, when it was enacted, was seen as an enabling measure, as it allowed people with intellectual/psychosocial impairments to do legal/financial transactions with the help of their guardians. The role of the guardian is to take care of, on behalf of persons with disabilities, all legal and financial transactions, including opening and operating bank account, banking transactions, post office accounts, transactions etc.; applying for loans and concessions; subscribing to company shares, mutual funds, bonds, securities in the financial market, and managing investments etc. Earlier, neither persons with certain disabilities nor their guardians were empowered to do these transactions. The concern that is being expressed now, with ratification of the CRPD, is that if the guardianship is removed and the several laws (related to property, opening bank accounts, access schemes, such as loans, etc.) which do not provide legal capacity to people with "unsound mind" remain unchanged, wouldn't one come back to square one? Wouldn't people with disabilities be left with 'nothing'? Therefore, if guardianship is to be reviewed, modified or removed, all other related laws need to be changed, to provide legal capacity, reasonable accommodations and provision for 'supported decision making'.

⁸⁷ Page 208, 'Harmonizing the Laws with UNCRPD', Edited by Dr. Amita Dhanda and Rajive Raturi, Human Rights Law Network, The Deaf Way Foundation, National Association of the Deaf, May 2010.

⁸⁸ Pages 59 and 60, 'Harmonizing Laws with UNCRPD', Edited by Dr. Amita Dhanda and Rajive Raturi, Human Rights Law Network, The Deaf Way Foundation, National Association of the Deaf, May 2010.

Progress and Concerns

The CRPD provides for full legal capacity, which India had ratified without reservations, and hence, “full legal capacity” is the law of the land.

On the basis of the CRPD, **the Supreme Court upheld the personal autonomy of a woman with intellectual impairment and ordered the continuation of her pregnancy**, as per her wish and choice, clearly stating that “consent of the pregnant woman is indeed an essential condition for proceeding with the termination of a pregnancy as per Medical Termination of Pregnancy Act 1971. The judgment also quoted the CRPD, “we must also bear in mind that India has ratified the Convention on the Rights of Persons with Disabilities (CRPD) on October 1, 2007 and the contents of the same are binding on our legal system.”⁸⁹ However, this is just a one off case where the lawyer was knowledgeable and also had the full support of Disabled Rights Group (DRG).

There is hardly any awareness about the CRPD in the country. The reality is that archaic laws are continuing to be used/misused to restrict legal capacity of people with certain impairments, particularly people with mental and intellectual impairments. **People are put through violent medical/religious practices, restraint, solitary confinement and are treated as “civilly dead”. They have no control of their own lives.**

The following case shows how all the rights of a woman were taken away from her, how she was labelled, discriminated, excluded and how the system actually allowed such ill treatment, leading to her “civil death”.

Chrysann (name changed), who was a married woman with two children, was taken for psychological evaluation by her husband because she gets angry very often...certain tests were done...she was given no details of the reports...One night, she was tricked and drugged and was admitted in a “mental hospital”, where she lived a life of a prisoner...She was forced to have tablets, injections, shock treatments and solitary confinement...(she is a naturopath and has never taken allopathic medicine in her life). Most times, she wouldn't even know what treatment was being given to her as it was done after drugging her. All she can remember are the after effects (bad headache lasting for 2-3 days, swelling in her hands, etc.) She was not allowed to meet anybody or go outside...She couldn't see her children...Later, when she came back home (after her mother intervened), she saw everything had changed in her house. The sign board at the door indicating that she is a professional practicing naturopathy had been taken off and she was told not to continue. The treatment had also affected her memory and slowed her down. Her social interaction suffered, as she could not remember her neighbours because of the shock treatment, medications, etc. (she was earlier a very outgoing person). It took time for her to recover...She stopped taking medicines (without telling her husband) as it made no difference. She started studying herself...She was feeling much better...She passed the insurance agent's exam with good marks. One day when she was cleaning the house, she realised all her papers

⁸⁹ Supreme Court of India, Record of Proceedings C.A. No. 5845 of 2009, Suchita Srivastava & Anr Versus Chandigarh Administration, 28/08/2009.

- bank papers, passport, etc had been taken away. Then, when her divorce matter came up for hearing, she realised she had no papers (including medical papers) to prove anything. She had lots of questions, "what would happen in the Court...after 10 years of such history, is somebody still considered to be mentally sick and only that? If you had a problem once and you're sick once, you'll be sick for always: is that it?" She tried getting the papers from the hospital. She was not given any information. Lies were fabricated in the Court. She lost the case, including access to her children.

This is the story of Chrysann (name changed) 35, who has been trying to get a 'normalcy' certificate from the same system which certified her 'insane'. This has proved to be an impossible task.

-Taken from 'Mad Lives - India', Bapu Trust for Research on Mind and Discourse, Stories and testimonies of how persons living with a mental illness survive.

There are also **instances where people with visual/hearing/physical disabilities have faced discrimination**. Though the laws do not attribute incapacity to people with these impairments, but in actual practice, they have been seen as incapable of making their own decisions.

Speaking from a purely legal perspective, the Indian constitutional and legal regime does not impute or attribute incapacity to blind persons. However, experientially, many blind persons feel that in actual practice, incapacity is attributed to equal basis with others; or when such banks refuse loan to blind persons owing to their blindness; or when they do not allow banking facilities like the cheque facility, ATM facility, net banking facility, or locker facility on an equal basis with others. Such attribution of incapacity in practice is also evident when a blind person is not allowed to stand a surety for others, for example, for obtaining bail, etc. or, when a magistrate refuses to accept a document duly attested by a blind gazetted officer who is competent to attest such documents.

-Taken from "Status of the rights of the blind in India with reference to harmonisation of the Indian legal regime with the United Nations Convention on the Rights of Persons with Disabilities (CRPD)", Prasanna Kumar Pincha, Senior Independent Consultant - Development, Human Rights and Disability, New Delhi.

1. Support Systems

Article 12 (3) and (4) mandates States Parties to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity and for appropriate and effective safeguards to prevent abuse in accordance with international human rights law.

The concept of legal capacity and supported decision making is quite new to the sector, which has been largely following the guardianship model.

However, **there are certain support structures that exist in the country**. The family support, the National Trust and its Local Level Committees (LLCs),

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NGOs, Peer Support Groups, etc. **These are not adequate, and may not necessarily follow the rights based approach.** There are also certain safeguards, such as, having a Local Level Committee (LLC) as an independent body, which can appoint/remove guardians and look after the best interests of persons with disability. It also states that the guardian must not mortgage, sell, lease, exchange or transfer the immovable property of the person with disability without the prior permission of LLCs.

Most of the support structures are based on presumed "incapacity". For instance, in the LLC guidelines, there is no mention about the role of person with disability for whom the guardian is being appointed, with respect to, her/his choices/autonomy/consent. The person cannot even complain against her/his legal guardian.

These support systems that exist have to be reviewed and restructured in the light of the CRPD and appropriate changes have to be made to ensure legal capacity.

A pilot project has been initiated as a joint initiative of Inclusion International and PARIVAAR, the National Federation of Parents' Associations for Persons with Intellectual and Developmental Disabilities and The National Trust to pilot supported decision making as a means of empowering adults with intellectual disabilities in their lives and the community, and to develop public awareness and support for the equal legal capacity of adults with intellectual disabilities. The project aims to develop support networks around 15-20 adults with intellectual disabilities in the surrounding communities. Based on the results of the project, consideration will be given to expanding in 2010.⁹⁰

This is a positive initiative. However, there was no information available on the internet or in the Annual Report of Ministry of Social Justice and Empowerment, about its results and the expansion plans. Moreover, it has been three years since the ratification of the CRPD. The work that has been done for setting up support systems and network is negligible. Neither the Ministry of Social Justice nor the Health Ministry has initiated any work in this area.

India is now in the process of formulating a new disability legislation based on UNCRPD. It is going to take time for it to become a law. The Government should however, take immediate measures to set up support network and guidelines, as mentioned in the CRPD.

Recommendations

- 1) Disability laws have to explicitly mention full legal capacity for persons with disabilities and should provide clear mandate/framework for supported decision making, keeping in mind the range of support from 0% to 100% that may be required, with safeguards, as mentioned in UNCRPD.

⁹⁰ Parivaar website <http://www.parivaarnfpa.org/uncrpd.php> accessed on 19th October 2011.

- 2) The new disability law may take time to be enacted. In the meantime, a policy framework could be created in lines with UNCRPD to expedite action.
- 3) Adequate funding should be allocated for setting up support structures.
- 4) The National Trust could play a larger role ensuring these policies and structures are in place. Its mandate should be expanded to cater to all those who need support.
- 5) All other related laws need to be amended that goes against the right to full legal capacity as per UNCRPD. These should also have provisions for reasonable accommodation and support to persons with disabilities.
- 6) There is very little understanding about 'legal capacity' and 'supported decision making'. Hence, it would be important to have discussions, documentation of best practices, researches, at various levels, nationally and internationally, to develop a better understanding.
- 7) It would also be important to create awareness and to build capacity among decision/policy makers, including legal fraternity, politicians, bureaucrats, health functionaries, bankers, social workers, disability professionals, community workers etc. and the larger public, to understand the 'paradigm shift' and to promote a culture of respect for personal autonomy for every individual.
- 8) Particular focus would be required to build capacity among people with disabilities to inform them about their rights and the formal and informal support that is available and how they can be accessed. In addition, specific programmes should be carried out to ensure people living in institutions, and those with high support need are able to exercise this right with the required support.
- 9) Last but not the least, involvement of persons with disabilities is crucial and their voices MUST be heard.

Article 13: Access to Justice

The text of Article 13 in the CRPD is given below.

- 1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.*
- 2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.*

Survey Findings

- The findings of the survey with respect to the efforts made by the Government to ensure access to justice for persons with disabilities in India are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	69%
Dissatisfied	18%
Satisfied	7%
Extremely satisfied	1%
Do not know much about the issue	5%

About 8% respondents have expressed satisfaction with respect to access of justice for people with disabilities. This could be because judiciary has played a significant role in protecting the rights of persons with disabilities by giving some favourable judgments. However, majority of the respondents (87%) have expressed dissatisfaction saying that the State's effort to ensure access to justice for persons with disabilities leaves much to be desired. About 5% have said that they do not know much about the issue indicating that even for disability leaders, access to justice is something they have not thought about or have not had access to or have not heard about. It can be conclusively said that Government needs to do much more on access to justice for disabled people.

Laws and Policies

The **Constitution of India**, under the Directive Principles of State Policy, 39A, states that "The State shall secure that the operation of the legal system promotes justice, on a basis of equal opportunity, and shall, in particular, provide free legal aid, by suitable legislation or schemes or in any other way, to

ensure that opportunities for securing justice are not denied to any citizen by reason of economic or other disabilities.”

The Disability Act, 1995, provides for appointment of the Chief Commissioner for persons with disabilities by the Central Government and Commissioners for persons with disabilities at the State level. “The Chief Commissioner may of his own motion or on the application of any aggrieved person or otherwise look into complaints with respect to matters relating to deprivation of rights of persons with disabilities; non-implementation of laws, rules, bylaws, regulations, executive orders, guidelines or instructions made or issued by the appropriate Governments and the local authorities for the welfare and protection of rights of persons with disabilities, and take up the matter with appropriate authorities.”

Under the chapter on ‘Non-discrimination’, the law states that the appropriate Governments and the local authorities shall, within the limits of their economic capacity and development, provide for ramps in public buildings, lifts and elevators adaptation of toilets for wheel chair users; Braille symbols and auditory signals in elevators or lifts. However, many important issues related to access to justice are not mentioned like reasonable accommodation, sign language interpreters in courts, accessible formats of charge sheet/judgments, guidelines for making arrests of persons with disabilities, accessibility of prisons, training of legal fraternity and police, etc.

The National Trust Act, 1999 and the **Rehabilitation Council of India Act, 1992**, do not have any clause or provision on access to justice. **The Mental Health Act, 1987**, Chapter 10, Miscellaneous, Section 91, states that “where a mentally ill person is not represented by a legal practitioner in any proceeding under this Act before a District Court or a Magistrate and it appears to the District Court or Magistrate that such person has not sufficient means to engage a legal practitioner, the District Court or Magistrate shall assign a legal practitioner to represent him.”

Based on the Study undertaken by Human Rights Law Network, The Deaf Way Foundation, National Association of the Deaf, the various related legislations like, The Criminal Procedure Code, 1908, The Evidence Act, 1872, The Legal Services Authorities Act, 1987, Probation of Offenders Act, 1958 require certain amendments to harmonise them with UNCRPD.⁹¹

Access to justice for citizens with disabilities is crucial. The Constitution of India and some **other laws** provide for certain aspects to ensure this right. For example, as per The Evidence Act, 1872, a witness who is unable to speak may give his evidence in any other manner in which he can make it intelligible, as by writing or by signs; but such writing must be written and the signs made in open Court. The Act states “lunatic is not incompetent to testify”.

There are laws that say that those with ‘unsound mind’ cannot write a will or file a complaint. Moreover, most of the laws are archaic and have to be reviewed in the light of the CRPD. Also, there is very little awareness of the rights, laws and

⁹¹ Page 61-64, ‘Harmonizing Laws with the UNCRPD’, Edited by Dr. Amita Dhanda and Rajive Raturi, Human Rights Law Network, The Deaf Way Foundation, National Association of the Deaf, May 2010.

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policies regarding access to justice amongst persons with disabilities and also amongst the legal fraternity and the police.

A Double Edged Sword: The CrPC in India

“The mentally ill accused person stands on a different footing from other under trial prisoners for the fact that such a person’s mental condition, when it falls for consideration before the adjudicating authorities, brings into play specific procedures under sections 328 and 329 of the CrPC (The Code of Criminal Procedure) that allow for postponement of her trial. If it appears to the adjudicative authorities that the accused is of ‘unsound mind’, and, that she is so incapacitated by her unsoundness of mind to be unable to defend herself or stand trial, the authorities are compelled under the CrPC to postpone her trial. The rationale underpinning postponement is easy enough to deduce – the fundamental right to a fair trial should not be violated in respect of a person who by reason of her mental condition is unable to instruct her counsel or comprehend the charges levelled against her or put forth her defence.

But, without basic procedural safeguards such as, a reasonable time limit on the period of postponement of trial, legal entitlement to treatment at mental health care facilities during the period of postponement, waiver of the condition to provide surety on release, and confinement (if at all) in a place other than a prison, postponement has proven to be the proverbial “double-edged sword”. The CrPC is invoked to protect the fair trial rights of the mentally ill accused but in reality, it causes and perpetuates prolonged, even lifelong confinement of such persons in prisons.⁹²

Progress and Concerns

The Government has taken some initiatives to ensure right to justice for persons with disabilities but a lot more needs to be done. There are two aspects to it. One is the law itself, and the other is the procedure for getting justice. Justice for the common man remains a tedious, long and inaccessible journey.

1. Number of Court Cases across India

One of the ways to see if there has been any progress vis-à-vis access to justice is to see if people with disabilities have been able to use the legal system to get justice. There is no specific data available in the country regarding number of cases filed by persons with disabilities. However, in the last 15 years or so, since the enactment of The Disability Act, 1995, **the number of cases has been**

⁹² ‘Sheathing a Double-Edged Sword: Recent amendments to the CrPC in the context of accused persons of ‘unsound mind’’, guest post by Aarthi Rajan, Posted on January 7, 2011 by Alok, accessed at <http://www.criticaltwenties.in/lawthejudiciary/sheathing-a-double-edged-sword-recent-amendments-to-the-crpc-in-the-context-of-accused-persons-of-%E2%80%98unsound-mind%E2%80%99> on 16th August, 2011.

steadily increasing but is not that significant when seen in perspective of the population with disability in the country. The Courts have given many positive judgements.

It was a Court case filed by a disability activist in 1997, that initiated the implementation of The Disability Act, 1995, which remained unimplemented till then. Another significant milestone with respect to disability rights was in 2004, when the Supreme Court of India gave a landmark judgment for making all polling booths accessible for people with disabilities, including accessible Electronic Voting Machines (EVMs) for people with visual impairment to vote independently. Courts have also played a proactive role by going beyond the letter of the Act. For instance, it recognised dyslexia as a disability even though it was not listed as a disability in The Disability Act and provided reservation for them in the Indian Universities.

There have also been a few cases which have referred to the CRPD. The Supreme Court mentioned the CRPD in the judgment which allowed a woman with intellectual impairment to continue with her pregnancy, taking into account her wishes, and thus, upheld personal autonomy and freedom of choice. Similarly, in another case, High Court, upheld the employer's obligation to provide reasonable accommodation for a person with a disabling medical condition, based on the Article 27 of the CRPD.

In the last three years since its ratification, there have been very few cases (which can be counted on fingers) based on the CRPD in the Courts of India.

The National Human Rights Commission (NHRC) has been deeply concerned about the protection and promotion of rights of persons with disabilities. The Commission is of the view that the persons with disabilities should enjoy all human rights on an equal basis with others. Towards this end, the Commission has adopted a multi-pronged approach which includes redress of individual complaints, legislative and policy reform spreading of awareness, etc.

The Commission has been involved since the formative stages of the CRPD. After the ratification by India in 2007, as a follow up action, the Commission appointed a Special Rapporteur on Disability related issues and constituted a Core Advisory Group on Disability to advise the Commission on matters connected with and incidental to the promotion, protection and monitoring of the human rights of persons with disabilities. The Commission has been advocating for the harmonisation of Indian laws with the UN Convention on Rights of Persons with Disabilities.

The Commission has advocated to the Government of India for the ratification of Optional Protocol to the UN Convention on the Rights of Persons with Disabilities and is of the view that the Optional Protocol will strengthen the accountability mechanism and serve as an additional tool for the promotion of the rights of persons with disabilities.

The Commission reviewed The Copy Right (Amendment) Bill, 2010 from Human Rights perspective and noted that it does not meet the demand of print disabled person. With a view to protect the rights of the print disabled people, the Commission made recommendations for amendments in The Copy Right

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(Amendment) Bill, 2010 which is being examined by the Parliamentary Standing Committee.

With a view to monitor the implementation of various laws, policies, concerning the rights of the persons with disabilities, Special Rapporteurs, NHRC have been visiting various States. The Commission has also asked all the State Governments to give wide publicity to the CRPD to create awareness regarding the rights of persons with disabilities.

- Annual Report, Ministry of Home Affairs, 2010-11

2. Accessibility and Accommodations

The CRPD provides for procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages. **There was no information available on the websites and the Annual Reports of Law Ministry or Ministry of Social Justice and Empowerment regarding any measures taken to provide accessibility for legal proceedings.**

Though there are examples of people with disabilities using the justice system effectively, there are innumerable people in the country who have faced and are facing several barriers in accessing justice.

"I had an issue with a telecom operator related to my bills. They continued to bill even after I had surrendered my telephone! The matter went to the Court. I realised that the hearing was on the first floor and there were no elevator in that building. I made a few enquiries if they can shift the Court downstairs for my sake. I could not get any information. I didn't know whom to approach for this. I called up a few NGOs, lawyers. They also could not help me. The only option I was left with was to request four people to carry me upstairs. It was too much of a risk to take for a comparatively small amount that I had to pay. So, I gave up!"

-Sunil (name changed), Software professional with disability working in IT Sector.

There are physical and attitudinal barriers that prevent people with disabilities from accessing justice on an equal basis with others.

There are about 10,000 Courts in India. Out of these, one Supreme Court, 21 High Courts, 3150 District Courts, 4861 Munsif and 1st class Magistrate courts and 1964 2nd class Magistrate courts are there.⁹³ Besides, there are many tribunals/forums. There are *lok adalats* (Peoples' Court) for settling their issues (relating to family, neighbours, property, etc.) at the village level through conciliation and compromise. There are also redress forums like Consumer Forum, Labour Court, Insurance Ombudsman, etc. for specific issues. Moreover, as mentioned above, persons with disabilities can approach the Chief

⁹³ Accessed at <http://legalserviceindia.com/article/I317-Justice-Delayed-is-Justice-Denied.html> on 15th August 2011.

Commissioner for Persons with Disabilities or the State Commissioners for Persons with Disabilities. There are National and State Human Rights Commissions. There are lakhs of Police Stations in the country where people go to file complaints of theft, harassment, loss of documents and many more issues.

There is no information available as to how many of these Courts, Tribunals and Police Stations are accessible for persons with disabilities.

As a result of advocacy by the disability sector, the Supreme Court and some High Courts have certain accessibility features, like ramps. However, most courts are inaccessible, including that of the Disability Commissioner's in many States. There are also issues about reaching these places, for people who have mobility difficulties.

"Among those buildings that need barrier-free features in the city are the disability commissioner's office on Church Road, collectorate, council hall and the regional transport office. There are scores of others."

-From 'Challenge for the disabled', Neha Madaan, Times of India, 7th November 2010.⁹⁴

There are also barriers in terms of procedures. The Guidelines for the Code of Conduct for the Police were issued by the Ministry of Home Affairs and communicated to Chief Secretaries of all States/Union Territories and Heads of Central Police Organisations on July 4, 1985. There are also Guidelines for making arrests compiled by the Commonwealth Human Rights Initiative. While these documents mention women, children and disadvantaged groups, there is no mention of persons with disabilities.⁹⁵

"I explained to the Police that I was a wheelchair user, who lived alone and neither did I have a car nor was the public transport system accessible to me, hence I could not come to the police station physically (to file an FIR). The final verdict was that either I rush to the police station now to get investigation started or just forget about my handbag. Of course going to the station was not possible so I had no option but to forget about my handbag. The issue here is not of my losing my handbag, but the inaccessibility for me as a disabled person to the police services. This is a situation that disabled and elderly people are bound to face more often. Today the question was only of my handbag but tomorrow it may be something more severe, but even tomorrow having access to the police service will be impossible.

The question is what does the police service have in place in terms of procedures to ensure that they are able to serve more vulnerable groups of people such as the disabled and the elderly who may have some special

⁹⁴ Accessed at http://articles.timesofindia.indiatimes.com/2010-11-07/pune/28225848_1_barrier-free-environment-buildings-disabled-friendly-barrier-free-building on 18th November 2011.

⁹⁵ 'Guidelines for Police Officers on Making Arrests', compiled by Aravinda Kosaraju, Commonwealth Human Rights Initiative, accessed at <http://www.humanrightsinitiative.org> on 18th November 2011.

needs. Is it reasonable to say that 'this is our procedure and sorry we cannot help you unless you follow our procedure no matter what your problems may be?

Today, in India, there is a lot of talk about accessibility, but in our narrow understanding all we look at is physical accessibility. I do not doubt that the police station will be physically accessible with the required ramps etc., but how good is that to someone like me who is unable to go till the station in the first place. Tomorrow if there are people with sensory impairments who want to make a complaint, does the police department have forms and information in alternate format that can be understood by vision impaired person? Do they have sign language interpreters, even if they are available on call bases, who can assist in lodging complaints of hearing impaired persons? Can the information provided by them in their website be read by all?

Here I am talking about something as basic as lodging a complaint with the police, which is just the tip of the ice berg and that probably for most is a considerably easy task, but for some of us is impossible. Today it is impossible for someone like me to access these basic services, then where are my rights as a citizen?"

-Shivani Gupta⁹⁶

People with disabilities, including people with mental disabilities, are eligible for free legal aid at the cost of the State. This is certainly a positive initiative. **There is no data on how many people with disabilities have used this service. There is no mention about any support such as providing a sign language interpreter or any other support, like home based service for persons with disabilities, to access free legal service.**

Free legal service alone not enough, support system required.

"People with disabilities have no effective access to justice when their rights are infringed. The Court of Chief Commissioner only deals with matters covered under existing Disability Act, 1995. However for other matters they have to face the mainstream justice system where they get no support in the alien system. Though disabled are included in the Legal Services Authority Act however the system is not geared to meet their needs.

-Taken from 'Harmonising Laws with UNCRPD', Human Rights Law Network, The Deaf Way Foundation, National Association of the Deaf, Edited by Dr. Amita Dhanda, Rajive Raturi, May 2010.

Talking about attitudinal barriers, there have been instances where the police themselves have been the perpetrators of the crime, instead of protecting persons with disabilities.

⁹⁶Accessed at <http://accessability-india.blogspot.com/search?updated-min=2010-01-01T00%3A00%3A00-08%3A00&updated-max=2011-01-01T00%3A00%3A00-08%3A00&max-results=5> on 16th November 2011.

Policeman attacks mentally challenged man with brute force.

Satna, Madhya Pradesh: A policeman, surrounded by others, stands above a man lying on the ground. The policeman, who is in uniform, raises a stick - a huge lathi - and brings it down on the man. The gathered crowd shouts "Maaro, maaro (beat him)." The policeman continues. At least seven blows are delivered. The man starts bleeding.

The victim, a 40-year-old naked Ram Krishna Agarwal - is mentally challenged. He lives with his family in Satna in Madhya Pradesh. When they saw the police attacking him, they were too intimidated to intervene. The police later ties up Ram Krishna and drags him by his legs on the ground before moving him to a police station. Nobody steps forward to help the victim. Local media and camerapersons - none of them from NDTV - say they filmed the incident as evidence of police brutality against a helpless man.

Ram Krishna allegedly got into a fight with his neighbours in his village because they were mocking his mental ability. When he got into a fight with them, neighbours called the police. Ram Krishna, now agitated, tried to fight two constables. The head of the local police station - named Balbir Singh Jaggi - then arrived. He is the one who is seen attacking Ram Krishna with brute force. He has since been suspended by the state's Home Minister, Uma Shankar Gupta.

Ram Krishna was taken to the police station and released after an hour. His family took him to a local hospital and has now moved him home.
-From NDTV website, 'Policeman attacks mentally challenged man with brute force', by Siddharth Ranjan Das, Updated on September 23, 2011 at 17:35 hours.⁹⁷

There are barriers of communication and information, which makes accessing justice quite difficult. Persons with or without disabilities, police apathy is well known. In case of a person with disability, the apathy and callousness takes a different dimension. **Rigid procedure and an insensitive attitude deter people with disabilities from approaching the police.**

"I can't access '100' (the police phone number), as I am deaf. How do I reach out for help? If I go in person to police station, would they be able to understand me?"
-A deaf person who is new in the city.

"Speech and communication are key in courtroom discussions. But if a speech and hearing impaired person is involved, the system becomes mute to his or her needs. The gamut of communication needed in a court of law presupposes

⁹⁷ Accessed at <http://www.ndtv.com/article/cities/policeman-attacks-mentally-challenged-man-with-brute-force-135739> on 12th November 2011.

the ability to communicate clearly and comprehensively. The need for communication, with lawyers, judges, witnesses and in writing, is so great that in fact most hearing persons are daunted at the prospect of going to courts and dealing with these situations. It is remarkable that in the 60 years of Independence and the active Indian Jurisprudence and the plethora of heinous crimes against deaf persons, no judge has ever felt the need to write a judgment including the right to interpreters and the rights of the deaf person in the justice system”

-Arun Rao, Disability Activist, Combat Law, Jan-Feb 2008⁹⁸

Some information is available through Internet. There are also online services. Government is also planning information kiosks in rural areas. **Most of the websites/kiosks are not compliant to web accessibility standards.** The Information and Technology Ministry had announced a policy in 2009 to make all Government websites compliant to WCAG 2.0 standards. However, there is no data on how many websites of High Courts and Tribunals are accessible.

“As part of the research work for this project, we were accessing various Acts in the country. Most of them were in PDF image formats and were not readable.”

-One of the Researchers of the Project.

3. Training

Article 13 (2) requires States to provide appropriate training for those working in the field of administration of justice, including police and prison staff.

The *Lal Bahadur Shastri* National Academy of Administration (LBSNAA), which provides training to new joiners in Civil Services has a module on disability. The Civil Services include the Indian Police Service. The Syllabus for the Basic Course Training Program for IPS Officers of Sardar Vallabhbhai Patel National Police Academy has a paper on ‘Ethics and Human Rights’. The details of the paper were however, not available.⁹⁹

Some NGOs have organised sensitisation sessions for police, lawyers, judges, etc. These are usually one off exercises which are self funded and are also limited in terms of geographical coverage. Nevertheless, these have had some positive impact.

The trainings provided to officials on disability related issues seem highly insufficient. Disability is not covered even in topics like human rights or issues of

⁹⁸ Accessed at http://combatlaw.org/wp-content/uploads/Combat_Law_Jan-Feb_2008.pdf on 16th November 2011.

⁹⁹ Accessed at <http://www.svpnpa.gov.in/Innerpage.aspx?st=Basic%20Course&cat=Training> on 7th November 2011.

disadvantaged or vulnerable sections of the society. The courses related to handling emergencies, traumas, first aids, do not cover specific needs of persons with disabilities. For instance, communicating with a deaf person; or ensuring the required support to persons with mental impairment. Most officials are not even aware of The Disability Act or Mental Health Act or UNCRPD.

"I was stopped by a traffic police. I could not understand why I was stopped. He said something and started beating me. When I tried to tell them I cannot speak or hear, he didn't believe me. He took away my licence. This happens all the time with deaf people".

-A deaf activist.

"The training of police personnel to identify deaf persons appears to be to beat them until it is amply evident that they are in fact deaf and in fact mute and therefore genuinely deserving of their protection! There is only one slight problem. The process by which this identification is made serves to warn deaf people off all further interaction with Police."

-Arun Rao, Deaf Way Foundation.

4. Awareness about Rights

There is hardly any awareness among people with disabilities about the various laws in the country. The awareness of The Disability Act itself is very low in the country though it was enacted over 15 years ago. The awareness of the CRPD is almost nil. There has hardly been any effort on the part of the Government to create awareness about the CRPD. The Annual Report of Ministry of Social Justice and Empowerment, 2009-10, has not mentioned any activities that has been undertaken in this regard. The CRPD has not even been translated in all Indian official languages and sign language. Even among those who have heard about the CRPD, many of them may not be aware that it can be used in Courts for seeking justice. Most lawyers are also not aware of the CRPD to be able to advice their clients to use it in Court to get justice.

The Department of Justice, Ministry of Law and Justice, Government of India is inviting proposals from organisations to create voice-based information kiosks. These kiosks will be placed in the States of Chhattisgarh and Jharkhand. The proposals are invited in the context of the GOI-UNDP "Project on Access to Justice for Marginalized People". The project is expected to enable empowerment of women and people belonging to marginalised groups (SCs, STs, minorities, children, disabled people etc.) The Project aims at exploring innovative ways of leveraging Information and Communication Technology (ICTs) to enable access of marginalised people to key information and awareness on legal issues. The belief is that access to key information, together with support from Civil Society Organisations and networks would enable marginalised sections to demand their legal entitlements and seek speedy and affordable justice services. A person visiting the info-kiosk would be

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able to access information on legal issues, including information on rights and legal entitlements and also how to access justice delivery system.¹⁰⁰

Though 'people with disability' has been mentioned in the target group of this project, it is yet to be seen if it would be fully accessible.

Accessibility in terms of location of the kiosks; height at which they are kept; ease of operation for people with orthopaedic and visual impairment; whether multimedia is accessible to people with different disabilities and is easy to understand for people with intellectual impairment are issues to be seen.

There is large scale lack of awareness among people with disabilities. Most people do not know their rights and how they can access the various services that are available.

"G is a deaf woman who was married to a hearing man for 17 years. During this period she bore 2 children and had to endure beatings and confinement. She was also not allowed to go out to meet other deaf people or attend social gatherings with them. Her husband travelled and had affairs with other women during this period and she was unable to say anything. During a legal awareness seminar she came forward with the details of her life and said she wished she could do something to change her life. She was helped with a divorce and all her maternal property which had been taken over was returned to her."

-Arun Rao, Deaf Way Foundation.

Recommendations

- 1) Various disability laws and other related laws need to be reviewed and amended to ensure the provision of right to justice for all persons with disabilities.
- 2) Guidelines and policies for the legal fraternity and police personnel need to include interactions with persons with disabilities.
- 3) Access to judicial/legal infrastructure, services and information needs to be ensured through provision for appropriate accommodation for persons with disabilities. These accommodations should be specified and methods to access them should be made clear and it should be well publicised.
- 4) Time bound targets should be made for making infrastructure, information and procedures accessible for persons with disabilities.
- 5) Ministry of Social Justice and Empowerment, Ministry of Law and Justice and Information and Broadcasting Ministry should have targeted programmes for awareness creation through mass media on the rights of persons with disabilities.

¹⁰⁰ 'ICTs for Enabling Access to Justice: Voice-based Information Kiosks', Government of India and UNDP Project, accessed at <http://lawmin.nic.in/doj/justice/kiosk.doc> on 10th November 2011.

- 6) The general awareness initiatives/campaigns by the Government or NGOs on various laws, such as Domestic Violence Act, Property laws etc. should be accessible to people with disabilities.
- 7) Training of legal fraternity and police personnel needs urgent attention to understand disability issues and understand the rights of persons with disabilities as equal to other citizens.
- 8) The Course curriculum for the same needs to be reviewed to incorporate disability issues.

Article 14: Liberty and Security of the Person

The text of Article 14 in the CRPD is given below.

<p>1. States Parties shall ensure that persons with disabilities, on an equal basis with others,</p> <p>(a) Enjoy the right to liberty and security of person;</p> <p>(b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.</p> <p>2. States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of the present Convention, including by provision of reasonable accommodation.</p>

Survey Findings

1. The findings with respect to the efforts made by the government to ensure the right to liberty and security of persons with disabilities in India is given below.

Rating	Percentage of Respondents
Extremely dissatisfied	55%
Dissatisfied	25%
Satisfied	6%
Extremely satisfied	0%
Do not know much about the issue	14%

There is a high level of dissatisfaction (80%), indicating that enough is not being done vis-à-vis ensuring that this right is guaranteed for persons with disabilities. There are instances of people with disabilities being locked up and chained in homes and institutions; police detaining people with disabilities, etc. This right is also not understood in general, with 14% respondents stating that they do not know much about the issue. One of the reasons could be that this may not directly affect a lot of people. And those who are affected do not have a medium to express their needs.

Laws and Policies

Article 21 of **Constitution of India** clearly states that, “No person shall be deprived of his life or personal liberty except according to procedure established by law.” Article 22 of the Constitution provides protection against arrest and detention. It provides for the right to information on the reasons for arrest; for being brought before a judge promptly, the right to have a proceeding before a court etc. Though there are clearly provisions in the Constitution of India on right to liberty, there are no specific provisions to ensure people with disabilities are protected in institutions where they are forcibly admitted.

The Disability Act, 1995, does not mention this right explicitly.

The Mental Health Act, 1987, provides for people with mental illness to be admitted in the hospital for ninety days, even without consent. Moreover, there is no option for voluntary discharge.

Progress and Concerns

There are two aspects here. One is to ensure that nobody is deprived of her or his liberty based on disability and second, persons who are deprived of their liberty should enjoy all the rights set forth in the Covenant, subject to the restrictions that are unavoidable in a closed environment. Furthermore, there is the right to be treated with humanity and respect for the inherent dignity of the human person, a fair public hearing and the right to review of a sentence.¹⁰¹

1. Right to Liberty

The involuntary detention allowed by The Mental Health Act is used and misused to deprive the right to liberty for persons with disabilities. Chaining, solitary confinement, etc. are routine practices in “mental hospitals”, other institutions and in families.

The Erwadi fire incident that occurred on 6th August 2001, when 28 inmates of a faith based mental asylum died in fire, was a wakeup call for the Mental Health Movement in India. (The inmates who died in the fire were bound by chains at *Moideen Badusha Mental Home* at Erwadi in Tamil Nadu.) As per Supreme Court directions, a Commission headed by N. Ramdas was set up to enquire into these deaths. The Commission recommended that care of mentally ill is to be improved, anybody wishing to setup a *mental home* to acquire a license and all inmates be *unchained*.¹⁰² However, even after 10 years of the Erwadi incident, the situation has not changed much.

¹⁰¹ ‘Understanding The UN Convention on the Rights of Persons with Disabilities’, Marianne Schulze, Edited by Handicap International, 2009.

¹⁰² Accessed at http://en.wikipedia.org/wiki/Erwadi_fire_incident on 16th November 2011.

"Five facilities were surrounded by fences and topped with barbed wire. Seven residential rehabilitation centres (RC) had facilities where locking mechanisms were used to prevent residents from exiting the facility or a portion thereof. I would therefore describe a significant portion of the RC that I visited as locked or closed facilities.

-From 'General Hospital, Psychiatric Unit and Rehabilitation Centres in India: Do Law and Public Policy present barriers to community based mental health services?', Kevin M. Cremin, An occasional study paper of The Centre for Advocacy in Mental Health, Pune, 2007.

"On October 20, 2010, Headlines Today did a report, "Families chain mentally-ill members", in which they featured many people with mental illness who have been chained in their home for many years. Family members who were interviewed said, they did not know how to take care of them. They believed that they were "possessed by demon". They had not been given any psychiatric or other treatment/support. Some of them had epilepsy, and they had not been given treatment for even that. For more information on the report, see the reference in the footnote.¹⁰³

I was discussing 'Mental Health' with a group of people at Lakhimpur in the far North East corner of Assam, when one of them informed me that a young boy who was affected by a mental illness, is being kept chained by his father. Proud of my role as an activist fighting for the 'rights of persons with mental illness', I rushed to this village some 30 kms away and confronted this 'father' who could be so cruel towards his own son.

The father who had a learned look despite being weighed down by poverty, replied calmly "I know my son is affected with a mental disorder, and needs proper medical treatment. But do you know, that for treatment I must take my son in this volatile condition to Tezpur Mental hospital, over 200 kms away. You can also see that I cannot take him by bus, and hiring a Taxi is obviously beyond my capacity. Also, I chain him to protect him from many of my neighbours - not to torture him. Do you know that when he is free, he wanders from house to house in the village talking nonsense - for that he is harassed and beaten up - no one understands that he is behaving abnormally because of an illness - not affecting the body but the mind"

No one can refute the logic of the father, as both the Government and Civil society have not yet succeeded in providing any major relief to the abject helplessness of the mentally ill and their families in any comprehensive manner. The father would have to cross two District Head quarters, Dhemaji and North Lakhimpur (meaning two Civil Hospitals) without available Psychiatrists to reach LGB Regional Institute for Mental Health, Tezpur. The father's problems would not end by reaching Tezpur. His son's condition would in all probability require indoor treatment. But the Mental Hospital at Tezpur,

¹⁰³ Accessed at <http://indiatoday.intoday.in/video/families-chain-mentallyill-members/1/117158.html> on 10th September 2011.

being the only such facility in the north east and so catering to patients from all over the region has only 318 beds. In this context, the Medical College at Dibrugarh has around 40 beds in the Psychiatric ward, Guwahati Medical College has 64 beds and Silchar Medical College has 20. With less than 500 available beds for psychiatric patients, it would certainly be not easy to get a vacancy.

-From 'Mental Health Services in North East India', An experiential note, Mukul Goswami.¹⁰⁴

2. Equal Treatment for People with Disabilities Deprived of Liberty

Regarding the issue of equal treatment with dignity of people who have been deprived of their liberty, **there has been very little being done in this area.** Police stations are not accessible; the police officials have little understanding of people with disabilities and their needs; there are no sign language interpreters to provide information, such as reason for arrest etc.

One related scheme which relates to human rights and fundamental freedoms with respect the Legal systems is **National Legal Services Authority (Legal Services to the Mentally Ill Persons and Persons with Mental Disabilities) Scheme, 2010.** It was adopted in the meeting of the Central Authority of National Legal Services Authority (NALSA) held on 8th December 2010 at Supreme Court of India. It says, "India being a signatory to the UN Convention on the Rights of Persons with Disabilities (CRPD) 2008 and since our country has ratified the Convention, it is obligatory for our legal system to ensure the human rights and fundamental freedoms of persons with disability (including mentally ill persons and persons with mental disabilities) are enjoyed on equal basis with others and to ensure that they get equal recognition before the law and equal protection of the law." **It provides detailed guidelines while rendering legal services to mentally ill persons and mentally retarded persons.** It recognises the human rights and fundamental freedoms of mentally ill persons, and talks of non-discrimination and reasonable accommodations. It also talks of awareness and sensitising programmes.¹⁰⁵

However, none of the other initiatives that deal with arrest/detention, etc. have disability mentioned in them. Ministry of Home Affairs and National Human Rights Commission (NHRC) have issued detailed policies and guidelines, detailing the do's and don'ts with respect to arresting/detaining people. The National Human Rights Commission of India came out with a document, '**Guidelines for Police Personnel on Various Human Rights Issues, dated 10th December, 2010.**' The documents has sections on protection of rights of children, women, SCs, STs, senior citizens, minorities, etc. However, this document **does not have any guidelines on the rights of persons with disabilities! The Guidelines for the code of conduct for the police** were issued by the Ministry of Home Affairs and communicated to Chief Secretaries of all States/Union Territories and Heads of Central Police

¹⁰⁴Accessed at http://www.ashadeepindia.org/mental_health_services.htm on 30th August 2011.

¹⁰⁵Accessed at [hslsa.nic.in/schemes/Scheme_for Mentally Ill%5B1%5D.doc](https://hslsa.nic.in/schemes/Scheme_for_Mentally_Ill%5B1%5D.doc) on 30th August 2011.

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Organizations on July 4, 1985, in Section 13, mentions **“striving to renounce practices derogatory to the dignity of women and disadvantaged sections of society”**. It however, does not explicitly mention persons with disabilities.

Recommendations

- 1) The Government needs to review all disability and other relevant laws to include liberty and security of persons with disabilities.
- 2) The Government needs to implement and allocate a budget for National Legal Services Authority (Legal Services to the Mentally Ill Persons and Persons with Mental Disabilities) Scheme, 2010.
- 3) Community support, awareness, sensitisation programmes need to be initiated to ensure a life of dignity for persons with disabilities within the family and community.

Articles 15 and 16: Freedom from Torture or Cruel, Inhuman or Degrading Treatment or Punishment and Freedom from Exploitation, Violence and Abuse

The text of Articles 15 and 16 in the CRPD is given below.

Article 15: Freedom from torture or cruel, inhuman or degrading treatment or punishment.

- 1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.*
- 2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.*

Article 16: Freedom from exploitation, violence and abuse

- 1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.*
- 2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.*
- 3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.*

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4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.
5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

Survey Findings

1. The findings with respect to the efforts made by the Government to prevent torture, exploitation, violence and abuse of persons with disabilities in India as per the CRPD are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	56%
Dissatisfied	30%
Satisfied	5%
Extremely satisfied	0%
Do not know much about the issue	9%

Majority (86%) of the respondents were dissatisfied with the efforts made by the Government to prevent torture, exploitation, violence and abuse of persons with disabilities in India as per the CRPD. The measures taken by the Government, if any, have not been sufficient or effective in controlling the every-day exploitation and humiliation faced by most people with disabilities. About 9% respondents said they did not know much about the issue indicating their limited knowledge of civil rights and the Government's effort to ensure it for persons with disabilities.

Laws and Policies

Article 21 of **Constitution of India** states that no person shall be deprived of his life or personal liberty except according to procedure established by law. Life or personal liberty has been held to include the right to live with human dignity and includes within its ambit a personal guarantee against torture or to cruel, inhuman or degrading treatment or punishment. Article 22 guarantees protection against arrest and detention in certain cases and declares that no person who is arrested shall be detained in custody without being informed about the grounds of such arrest and cannot be denied to consult and defend himself/herself by legal practitioner of his choice. Article 22 directs that person

arrested and detained in custody shall be produced before nearest Magistrate within 24 hrs of such arrest. Article 20 (3) provides that accused shall not be compelled to witness against himself as this would amount to self incrimination.¹⁰⁶ These Constitutional provisions apply to all citizens of India, though persons with disabilities have not been specified.

The Disability Act 1995 does not have any provision or clause on protection or prevention from torture or cruel, inhuman or degrading treatment or punishment & from exploitation, violence and abuse.

Under guidelines for appointment of a guardian, **The National Trust Act, 1999** states that the application for guardianship for personal care and maintenance shall be accepted to cover areas including 'protection from exploitation and abuse & protection of constitutional and human rights.' Under Procedure for removal of Guardian, the following Acts of commission or omission constitute abuse or neglect on the part of the guardian.¹⁰⁷

- Solitary confinement of person with disability in a room for longer period of time.
- Chaining of the person with disability.
- Beating or treating a person with disability resulting in bruises, skin or tissue damage.
- Sexual abuse.
- Long deprivation of physical needs such as food, water and clothing.
- No provision or non-compliance of rehabilitation or training programmes as specified by experts in the field of disability rehabilitation.
- Misappropriation or mis-utilisation of the property of the person with disability.
- Lack of facilities or no provision of trained or adequate staff for meeting the training.

According to the **Mental Health Act 1987**, Chapter 8, Clause 81, Protection of Human Rights of Mentally Ill Persons,

- (1) No mentally ill person shall be subjected during treatment to any indignity (whether physical or mental) or cruelty.
- (2) No mentally ill person under treatment shall be used for purposes of research, unless-
 - (i) such research is of direct benefit to him for purposes of diagnosis or treatment; or
 - (ii) such person, being a voluntary patient, has given his consent in writing or where such person (whether or not a voluntary patient) is incompetent, by reason of minority or otherwise to give valid

¹⁰⁶ From 'India's Response Against the Act of Torture', by Divya Vikram, Law Resource India, 2010, accessed at <http://indialawyers.wordpress.com/2010/07/22/india%E2%80%99s-response-against-the-act-of-torture/> on 15th November 2011.

¹⁰⁷ Accessed at http://www.thenationaltrust.co.in/nt/images/stories/list/nt_rules_regulations.pdf on 15th November 2011.

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consent, the guardian, or other person competent to give consent on his behalf, has given his consent in writing for such research.

- (3) Any person who detains a mentally ill person otherwise than in accordance with the Act, shall be punishable with imprisonment for two years or with a fine of Rs. 1000/- or with both.

There are several **other legislations**, related to **women** rights, which automatically also apply to women with disabilities (even though there may not be any specific mention about disability). For example, the Immoral Traffic (Prevention) Act, 1956; the Dowry Prohibition Act, 1961 (Amended in 1986); the Indecent Representation of Women (Prohibition) Act, 1986; the Commission of Sati (Prevention) Act, 1987 (3 of 1988); Protection of Women from Domestic Violence Act, 2005, etc. There are also some other **child** related laws like the Juvenile Justice Act, 2000 and Juvenile Justice Act Amendment, 2006; The National Commissions for Protection of Child Rights Act, 2005 and Amendment 2006; The Immoral Traffic Prevention Act 1956. The Maintenance and Welfare of Parents and Senior citizens Act, 2007 is meant to uphold the rights of senior citizens.

These Acts have to be suitably amended to include issues of persons with disabilities and provide accommodations and support to persons with disabilities. In the meantime, effort should be made to ensure accessibility of all existing services, such as shelter homes, counselling, etc. for persons with disabilities. Authorities and people in charge of providing these services (protection officers, police officers, shelter home in-charge, counsellors, lawyers, social workers, etc.) need to be sensitised to provide the necessary support to persons with disabilities.

Article 15 of the CRPD states that "no one shall be subjected without his or her free consent to medical or scientific experimentation". **The Indian Council of Medical Research (ICMR) Guidelines for Biomedical Research** mentions that for all biomedical research involving human participants, the investigator must obtain the informed consent of the prospective participant or in the case of an individual who is not capable of giving informed consent, the consent of a legal guardian. Informed consent protects the individual's freedom of choice and respect for individual's autonomy and is given voluntarily to participate in research or not. Moreover, the selection of special groups as research participants mentions the rights and welfare of mentally challenged and mentally differently able persons who are incapable of giving informed consent or those with behavioural disorders must be protected. Appropriate proxy consent from the legal guardian should be taken after the person is well informed about the study, need for participation, risks and benefits involved and the privacy and confidentiality procedures. The entire consent process should be properly documented.¹⁰⁸

Based on CRPD's provision in Article 12, which provides for shifting from substituted decision making to supported decision making, the above

¹⁰⁸ From 'ICMR Ethical Guidelines for Biomedical Research on Human Participants', Indian Council of Medical Research, 2006, accessed at icmr.nic.in/ethical_guidelines.pdf on 12th November 2011.

mentioned guidelines would have to be suitably amended to ensure the same.

Progress and Concerns

The progress and concerns cover the issues of consent for scientific experimentation; prevention of torture, abuse, etc.; monitoring and redress mechanism; government's efforts towards recovery, rehabilitation and social integration; and issues related to age and gender.

1. Free Consent to Medical or Scientific Experimentation

Like mentioned in the above section, the laws do not adequately protect persons with mental impairment who may be considered "incompetent" in the way it is mentioned in CRPD. In the absence of clear laws and support systems in the country, there may be instances of people with intellectual or mental impairment who are being used as subjects for experimentation. **Moreover, the attitude of the society that regards life of persons with disability as less worthy than non disabled people leads to people with disabilities being used as guinea pigs for various experiments. Most of these cases do not get reported, as it is done by doctors and many times these are not seen as violation of rights.** In a country where doctors are considered superior, one hardly questions them. The issues related to forced sterilisation, organ transplants etc. are covered in the Chapter on Article 10, Right to Life and Article 14, Right to Integrity. Some people face multiple disadvantages, of gender, caste, age (children/ elderly) and hence, more vulnerable than others.

2. Prevention from Exploitation and Abuse

To prevent the exploitation/abuse/torture of persons with disabilities, it is important that they themselves are aware of their rights and so are their families. However, the Government has not played any significant role in creating awareness regarding the rights. Sometimes the exploitation happens within the families and sometimes outside it. And in both these scenarios, the person with disability does not know where to go for protection.

People with disabilities are often victims of neglect by their **family and relatives**. It is a fact that continued neglect can have a grave impact on victims in the longer run. The media has time and again reported on physical violence and abuse. But the stories of neglect, discrimination and indifference, mental torture (in certain cases) or denial of even basic right to respect and dignity within families and immediate social surroundings go unreported. **Legally and socially, very little has been done to address the issue of neglect.** Victims suffer in silence and are unable to express themselves in such a scenario. Lack of awareness about their rights and lack of any or very little support systems only compound the problem.

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There are a lot of instances of neglect/abuse in **institutions**, where people with disabilities are not entitled to basic human dignity, and even caregivers say that it is not a serious issue!

What is the fuss about?

The incident took place on March 8, 2008, a day when some of us were busy observing International Women's Day. The daughter of a female patient went to visit her mother at Pavlov Mental Hospital, a government-run hospital in Kolkata, West Bengal. As the patient's condition was serious, Doctor Ashis Acharya took the girl into the ward where her mother was. There, they were both shocked to see that all the female patients were stark naked. According to hospital authorities, this was because their clothes had gone for washing. When Dr Acharya protested, the hospital staff started arguing with him. A nurse, when questioned, explained that a second set of clothes was usually given to the patients when one set went for washing, but that stripping mentally ill patients of their clothes was "not a serious issue". According to the reporter who was following up the case, the hospital superintendent claimed it was a non-issue and he did not understand what all the fuss was about.

-From 'No rights for the mentally disabled', Shampa Sengupta, Info Change News & Features, April 2008.¹⁰⁹

Such incidents also showcase the weak **monitoring mechanism in institutions** run for disabled people including mental hospitals.

There are cases of wrongful or fraudulent confinement, overuse of shock treatment, presence of solitary confinement, sexual exploitation in the institutions. Many Psychiatric Units continue to use direct Electro-convulsive Therapy (ECT) (commonly known as shock treatment) on persons with mental impairment.

Many Psychiatric Units use Electro-convulsive Therapy (ECT) (commonly known as "shock treatment) on mentally ill persons. "All the General Hospital Psychiatric Units (GHPUs) that I visited have ECT facilities and they are used for as many as 20 ECT treatments per day. It did not appear that the GHPUs were following a uniform procedure as to how and when ECT is to be used."

-From 'General Hospital Psychiatric Unit and Rehabilitation Centres in India: Do law and public policy present barriers to community based mental health services', by Kevin M. Cremin, The Centre for Advocacy in Mental Health, Pune, 2007.

Saarthak, an NGO, filed a Public Interest Litigation (PIL) in 2001, seeking ban on ECTs, calling it a "barbaric" practice. However, a few associations of Psychiatrists opposed the petition citing that it is useful in some cases of mental illness. Unfortunately, the debate continues and so does the practice of

¹⁰⁹ Accessed at <http://infochangeindia.org/disabilities/analysis/no-rights-for-the-mentally-disabled.html> on 20th September 2011.

ECT. "Another grim aspect of this case is that the consumer's narratives on the ECT experience have neither been cited nor summoned by the Court. This can be attributed to the entrenched legal construction and a disqualifying legal regime. The matter is being played out as a scientific controversy instead of a human rights issue."

-From Chapter 10 of 'International and National Law on Selected Civil Rights', National Human Rights Commission.¹¹⁰

There is also abuse, exploitation and inhuman treatment of persons with disabilities by the **Police, and other security officials.**

"An instance in this regard is the rape of a deaf girl in a police van in Kolkata, West Bengal, in September 2000. She could not communicate the details of the incident and the medical team refused to accept her statement. They failed to take into account that the girl had not received any training in how to communicate and had developed a sign language of her own."

-From 'Protecting women with disabilities from violence', by Swagata Raha, Infochange Disabilities.¹¹¹

Policeman attacks mentally challenged man with brute force

"A policeman, surrounded by others, stands above a man lying on the ground. The policeman, who is in uniform, raises a stick - a huge lathi -and brings it down on the man. The gathered crowd shouts "Maaro, maaro (beat him)." The policeman continues. At least seven blows are delivered. The man starts bleeding. The victim, a 40-year-old naked Ram Krishna Agarwal - is mentally challenged. He lives with his family in Satna in Madhya Pradesh. When they saw the police attacking him, they were too intimidated to intervene.

The police later ties up Ram Krishna and drags him by his legs on the ground before moving him to a police station. Nobody steps forward to help the victim. Local media and camerapersons - none of them from NDTV -say they filmed the incident as evidence of police brutality against a helpless man.

Ram Krishna allegedly got into a fight with his neighbours in his village in Madhya Pradesh's Satna district because they were mocking his mental ability. When he got into a fight with them, neighbours called the police. Ram Krishna, now agitated, tried to fight two constables. The head of the local police station - named Balbir Singh Jaggi - then arrived. He is the one who is seen attacking Ram Krishna with brute force. He has since been suspended by the state's Home Minister, Uma Shankar Gupta.

Ram Krishna was taken to the police station and released after an hour. His family took him to a local hospital and has now moved him to home. NDTV.com; 23rd September 2011¹¹²

¹¹⁰ Accessed at <http://nhrc.nic.in/Publications/Disability/chapter10.html> on 1st October 2011.

¹¹¹ Accessed at <http://infochangeindia.org/disabilities/backgrounder/protecting-women-with-disabilities-from-violence.html> on 1st October 2011.

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Dr. Victor John Cordeiro, Disabled Activist, President, RED-India, Rashtriya Viklang Manch (National Confederation of Disabled), recently brought to the notice an incident in which a poor visually impaired person eventually died due to (railway) police atrocities (See Box). This is not the first incident of inhuman and brutal acts of the railway administration but is a routine activity. There were several incidents of this nature, which have been reported to the concerned authorities but there was no response.

Brutal, insensitive, discriminatory acts of railway administration against people with disabilities.

Kriparam, son of Ramdas from Gahal village of Harda District, Madhya Pradesh. He is a visually impaired person, married and has a 6 months old daughter. His wife is also a disabled person and the entire family depended on the income of Kriparam who was selling books at the Harda railway station. He was killed by RPF (Railway Police Force) staff of Harda station on 22nd September 2011. When he was selling books at the Harda railway station, a few RPF staff had an unnecessary argument and harassed him. He was then arrested and was beaten up so badly that he died on the way to the hospital. He was the only earning person and bread winner in the family whose death has caused serious and unrecoverable loss to the family.

-Email from Dr. Victor John Cordeiro, President, RED-India, Rashtriya Viklang Manch, National Confederation of Disabled, dated 28th September 2011.

3. Monitoring and Redress Mechanism

The role of the Central Authority for Mental Services and the State Authority for Mental Services is to "supervise psychiatric hospitals and psychiatric nursing homes and other Mental Health Service Agencies (including places in which mentally ill persons may be kept or detained) under the control of the Government".

There are monitoring and redress bodies specifically for persons with disabilities such as the Central Authority for Mental Services, State Authority for Mental Services, National and State Disability Commissioners. There are institutions which work on human rights and women and child rights issues such as the National Human Rights Commission, National Commission for Women, National Commission for Protection of Child Rights, Panchayats and Courts, legal aid cells and NGOs. They also have a role to play in monitoring the status of persons with disabilities vis-a-vis torture, cruel/inhuman or degrading treatment or punishment, exploitation, violence and abuse. The Ministry of Home Affairs, the Ministry of Health and Family Welfare, the Ministry of Social Justice and Empowerment and the Ministry of Information and Broadcasting, the police department and the judiciary also have a responsibility in ensuring protection of people with disabilities from any form of human rights violation. **The existing**

¹¹²Accessed at <http://www.ndtv.com/article/cities/policeman-attacks-mentally-challenged-man-with-brute-force-135739> on 1st October 2011.

disability specific mechanisms have not been very effective in preventing or monitoring issues of rights of persons with disabilities, particularly in the areas of abuse etc, as the legislations themselves are silent about these matters. With respect to other human rights institutions, disability is seldom seen as a cross-cutting issue by the authorities and the coordination between them is often missing. The victim with disability often remains clueless about where to go and has little/no information regarding any of these redress mechanisms.

There is lack of data and documentation on persons with disabilities, including women, children and the elderly, facing violence, abuse and exploitation. The Ministry of Home Affairs in its Annual Report 2010-11, talks about crimes against women, the steps taken to tackle the issue etc. Women and children with disabilities are more prone to violence and abuse but little or no data and documentation work has been undertaken by the concerned authorities.

Very few cases of exploitation of persons with disabilities reach the Courts. However, out of those cases that have reached, a few have received favourable judgments and sensitive intervention from the court.

In the case of *Tulshidas Kanolkar vs. State of Goa*, the Supreme Court of India expressed anguish at the repeated rape of a mentally challenged woman and observed that in such a case, apart from physical violence, there is also "exploitation of her helplessness". Justice Arijit Pasayat drew attention to the fact that while Section 376(2)(f) of the Indian Penal Code prescribes higher penalty for rape of a woman below 12 years of age, it is exigent on the legislature to prescribe a higher penalty for the rape of a mentally challenged woman whose *mental age* may be less than 12 years.

-From 'Protecting women with disabilities from violence', by Swagata Raha, Infochange Disabilities.¹¹³

4. Government's efforts to help in Recovery and Rehabilitation, Social Integration

There are **no specific measures that have been taken by the Government to help persons with disabilities who have been victims of abuse/exploitation, etc. to be rehabilitated.** There is hardly any information about victims of violence/ abuse, etc. There are rehabilitation centres for victims of crime. They are given compensation, financial assistance, medical support and rehabilitation services. Most of the existing rehabilitation mechanisms, services and packages available for general population remain inaccessible for people with disabilities. Most of the officials/professionals providing these services have hardly any awareness to even interact/communicate with persons with disabilities. Even NGOs dealing with women and children issues which are

¹¹³Accessed at <http://infochangeindia.org/disabilities/backgrounder/protecting-women-with-disabilities-from-violence.html> on 2nd October 2011.

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involved in providing support and rehabilitation do not take up issues of people with disabilities and may transfer their responsibilities to disability NGOs.

“The Children’s homes which house the “rescued” children work towards ensuring their rehabilitation. However, when it comes to disabled children they have little to offer.”

-Shared by a disability activist with DEOC.

“There seems to be little coordination between NGOs working in the field of disability and those working in the field of women’s rights and child rights and therefore women and children with disabilities who are victims of violence or abuse do not get a supportive rehabilitation environment anywhere. When it comes to torture, abuse and exploitation, disability becomes ‘nobody’s baby’.”

-Shared by a disability professional with DEOC.

Recommendations

- 1) All laws, policies and guidelines, existing and upcoming, meant for the protection of citizens against abuse, violence and exploitation, especially women and children, (like the Torture Bill, 2010, Sexual Harassment at Workplace Bill, 2010) should be harmonised with CRPD. The Criminal Procedure Code, Indian Penal Code, Indian Evidence Act, Juvenile Justice Act etc., should also be harmonised with CRPD.
- 2) Abuse and exploitation of people with disabilities should invite severe punishment for the accused under the law.
- 3) State-run institutions and other organisations catering to people with disabilities should be subjected to stricter monitoring. If found violating rules and laws, harsher punishment and penalties should be levied.
- 4) There should be specific programmes, including setting up of a redress mechanism, for addressing issues of persons with disabilities. The existing redress mechanisms for women, children, senior citizens, minorities, should be made inclusive and sensitive to disability issues.
- 5) The concerned Ministries, Commissions etc. should ensure documentation of abuse, violence, torture, neglect and exploitation of persons with disabilities.
- 6) Awareness campaigns through mass media should be undertaken to educate people with disabilities on their rights and the community at large.
- 7) Sensitisation/training programmes should be undertaken to educate professionals (medical, para-medical, legal, social work, etc.), officials, and other people involved in supporting victims of crime and abuse to be able to provide their support and services to people with disabilities.

Article 17: Protecting the Integrity of the Person

The text of Article 17 in the CRPD is given below.

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

Explanation

According to the CRPD Explanation document of Handicap International, 2009, 'The stand-alone provision is aimed at issues related to involuntary treatment.'

Survey Findings

1. The following were the findings with respect to the efforts made by the government to protect the integrity of persons with disabilities in India.

Rating	Percentage of Respondents
Extremely dissatisfied	57%
Dissatisfied	21%
Satisfied	10%
Extremely Satisfied	0%
Do not know much about the issue	11%

About 78% of persons with disabilities who responded to the Survey, were dissatisfied with the implementation of Article 17 of CRPD. They seem to feel that the integrity of the person is not respected in the country, especially when it comes to taking consent for treatment.

There are cases where girls/women with disabilities are forced to undergo hysterectomy and many cases of people with mental impairment admitted to institutions where consent is not taken from the individual. There has been some awareness as a result of NGOs and activists promoting the rights of persons with disabilities. However, their reach and impact have been limited. Moreover, the laws themselves do not support the integrity for people with certain disabilities. 11% of the respondents reported that they did not know much about the issue, indicating the fact that this is the right that is not understood much even amongst the respondents who were chosen because of their broader understanding and knowledge of disability issues.

Laws and Policies

The **Constitution of India** does not mention specifically the right of integrity of persons with disabilities. **The Disability Act, 1995**, too does not mention anything regarding the right to integrity of persons with disabilities. **The National Trust Act, 1999**, provides for guardians who can take decisions on behalf of persons with disabilities, thus restricting the right to integrity, as per CRPD.

The Mental Health Act, 1987, has provisions that allow for people to be admitted as in-patients in a psychiatric hospital/nursing home on an application made by a relative or a friend. The application form should be accompanied by two medical certificates from two medical practitioners. Thus it allows for involuntary treatment, contradicting the provisions as per CRPD.

India needs to amend the disability legislations and other related policies and guidelines, including medical ethics, to ensure conformity with the provisions of the CRPD.

Progress and Concerns

The State has not taken any proactive initiatives to implement the right to integrity of persons with disabilities as mentioned in the CRPD. There are no guidelines and support services to ensure informed decision making, particularly for people with intellectual or mental impairment or multiple disabilities or having communication difficulties.

There have been several instances where parents, guardians and institutions have gone for hysterectomy of people with disabilities because of their inability to maintain personal hygiene during menstruation. There are in-numerous cases where people have been put to forced treatments, including medications and direct Electroconvulsive Therapy (ECT) on people with psychosocial impairments. There are also instances of religious beliefs/faith healing which are forced on people with disabilities by families and the community.

Involuntary treatment is not prevented (it is sometimes even supported) by laws, hence, such acts are not even seen as violation of rights.

Mumbai: "In a five-page affidavit submitted to the Bombay High Court, Shahdeo Ware, Deputy Secretary of Women and Child Development Department, has endorsed guidelines vetted by four government doctors recommending hysterectomies on mentally retarded women with an intelligence quotient (IQ) below 50. DNA (the news service) interacted with 12 mentally disabled girls (over 16 years of age), all with an IQ below 50, at the SPJ Sadhana School at Peddar Road on Monday and found that all of them were aware of their menstrual cycles and were capable of maintaining hygiene personally. Labelling the government's move as "an easy way out", the principal, Sister E Gaitonde, said, "Persons with IQ as low as 20 can be taught

how to maintain personal hygiene. All it takes is a little time and commitment.”

-From 'Hysterectomies the answer', Government, January 29, 2008, Daily News and Analysis (DNA).¹¹⁴

An incident of children being buried upto their neck in a pit of soil has come to light in Gulbarga district of Karnataka. Some parents buried their children, many of them upto their necks, in a pit for the duration of the eclipse. The burying act was a part of a ritual that they believe will heal their children from handicaps or disorders that afflict them. The process started an hour before the start of the eclipse. It went on till eleven in the morning as the parents watched mutely even as their kids cried out. More than sixty children were forced to go through the torture. Some of them were from neighbouring Andhra Pradesh and Maharashtra.

This strange ritual has been held here over the past 5 years during every eclipse. The parents seemed oblivious of the fact that the children felt traumatised or that there was any danger of some insect bite while the child was buried up to the neck in soil. The fact that the act could also bring another untold disease through infection also missed the desperate parents.

-From 'Parents bury kids in soil on eclipse day', July 23, 2009, IBN Live.¹¹⁵

Recommendations

- 1) The disability and other laws need to be amended to not only explicitly mention this right in all relevant legislations but also to amend all the laws like Mental Health and other Medical Guidelines which violate this right.
- 2) Clear guidelines and procedure should be detailed out with respect to informed consent for any medical interventions for persons with physical and mental impairment.
- 3) Consent Form for treatment should be in easy to understand and in accessible format.
- 4) The Government should initiate the development of suitable support networks and services, including promoting self help groups, appointing counsellors, social workers etc., for persons with disabilities and families, so that counselling, peer interaction, etc. happen so as to ensure informed decision making.
- 5) Rehabilitation, support services and social security should be strengthened to ensure a better quality of life for persons with disabilities, which will in turn reduce the number of such cases.
- 6) Awareness about this right for persons with disabilities, families, medical and para medical professionals, legal fraternity and society in general, is crucial to ensure the implementation of this right in the right spirit.

¹¹⁴Accessed at http://www.dnaindia.com/mumbai/report_hysterectomies-the-answer-govt_1148030 on 10th September 2011.

¹¹⁵ Accessed at <http://ibnlive.in.com/news/parents-bury-kids-neckdeep-in-soil-on-eclipse-day/97692-3.html> on 10th September 2011.

Article 18: Liberty of Movement and Nationality

The text of Article 18 in the CRPD is given below.

<p>1. States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including by ensuring that persons with disabilities:</p> <ul style="list-style-type: none">a) Have the right to acquire and change a nationality and are not deprived of their nationality arbitrarily or on the basis of disability;b) Are not deprived, on the basis of disability, of their ability to obtain, possess and utilize documentation of their nationality or other documentation of identification, or to utilize relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement;c) Are free to leave any country, including their own;d) Are not deprived, arbitrarily or on the basis of disability, of the right to enter their own country;
<p>2. Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.</p>

Survey Findings

1. The findings with respect to the efforts made by the government to ensure liberty of movement and nationality are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	36%
Dissatisfied	22%
Satisfied	20%
Extremely Satisfied	1%
Do not know much about the issue	22%

Compared to other questions in the survey, this has the maximum people (22%) saying that they do not know much about the issue. There is also higher level of satisfaction (20%) compared to other survey questions indicating that there is no apparent discrimination with respect to liberty of movement and nationality. The fact that over 50% people have expressed dissatisfaction indicates that are issues that need to be addressed. There are instances of discrimination and barriers to liberty on movement and nationality.

Laws and Policies

The **Registration of Births and Deaths Act** (RBD Act), 1969, was enforced in most parts of the country in 1970. The Act provides a uniform law for compulsory registration of births and deaths across the country. There is no specific question on disability in the Birth Registration Form. Hence, procedurally, all children, irrespective of whether they have a disability or not, are registered, if parents apply for their registration.

The Disability Act, 1995 and National Trust Act, 1999, do not have any specific clause with respect to the right of liberty of movement and nationality.

The Mental Health Act, 1987 allows for involuntary admission to any psychiatric hospital or psychiatric nursing home for treatment. For the discharge too, one needs permissions. It therefore, **restricts the liberty of movement for persons with mental illness.**¹¹⁶

There are no laws that prevent any citizen with disability **to move from one State to the other**, like any other Indian citizen.

With respect to **foreigners coming to India**, instructions issued by Bureau of Immigration, India, mentions that a foreigner may be refused entry in case she/he is "insane"¹¹⁷

Progress and Concerns

1. Registration of Birth

The registration of births and deaths in the country is done by the functionaries appointed by the State/Union Territory Governments under the RBD Act, 1969. The Registrar General, India coordinates and unifies the registration activities across the country while the Chief Registrars of Births and Deaths are the chief executive authorities in the respective States.¹¹⁸

The proportion of registered births and deaths has witnessed a steady increase over the years. The registration level of births for the Country in 2007 has gone up to 74 percent, thus, registering an increase of about five percent for births over the previous year. However, wide variations across the States in the level of registration have continued to persist. The States of Goa, Himachal Pradesh, Meghalaya, Mizoram, Nagaland, Kerala, Punjab, and Tamil Nadu and Union Territories of Chandigarh, Delhi and Puducherry have achieved cent per cent level of registration of births. The States of Gujarat, Haryana, Karnataka, Sikkim

¹¹⁶Part 3, Reception Orders, of The Mental Health Act gives details on the circumstances under which the person with mental illness may be admitted and the procedures that are required to be followed.

¹¹⁷Accessed at http://www.immigrationindia.nic.in/instr_foreigners2.htm on 15th November 2011.

¹¹⁸ Page 255, Annual Report of Ministry of Home Affairs, 2010-11.

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and West Bengal have achieved more than 90% level of registration of births. However, this level is still less than 50% in States of Bihar and Jharkhand.¹¹⁹

There is a clear mandate for registering all births in the country. India has still not reached 100% registration of birth in spite of the Act, which was enacted more than 40 years ago. **About 26% of births are still not registered in our country. Registration rates are lower particularly in slums, difficult terrains, remote areas, areas of conflict and rural areas.** Though there has been no specific study with respect to the registration status of children with disabilities, one can logically assume that the chances of children with disabilities not getting registered would be high due to many reasons. When a child with disability is born, the family may be in a state of shock/confusion and registering may not even come to their mind. There are many children with disabilities on streets; some children are abandoned at birth, hidden from the society etc.

The Birth Certificate is useful for getting admission in schools. Many parents get the certificate done at that time. Many children with disabilities who are not being sent to schools remain without birth certificates. In India, there are other options, in case one does not have birth certificate, for school admission and getting other benefits. Hence, the motivation for getting birth certificate is very low in the country in general and this applies to children with disabilities as well.

In the Annual Report of Ministry of Home Affairs, apart from the statistics/data on birth registrations, there is no mention of measures to address issues related to birth registrations of children with disabilities.

However, there were a few media reports in the internet of certain initiatives of NGOs and the State Government for creating awareness on birth registration in general. For example, introduction of 'Bhagyalakshmi scheme' in Karnataka by the State Government, has increased the registration of births in the State.¹²⁰

2. Liberty of Movement

2.1 Travelling within India

There are no restrictions as such for persons with disabilities to travel anywhere in the country. There have been a few initiatives to make travel non-discriminating for persons with disabilities. **However, people with disabilities have been refused entry in public transport, drivers/operators have misbehaved and inaccessible infrastructure and procedures, have prevented people with disabilities from travelling. Road and Rail travel continues to be very inaccessible for most people with disabilities.** There have been some initiatives for making them accessible (Please see the chapter on Accessibility). However, the impact has been minimal.

Based on several complaints from passengers with disabilities, the Director General of Civil Aviation (DGCA) issued Guidelines for "Carriage by Air of Persons

¹¹⁹ Page 255, Annual Report of Ministry of Home Affairs, 2010-11.

¹²⁰ The scheme offers financial help of up to Rs. 100,000/- for a girl child belonging to a BPL family after she completes 18 years of age.

with Disability and/or Persons with Reduced Mobility” on 1st May 2008. It clearly states that no airlines should refuse either to carry persons with disabilities or to provide aids, assistive devices, guide dogs etc. It also states that airlines should provide necessary support to passengers with disabilities for example, making available wheelchairs and ambulift. It further details various other aspects including the sensitisation of staff, boarding and seating procedures, complaint procedure etc.

In spite of these Guidelines, there have been a few instances of private airlines refusing to board persons with disabilities.

On 10th May 2011, Kingfisher Airlines, a private airline, made Shabnam Mansuri, a blind woman and her two children disembark from her connecting flight to Goa and left them unattended for nearly an hour and a half while the plane took off without them. The airline's staff told her that she could not travel with two kids because she was blind.¹²¹

2.2. Travelling outside India

There are no apparent restrictions for persons with disabilities travelling to any country, like anybody else. However, there are instances like visa procedures which have been found to be discriminating.

Shivani Gupta, Accessibility Expert, had been invited for a business meeting to London on a short notice. The invitation letters stated very clearly that Shivani has a disability and that she will be accompanied by her carer, with the carer's name clearly mentioned. *They also mentioned in the letter that all expenses for both of them regarding travel and hotel accommodation will be borne by our company.*”

Shivani applied for their visas under 'Business Visa' category as the invitation letter said that she was travelling for a business meeting. At the time of submitting the forms the lady at the counter informed her that she would need to fill another form for her carer as she was going to be in her service during the travel and cannot be given business visa which was only Rs 5000/-. The fee for the other visa was about Rs 18,000/-. She went ahead and filled the business visa for her and her carer. The visa of the carer was rejected stating she was not travelling for business!

Shivani has questioned this in her blog, “Is it not discriminatory that I am required to pay a heightened visa fee of Rs.18,000/- for my personal carer's visa just because I cannot travel without her? It is more like a fine I need to pay to the UK Government because I am disabled and require a personal carer. The repercussion of this on me was that I was unable to travel also and

¹²¹ Mid Day Website, 21st May 2011, accessed at <http://www.mid-day.com/news/2011/may/210511-Shabnam-Mansuri-Kingfisher-crew-blind-woman-disembark-Airline-mumbai.htm> on 10th December 2011.

had to miss my business meeting and miss the future business prospects just because my carer was refused a visa. Is it fair?"¹²²

Recommendations

- 1) The Disability Act, National Trust Act and Mental Health Act and other Acts related to liberty of movement and nationality should state clearly that people should not be discriminated and they should be provided reasonable accommodation to exercise this right with dignity.
- 2) An awareness drive needs to be undertaken to ensure that infants with disabilities get birth certificate.
- 3) Ministry of External Affairs should negotiate with other countries to ensure that persons with disabilities and their caretakers/helpers are not discriminated against when it comes to travel visas and immigration.
- 4) Bureau of Immigration, Ministry of Home Affairs should amend its policy that says that foreigners who are "insane" may not be allowed to travel in India.
- 5) Strict action is required to be taken against National and Private Airlines if they discriminate against persons with disabilities and their caregivers. Guidelines and training needs to be provided on a regular basis to the Airlines management and staff as well as those working at airports.
- 6) Guidelines, policies and training need to be provided to the Railways and Road Transport for support to persons with disabilities.
- 7) Redress mechanism should be put in place for any complaints received from persons with disabilities in terms of mobility.
- 8) There should be sign language interpreters in visa offices, passport offices, enquiry counters and immigration. These offices should be accessible with proper signages for persons with disabilities.
- 9) The online information and application forms on websites should be in accessible formats for persons with visual disability.

¹²²Accessed at <http://accessability-india.blogspot.com/2011/05/disability-and-uk-visa.html> on 12th November 2011.

Article 19: Living Independently and Being Included in the Community

The text of Article 19 in the CRPD is given below.

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*
- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

Survey Findings

1. The findings with respect to the efforts made by the government to promote independent living for persons with disabilities and be included in the community are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	53%
Dissatisfied	31%
Satisfied	15%
Extremely Satisfied	0%
Do not know much about the issue	1%

There is a 15% satisfaction with respect to the Right to living independently and being included in community. In the last decade or so, with a comparative increase in education and employment opportunities and awareness, persons with disabilities have taken steps to staying independently in hostels, as paying guests, in rented and owned apartments. This is particularly so in metropolitan cities. 84% respondents expressing dissatisfaction indicates that there are many hurdles and barriers that people with disabilities still have to face if they have to choose to live independently and that the community services, facilities and support are highly inadequate in the country. Many do not even have a choice!

Laws and Policies

Clause 43 under the 'Affirmative Action' Section of **The Disability Act, 1995**, provides for schemes for preferential allotment of land for certain purposes. It states that, "The appropriate Governments and local authorities shall by notification frame schemes in favour of persons with disabilities, for the preferential allotment of land at concessional rates for

- House.
- Setting up business.
- Setting up of special recreation centres.
- Establishment of special schools.
- Establishment of research centres.
- Establishment of factories by entrepreneurs with disabilities."

Clauses 44, 45 and 46 deal with non discrimination in transport, road and built environment. The law has no mention of accessibility to products and services.

Chapter 3 of the **National Trust Act, 1999**, 'Objects of the Trusts' has following relevant points.

- To enable and empower persons with disability to live as independently and as fully as possible within and as close to the community to which they belong.
- To strengthen facilities to provide support to persons with disability to live within their own families.
- To extend support to registered organizations to provide need based services during the period of crises in the family of persons with disability.
- To deal with problems of persons with disability who do not have family support.

The **Mental Health Act, 1987**, deals mainly with admission, treatment and detention in psychiatric hospitals and does not talk of rights or community services or independent living.

Progress and Concerns

1. Choice of Residence

In India, one can live in family homes, hostel for education/employment, rented or leased premises, one's own apartment/house or in institutions like psychiatric hospitals/nursing homes/residential care/beggars home/old age homes/night shelters, etc.

Majority of people with disabilities in our country do not have a choice with regard to their place of residence and where and with whom they can live on an equal basis with others. A few empowered people with disabilities have been able to make their choice and are leading an independent life, especially those who have employment. Women with disabilities find it more difficult than men to make that choice due to certain stereotypical attitudes present in society.

There is also a tendency to look at hostels/homes as the first or only option for persons with disabilities. Most schools for blind people and deaf people have been residential. People with mental illness are treated in residential facilities. Many families of children with intellectual disabilities look for hostels/homes, when they are unable to look after their child. Older parents of persons with disabilities also look for homes as they fear for what would happen to them when they are no more there to give care.

Generally, rural communities and joint families are more inclusive than urban communities and nuclear families in India. The choice, many a times, depends on who can 'take care' of the person with disability. The attitude of the family towards the person with disability would sometimes depend on the economic status of the person.

"One married young couple (both husband and wife have disability), well employed, in a metropolitan city, could not find any house for rent. House owners were just not willing to give their house to them! Many did not think they will be able to manage and take care of their house well! A woman using a wheelchair who moved to another city after getting employment, could not find a house to live, as the owners could not believe she can live alone! There is no protection against discrimination for such cases."

-A disability activist.

"I have a child with deaf-blindness. I am wondering if putting her in residential school for deaf-blind would help. I would not have thought of this option if she was not a person with disability. My other children are not going to a residential school. I do not think I have a choice here, as there no facilities in the regular school."

-A parent.

"Maharashtra Government and few other State Governments give Rs. 50,000/- to people who marry a person with disability. This has been highly criticised by the disability sector, saying it is promoting charity and pity. If the Scheme is changed in such a way that Rs. 50,000/- is given to a person with disability who is marrying (whether to a disabled or non disabled person), it would be seen as empowering and would cover some costs for setting up a home for the newly wed." A disability activist.

2. Access to Range of Homes

One of the important aspects of independent living is access to housing.

There is reservation for persons with disabilities in the Government housing schemes. Housing is a State subject and the implementation varies from State to State. Some States provide 3% reservation for persons with

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disabilities, some provide 1% and some provide none! Some States provide reservation to people with only certain disabilities. There have also been court cases to implement the scheme by aware citizens who have received favourable orders.

The Delhi Development Authority (DDA) has a policy for preferential allotment of houses/land to persons with disability. It states that¹²³

- (i) 1% reservation in allotment of flats and plots and 5% reservation in allotment of shops will henceforth be provided to the persons with disability as defined in Section 2 of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995. The above reservation will not be applicable in case of auction mode of disposal.
- (ii) Allotment of flats to persons with disability will be made at Ground Floor.
- (iii) The allotment of DDA flats to persons with disability would be on hire purchase basis. The initial payment in case of hire purchase allotment would be 25% instead of 50% of the total cost applicable for general category. Rest of the amount would be taken in monthly instalments.

Poverty and disability are highly correlated. Hence, poor people are more likely to have one disability or the other. Till now, there has been no effective study of collecting data of poor people with disabilities in the country.

There are certain housing schemes targeting the rural and urban poor in the country. The Ministry of Rural Development started implementing its major housing scheme of **Indira Awaas Yojana** (IAY) as an independent scheme from 1st January 1996. The role of the State Government is confined to merely facilitating the use of local, low cost, environment-friendly, and disaster resistant technologies and also in encouraging the construction of sanitary latrines and smokeless *chulhas*. There is no prescribed design or technology and no contractors are involved. There is 3% reservation for persons with disabilities under the scheme. **Only beneficiaries who have house-sites are selected and thus, the very poor who do not have a plot of land are not within the purview of the scheme. This is a serious problem, since these are the people who are the most vulnerable.**¹²⁴

The Annual Report states that the total number of Dwelling Units completed during the period 2010-11 (up to December 2010) was 2,686,117 out of which 33,118 (1.23%) houses were allotted in the name of persons with disabilities. This is way below the 3% which is mandated by the law.

The Government has initiated the **Rajiv Awas Yojana (RAY)** which aims at providing support to States that are willing to provide property rights to slum dwellers. The proposal of the Scheme has been submitted for consideration of the Cabinet Committee on Economic Affairs as on 10th February 2011. In the

¹²³ Accessed at www.dda.org.in on 10th October 2011.

¹²⁴ See the Eleventh Five Year Plan.

mean time, the preparatory phase of RAY has already commenced and States are being assisted to draw up their Slum-free Plans of Action...Under the Scheme, a sum of Rs. 60 crore has been released to 20 States for preparing Slum free City Plans.¹²⁵ **Nothing specific has been mentioned about disability in the Scheme.**

The National Trust has a scheme called **GHARAUNDA** (Group Home and Rehabilitation Activities Under National Trust Act for Disabled Adults). The objectives are to encourage assisted living with independence and dignity; to facilitate establishment of requisite infrastructure for the assured care system throughout the country and provide the care services at an affordable price on a sustainable basis. The scheme is, at present, sanctioned to 7 places – KPAMRC in Bangalore, Open Learning System in Bhubaneswar, Prayas and Partner Hoogly in West Bengal, Savali in Pune, Govt. of Chattisgarh in Raipur and Government of Uttarakhand in Haridwar.¹²⁶

3. Community Services

For living independently, **availability, accessibility and affordability of community services** is crucial for any person with disability and the Government seems to have done little to ensure these. **Services specific to persons with disabilities** also need to be easily available, accessible and affordable in order to support them for living independently and also for helping them to be an integral part of the community.

Community services like shops, ambulance, auditoriums, cinema halls, clinics and hospitals, places of worship, restaurants, offices, banks and banking services, helpers like gardeners, plumbers, carpenters, maids, etc. are some of the services needed by persons with disabilities to live independently and in the community. Many of these services are provided by private or unorganised sectors. **There is little control of the Government over their availability, the sensitivity of the people in charge and the policies governing them.**

Lack of accessibility of roads, transport and built environment poses extreme difficulty for people with disabilities to go anywhere in the community and to access services.

There has been some work in the area of accessibility. For example, some newly built large malls, large offices, large hospitals etc., have certain accessibility provisions, particularly in the metropolitan cities. However, in local communities, the smaller shops, restaurants, clinics, parks, coaching centres, ATMs, gymnasiums, parlours, etc. which one accesses on a daily basis remain largely inaccessible. There has hardly been any initiative to make these places accessible. In the last few years, there has been a huge increase in the number of shops, restaurants, banks, cafes, etc. and yet none of these seem to be accessible nor do they provide accessible services. Public transport, roads, footpaths etc. are also mostly inaccessible for persons with disabilities.

¹²⁵ Page 36, Annual Report, Ministry of Housing and Urban Poverty Alleviation, 2010-11.

¹²⁶ Page, 147, Ministry of Social Justice and Empowerment, Annual Report 2009-10.

Services, like health care and rehabilitation services, are not accessible for persons with disabilities, be it in rural or urban areas. Government has not taken any measures to provide home based services for persons with disabilities. **No steps have been taken by the Government to provide safety and security to people with disabilities living independently.**

In rural areas, even to access basic services like clean drinking water, education, medicines, post office, a person with disability has to walk or take local transport which is often inaccessible. The terrain may be difficult. The person may need a personal attendant with her/him.

One of the major aspects of independent living for many people is the **access to personal assistance**. The National Trust has launched a scheme called '**Sahyogi**' – **Care Givers Training & Deployment**. Under the scheme, Care Givers Cells (CGCs) have been set up in selected NGO Centres across the country. A website (www.sahyogi.org) has been launched for the scheme including on line registration of Care Seekers. (Page, 147, Ministry of Social Justice and Empowerment, Annual Report 2009-10). So far, 40 CGCs have been set up in the country. **184 caregivers have been trained so far (till December 2009). This number is extremely low compared to the demand that exists. Moreover, care giving services have become quite expensive and hence unaffordable by most people with disabilities. There is no support from the Government to subsidise these services.**

"One family in Bangalore has been trying to appoint a caregiver for their child with cerebral palsy for the last two years. They have still not been able to find a person. They have also registered with the Care Giving Cell of the National Trust. They have not even got a call from the cell."

-Rama Chari, DEOC

"I am a wheelchair user living alone. I wanted to call a doctor home when I was ill. All the doctors in the neighbourhood refused to come citing one reason or the other. Every time I have to get the catheter changed, I find it very difficult to get a nurse. They just refuse to come or charge exorbitantly."

-Seetha

There are no **support networks** for persons with disabilities, especially for people with high support needs, who may need help in "supported decision making". Government has done nothing to build such networks.

There is **lack of awareness** in the community about disability. There have been instances where neighbours or relatives themselves have been completely insensitive to the needs of persons with disabilities.

Psychiatrist Fabian Almeida was stunned when the co-operative society next to his clinic outside Mumbai wrote to him complaining about his patients with mental disabilities. He was told that those receiving treatment for conditions

ranging from depression and obsessive compulsive disorder to hyperactivity and dyslexia were a nuisance to other residents.¹²⁷

People in general in the urban areas have become indifferent to others around them. Neighbours seldom care for each others' needs. Isolation and depression is also on the rise.

In an appalling case of self-deprivation, apparently induced by severe depression and fear, two sisters in their early forties were rescued by the Noida Police on Tuesday from their first-floor flat in a house in Sector 29. The two sisters had been staying in isolation for around seven months. They had been starving and were emaciated with no source of income with their power, water and phone connections having been snapped. According to the cops, the women had lost their parents in quick succession and their brother had moved out of the house. When their pet dog too died, they withdrew from the world. There are four other flats in the apartment but since they rebuffed some initial attempts to reach out to them, no one bothered to find out how they were doing.¹²⁸

Recommendations

- 1) Disability Laws should explicitly mention the right to live independently and be included in the community.
- 2) Loans at concessional rates can be provided to buy houses, to make houses accessible and to buy vehicles.
- 3) The Government needs to focus on raising awareness regarding the rights of persons with disabilities through highlighting role models so that the community at large is more accepting towards disability.
- 4) The Government needs to closely monitor effective implementation of housing schemes to ensure fulfilment of 3% quota.
- 5) 'Gharunda' scheme of assisted independent living should be expanded and strengthened to more people with disabilities.
- 6) Sahyogi scheme should be strengthened and expanded to cater to more people with disabilities and all types of disabilities who need attendant services. Their training should be based on the practical and functional needs of persons with disabilities. The rates should be subsidised by the Government to ensure a wider reach.
- 7) Independent living is also largely dependent on accessibility of community infrastructure and services and therefore the Government needs to ensure the same through guidelines, government orders, funds, trainings, etc.

¹²⁷ Mental health and disability stigmas thrive in India, 25th September, 2011, Disability News India, accessed at <http://www.disabilityindia.com/html/news.html#mhds> on 1st November 2011.

¹²⁸ Noida horror: Sisters starve all alone, 13th April 2011, The Times of India, accessed at http://articles.timesofindia.indiatimes.com/2011-04-13/delhi/29413064_1_sisters-noida-police-depression on 1st November 2011.

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- 8) Home based services, for doctors, nurses, etc. should be provided by Government hospitals at subsidised rates.
- 9) All hostels (for students and for those who are employed) should have some rooms that are accessible. The Government should launch a scheme to construct new hostels in every major city of the country and these need to be completely accessible for persons with different disabilities.
- 10) Effective redress mechanism with penalties to be established to ensure people with disabilities are not harassed in the community by any service provider.
- 11) The Village Panchayats, Block level leaders, Resident Welfare Associations should be sensitised on the rights of persons with disabilities and also handle cases of complaints.
- 12) Local Police should ensure security of people with disabilities staying alone.
- 13) The Indian culture which promotes relationships and interdependence- families, relatives, community-should be revived.

Article 20: Personal Mobility

The text of Article 20 in the CRPD is given below.

States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

- (a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;*
- (b) Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;*
- (c) Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;*
- (d) Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.*

Survey Findings

- The findings with respect to the efforts made by the government to ensure that persons with disabilities have access to mobility and other assistive aids and technologies at affordable cost are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	45%
Dissatisfied	44%
Satisfied	10%
Extremely satisfied	0%
Do not know much about the issue	1%

Across all respondents, as high as 89% felt dissatisfied with the Government's efforts to provide choice in personal mobility to persons with disabilities. Only 10% were satisfied, which may be because they personally may not have faced mobility challenges.

Mobility is of immense importance, be it within the house or going outside for schooling, employment or leisure. And the fact that people are dissatisfied reflects that people with disabilities largely remain dependent. They have little choice or options to choose from. Aids that are affordable are not of good quality. Good quality ones are unaffordable. Further, personal attendants are not available or available only at a very high cost. Lastly, plans for research into mobility aids remains on paper or if they do materialise, exist only as prototypes.

Laws and Policies

The Disability Act, 1995 mentions in the chapter on 'Affirmative Action' (Clause 42) that "The appropriate Governments shall by notification make schemes to provide aids and appliances to persons with disabilities." Under the chapter on 'Research and Manpower Development' (Clause 48c), it mentions that the Government shall "promote and sponsor research, *inter alia*, in the area of development of assistive devices including their psycho-social aspects."

There is no specific mention of the need for personal mobility for independence, the need for mobility training and the training personnel required, the need for personal assistants, or the need to have various options for mobility aids and equipments to choose from.

Though one of the objectives of **The National Trust, 1999**, is "to enable and empower persons with disability to live as independently and as fully as possible within and as close to the community to which they belong".

The Mental Health Act, 1987, does not mention personal mobility in any form. However, there are provisions that allow involuntary admissions. Even if one gets admitted voluntarily, the discharge is decided by a Medical Board. It is a clear curb on the independence and the choice of the person.

The **Motor Vehicle Act, 1988**, Clause 8(4) states that "If, from the application or from the medical certificate referred to in sub-section (3) it appears that the applicant is suffering from any disease or disability which is likely to cause the driving by him of a motor vehicle of the class which he would be authorised by the learner's licence applied for to drive to be a source of danger to the public or to the passengers, the licensing authority shall refuse to issue the learner's licence; Provided that a learner's licence limited to driving an invalid carriage may be issued to the applicant, if the licensing authority is satisfied that he is fit to drive such a carriage." The Government needs to review the Act and the guidelines for the licensing authority to issue the learner's licence.

In a landmark judgement which will benefit millions of deaf people in the country, the Delhi High Court has opened the doors for deaf people to take a driving test, and if they pass, to get a driving licence for the first time in India. Prior to this, the Motor Vehicles Act and Rules automatically disqualified a deaf person from obtaining a licence on the presumption that deaf persons would be a danger to the public.¹²⁹

The Indian Railways Act, 1989, Section 56 states, "A person suffering from such infectious or contagious diseases, as may be prescribed, shall not enter or

¹²⁹ Deaf eligible to undertake driving test, licence: Delhi HC, New Delhi, 15th February, 2011, accessed at http://hrln.org/hrln/index.php?option=com_content&view=article&id=612:deaf-eligible-to-undertake-driving-test-licence-delhi-hc&catid=28:pils-a-cases&Itemid=155 on 15th September 2011.

remain in any carriage on a railway or travel in a train without the permission of a railway servant authorised in this behalf.¹³⁰ This law has to be suitably amended to ensure non discrimination of persons with disabilities as per CRPD.¹³¹

Progress and Concerns

The crucial points with respect to personal mobility are choice and independence of persons with disability to move around freely and availability, affordability and quality of mobility aids. The Article includes provision for personal assistants, mobility training, aids, devices, assistive technologies and research, development, manufacturing and promotion of these aids. Very closely related to personal mobility is making roads and infrastructure accessible. (Issues concerning accessibility are covered in the section on Article 9).

1. Availability, Affordability and Quality of Mobility Aids, Assistive Devices and Technologies

One of the major manufacturers of assistive devices, set up in 1972 by Government of India, is the Artificial Limbs Manufacturing Corporation (ALIMCO), a non-profit company. They manufacture 355 types of aids and appliances, including mobility aids like crutches, manual/motorised tricycles, manual/motorised wheelchairs, artificial legs, callipers, spinal braces etc.¹³²

The Government has a scheme, 'Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances (ADIP)' through which aids and appliances are distributed to people with disabilities. The main objective of the ADIP Scheme is to provide grant-in-aid to the various implementing agencies (NGOs/National Institutes/District Disability Rehabilitation Centres/ALIMCO/State Handicapped Development Corporation/other local bodies) to assist the needy persons with disabilities in procuring durable, sophisticated and scientifically manufactured, modern, standard aids and appliances. Through the ADIP Scheme, while the number of beneficiaries in 2006-07 were 307,000, it dropped to 210,591 beneficiaries in 2008-09. Aids are also distributed through the ADIP scheme under the Sarva Shiksha Abhiyan scheme for children between the age of 6-14 years.¹³³ Latest data for 2010-11 was not available.

The quality of the products of ALIMCO and the procedure of ADIP Scheme have been highly criticised not just by persons with disabilities but also by the Planning Commission. The Mid Term Report of XI Five Year Plan itself says that "ALIMCO products are believed to be costly and also have low acceptability among users. "Procedures under the ADIP scheme need to be

¹³⁰ 'Harmonizing Laws with the UNCRPD', Report prepared by the Centre for Disability Studies, NALSAR University of Law, Hyderabad, Human Rights Law Network, The Deaf Way Foundation, National Association of the Deaf.

¹³¹ "Leprosy cured' people have been denied entry by the Railway authorities citing this clause.

¹³² Accessed at <http://www.artlimbs.com/profile.htm> on 10th October 2011.

¹³³ Page 110-112, Annual Report, Ministry of Social Justice and Empowerment, 2009-10.

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simplified so as to facilitate easy availability of the much-needed aids and appliances to persons with disabilities.”

The cost of most of the aids and appliances provided under the scheme is Rs. 6000/- or less. The aids and appliances are given free to a person whose family income is less than Rs. 6500/- per month and at 50% of the cost to those with income between Rs. 6500/- and Rs 10,000/- per month. Further, a travelling cost of Rs. 250/- for a beneficiary irrespective of number of visits to the centre is given. Boarding and Lodging Expenses at the rate of Rs. 30/- per day for a maximum duration of 15 days is provided. The travel allowances are only for those people whose total income is upto Rs. 6,500/- per month.¹³⁴

The cost limit of the aids and appliances under the scheme reduces the quality of the products substantially. Further, the income limit for availing the benefit from this scheme limits the number of people who are eligible.

2. Import of Mobility Devices

There are very few assistive aids and technologies which are manufactured in the country, except for some basic ones like the wheelchair, etc. Even these are not of very good quality, as mentioned in the above section.

There is full exemption from customs/excise duty on assistive devices, rehabilitation aids imported by persons with disabilities. This was a result of advocacy done by the National Centre for Promotion of Employment for Disabled People (NCPEDP) and the Disabled Rights Group (DRG) in 2003.¹³⁵ Though the duties are exempted, the costs of these goods are still quite high and hence, unaffordable by most people with disabilities in India. Moreover, these exemptions can be availed by individuals who have contacts abroad.

3. Promoting Production of Mobility Aids

There have not been any measures on the part of the Government to promote manufacturing or marketing of assistive devices in the country. **None of the larger bicycle or automobile companies in India manufactures mobility aids.** Most manufacturers of mobility aids are either small scale or are distributors of imported aids. **There are no incentives or schemes/funds to encourage manufacturers to get into the production of mobility aids.** There is also lack of research in this area. There are institutions like the National Institute of Design and the Indian Institutes of Technology that undertake such types of research but most of what they do remain as prototypes and hardly ever come into production.

¹³⁴ Ministry of Social Justice and Empowerment's website, accessed at <http://socialjustice.nic.in/adipmain.php> on 15th October 2011.

¹³⁵ Accessed at http://www.telegraphindia.com/1030131/asp/nation/story_1623922.asp on 15th November 2011.

4. Vehicles

There is a direct relation between personal mobility and transport. **There are hardly any modes of transport that are totally accessible to persons with disabilities.**

In India, the majority of the population depends completely on the public transport system for their personal mobility, which at this point in time is quite inaccessible. This aspect has been covered in detail in the section on Article 9.

There are no manufacturers of totally disabled-friendly vehicles, for example, wheelchairs that can go into a car. There are very few people who make these modifications in India and not everyone is able to access them. **The Government and large private taxi services (Meru, Easy cab etc.) do not offer a choice of accessible vehicles.** There are one or two organisations that offer accessible taxi services in a few metropolitan cities but they have very few vehicles and very few people are aware of this service. There have been many instances where taxi and auto rickshaw drivers have refused carrying passengers with disabilities or have spoken rudely to them or refused to assist them in any way or charged them much higher fare. **Most four wheelers do not have enough space in the boot (dicky) or carrier on the top for keeping a wheelchair.**

There is excise duty exemption for people with disabilities on purchase of cars. The Excise Duty on motor cars for disabled people is reduced from 16% to 8% and are further exempted from the National Calamity Tax of 1%.¹³⁶ There is also exemption from Road Tax.

People with disabilities find it extremely difficult to get these exemptions. There is a lack of awareness among the manufactures/distributors about these exemptions. Some manufactures insist on medical certificates to prove that the person can drive the car. There are also several issues faced at the RTO where people with disabilities are harassed for registering a modified vehicle.

Another major issue is that people with disabilities are often denied driving licenses due to prevailing misconceptions. A landmark judgment was passed by the Delhi High Court in 2011 which opened doors for deaf people to take driving test to get driving licences. This issue has been dealt with in detail in the section on Laws and Policies.

5. Information

There are many websites that give information on the latest technologies and different assistive devices for persons with disabilities. **However, there seems to be hardly any Resource Centres in the country where one can actually go and try out and see these devices to know which would work for a particular individual.**

¹³⁶ 'Disability and the Union Budget' NCPEDP Website, accessed at <http://www.ncpedp.org/access/acc-suc2.htm>. on 12th November 2011.

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Sambhav, an initiative of The National Trust with Action for Ability Development and Inclusion (AADI) in New Delhi, showcases various aids and assistive devices at one place. This is a step in the positive direction. However, in a country as large as India, there needs to be many more such centres.

Moreover, there is a **lack of professionals like engineers, carpenters, welders etc., who can make assistive devices for mobility to meet individual needs**, within the individual's community. There is also a lack of professionals like therapists who can advise on what modifications are needed to be made in an assistive aid to maximise functionality/independence to minimise secondary deformities and pain.

Enquiries and bookings using phone and Internet have made it slightly easier for persons with disabilities to get information about devices and technologies and to make travel arrangements. **However, these mediums are not totally accessible for persons with disabilities.** For instance, the rail booking cannot be done online for persons with disabilities. They have to go to the booking counter, as they have to show the disability certificate.

The emergence of free GPS-based navigational tools from Google and Nokia has been found to be useful for people with visual impairment.

6. Mobility in Different Terrains

India is a big country with different terrains - hilly areas, desert, *kuchha* roads, etc. and with different weather conditions. **There are hardly any efforts on the part of the State to make mobility aids suitable for these terrains.**

7. Personal Assistants/Escorts

Some people with disabilities have difficulty moving about within their homes, outside and travelling and so require assistance from an escort. People face a lot of difficulty in getting personal assistants. There is a scheme, '**Sahyogi**', **initiated by The National Trust** which aims at promoting care giving services by establishing care giving cells and training care givers. **The impact of the scheme has been minimal. The cost of care givers is also quite high and the Government has not taken any steps to subsidise it.**

Provision of personal assistance/escorts is an accommodation that is required for persons with disability to ensure their right to personal mobility. Some airlines have recognised this and provide escorts to people with disabilities at the airport and in the aircraft. The Director General of Civil Aviation has issued guidelines, "**Carriage by Air of Persons with Disability and/or Persons with Reduced Mobility**" effective from 1st May 2008. It clearly states that "**once a passenger has bought a ticket for travel, it is obligatory on part of the airline that he reaches the aircraft from the departure lounge, and at the end of the journey from the aircraft to the arrival lounge exit, without incurring any further expenditure.**" Further, it states that aids and assistive devices and guide dogs should be allowed in the cabin. It mandates the availability of wheel

chairs and other assistive devices at all airports; ambulifts at every airport, sufficient direction signages, including the information regarding the availability of assistance for people with disabilities and assistance in the airport and the aircraft for those who need it.¹³⁷

The Railways provides concessions to escorts but does not provide any personal assistance to travellers with disabilities who travel alone. A few employers have also provided this support to persons with disability, particularly when they are travelling.

However, these are only few instances. Most places do not recognise personal assistance as reasonable accommodation. State has not taken any effort to promote and subsidise this much needed service.

People with disabilities also face a lot of issues with their Personal Assistants who are provided by private agencies. They are not provided training on disability etiquettes and rights. Many of them do not have the right attitude and have also taken advantage of the situation and abused persons with disabilities.

“Persons with disabilities have to depend on the convenience of the caregiver on how and when to travel. The independence of choice of time remains with the caregiver and not us (persons with disabilities). There is no professionalism. They do it as a favour. This is a little frustrating.”
-A person with disability

8. Lack of policy on Guide Dogs and other service animals

India currently does not have a law or policy on Guide dogs and other service animals. In developed countries, service animals are playing a great role in enhancing the independence and mobility of persons with disabilities. **No effort has been made so far in this country to explore this possibility.**

9. Mobility training

There is a lack of trainers to teach mobility, teach driving and the use of mobility aids for persons with disabilities. This is especially true for persons who acquire disability at a later stage in their lives. The Rehabilitation Council of India (RCI) conducts a one year course called Bachelor in Mobility Science in the field of visual impairment.¹³⁸

Mobility training needs to become an integral part of all training courses conducted by the Rehabilitation Council of India and by NGOs. It needs to include the importance, safety and security, methodology, new aids and technologies, fitting and repairing of aids etc.

¹³⁷ Accessed at dgca.nic.in/cars/d3m-m1.pdf on 12th November 2011.

¹³⁸ Accessed at <http://rehabcouncil.nic.in/programmes/crregular.htm> on 12th November 2011.

"I went to an NGO in Bangalore for finding information about mobility training after I started losing my sight. I was uncomfortable to get trained from a male trainer. There were no female trainer there. I am still to find a female trainer who can come home and train me. There are hardly any mobility trainers in the country. As a result, most of us stay at home and do not venture out alone even to the shop near by. Even within home, we are restricted and are not allowed to work in kitchen. Mobility training is crucial to give us and our family members confidence."

-Shared by a woman with vision impairment in a meeting in Bangalore organised by Retina India, 2010.

Recommendations

- 1) Review and amend existing disability and other relevant legislations and guidelines to facilitate personal mobility of persons with disabilities.
- 2) Incentives and schemes (tax exemptions and subsidies) for companies manufacturing mobility aids, including making it easier for foreign manufacturers to sell their products here in India.
- 3) Vehicle manufacturers should be encouraged to manufacture fully accessible vehicles in all ranges.
- 4) Government and the private taxi service (Easy Cab, Citi Taxi, Meru cabs etc.) should mandatorily have taxis that are accessible. The charge should be the same as travelling in any other taxi. They should extend any support that persons with disabilities may require and be courteous to them.
- 5) A clear mandate should be set to ensure no taxi or auto rickshaw or any other public transport should refuse taking a passenger with disability or their mobility aids. Redress mechanism is needed for this.
- 6) Time bound plan should be set to make public transport accessible for persons with disabilities across the country.
- 7) Loans/subsidy to purchase vehicles and to make them usable as per individual needs.
- 8) Schemes and subsidies for acquiring personal attendants.
- 9) The training curriculum for personal attendants, drivers, conductors and other relevant officials should include disability etiquette and rights.
- 10) Development of human resource for providing mobility training.
- 11) Resource Centres across India and a comprehensive website to exhibit and to purchase the various mobility aids and technologies.
- 12) NGOs to provide training to local welders, carpenters etc. in order to provide them with suitable skills to repair mobility aids and to make changes in the aids to suit individual needs.

Article 21: Freedom of Expression and Opinion, and Access to Information

The text of Article 21 in the CRPD is given below.

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

- (a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;*
- (b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;*
- (c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;*
- (d) Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;*
- (e) Recognizing and promoting the use of sign languages.*

Survey Findings

- The findings of the survey with respect to the efforts made by the Government to ensure that persons with disabilities have freedom of expression and opinion, and access to information is given below.

Rating	Percentage of Respondents
Extremely dissatisfied	56%
Dissatisfied	31%
Satisfied	10%
Extremely satisfied	1%
Do not know much about the issue	1%

From the above data, one can see that 11% of the respondents are satisfied with the efforts made by the Government while 87% are dissatisfied. The satisfaction expressed by some respondents could be because of the

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Government's efforts in adopting the Web Accessibility Guidelines for Government websites. About 87% respondents have expressed dissatisfaction, which clearly indicates that much needs to be done to improve access to information for persons with disability. Sign language has not been developed or recognised; Braille and audio books are not widely available; not much has been done in the area of promoting/developing augmentative communication; assistive technologies for effective communication are not available or affordable; media remains inaccessible. These are some of the areas of concern for persons with disabilities.

Laws and Policies

The Constitution of India includes, in its Preamble, the liberty of thought, expression, belief, faith and worship. Article 19 (1)(a) states that "All citizens shall have the right to freedom of speech and expression".

The Disability Act, 1995, has certain provisions that refer to accessibility to information for persons with disabilities. These are given below.

- In Chapter V, Education, clause 27(e) touches upon the need to impart information through interactive electronic and other media. 27 (f) mentions providing every child with disability, free of cost, special books and equipments needed for his education. Clause 28 mentions that research should be initiated for designing and developing new assistive devices, teaching aids, special teaching materials or such other items as are necessary to give a child with disability equal opportunities in education. Clause 30(c) provides for the supply of books, other materials to children with disabilities attending school. Clause 31 provides for amanuensis (a person employed to take dictation or to copy manuscripts) to blind students and students with low vision for assisting in writing.
- In Chapter VIII, on Non-Discrimination, we have the following clauses that encourage the setting up of appropriate signages and so on. Clause 44 (c) Engraving on the surface of the zebra crossing for the blind or for persons with low vision; 44 (d) Engraving on the edges of railway platforms for the blind or for persons with low vision; 44 (e) Devising appropriate symbols of disability; 44 (f) Warning signals at appropriate places. Clause 45 provides for (a) Installation of auditory signals at red lights in the public roads for the benefit of persons with visual handicap; Clause 46(c) Braille symbols and auditory signals in elevators or lifts;
- There are many points related to accessibility that have not been mentioned in The Disability Act such as development and use of sign language, alternative and augmentative mode of communication, availability of information in accessible formats, accessibility of Internet, etc.

The **National Trust Act, 1999**, and **Mental Health Act, 1987**, have certain provisions that curb the freedom of expression and opinion for persons with disabilities. As per the National Trust Act, "parent or a relative of a person with disability or a registered organisation" can remove the guardian of a person with disability on certain grounds mentioned in Article 17 of the Act. The person with disability herself/himself does not have a say in it. The Mental Health Act allows

for involuntary admission into institutions of a person with mental health issues without her/his own consent.

The other legislations related to access to information, media, intellectual property and Information Technology such as the Copy Right Act, 1957, The Right To Information Act, 2005, The Official Languages Act, 1963, The Prasar Bharati Act, The Broadcasting Code, Cable Television Networks (Regulation) Act, 1995 and the Cinematograph Act, 1952, should be reviewed to make it comply with the provisions present in the CRPD.

The Right to Information (RTI) Act, 2005, Clause 7(4), states "Where access to the record or a part thereof is required to be provided under this Act and the person to whom access is to be provided is sensorily disabled, the Central Public Information Officer or State Public Information Officer, as the case may be, shall provide assistance to enable access to the information, including providing such assistance as may be appropriate for the inspection." Not many persons with disabilities are aware of this provision. Moreover, the officer in charge of replying to the RTI letter may not be equipped to reply in an accessible format.

National Informatics Centre (NIC), The Department of Information Technology, Ministry of Communications and Information Technology, has developed 'Guidelines for Indian Government Websites' in accordance to international standards to ensure that the websites belonging to any constituent of the Government at any level are user friendly, secure and easy to maintain. The Guidelines include W3C Web Content Accessibility Guidelines (WCAG 2.0).

Progress and Concerns

1. Freedom of Expression - Developing and Facilitating Means, Modes and Formats for Communication

To ensure freedom of expression and opinion of persons with disabilities, it is essential to ensure that they are given the choice to give their information or opinion in the means of communication that they can express best in. Article 2 defines "Communication" as including "languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology." The definition of "Language" includes "spoken and signed languages and other forms of non-spoken languages."

Accepting and facilitating the various means and modes of communication would require **developing it and training persons with disabilities and others in it**. For example, facilitating sign language/tactile communication would require recognising sign language as an official language and training deaf people and the interpreters in it. Similarly, facilitating the use of Braille would require recognising Braille as an official script and training blind

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people to use and train others to provide information in Braille. Certain forms of communication would require the use of assistive technologies. These would have to be developed, made easily available, people with disabilities would have to be trained and its usage for official communication be allowed.

Some steps taken by the Government in this area are given below.

- Setting up of the **Indian Sign Language Training and Research Centre** - A significant step to develop and promote Sign Language in the country. (Detailed in the chapter on Article 9).
- An **Order from the Delhi High Court to appoint sign language interpreters** in public places like railway stations, airports, bus depots, hospitals, police stations, educational institutions and Government offices.
- Supreme Court Order to make Polling booths accessible for persons with disability in 2007 and Government's effort to make General Elections 2009 accessible. (This aspect has been covered in detail in the chapter on Article 29)
- The Media Lab Asia, under the Department of Information Technology (DIT), has undertaken one project, '**Shruti-Drishti**' (Text to Speech & Text to Braille), with a special web browser for persons with visual impairment being developed. It is benefiting 4081 blind students and 80 teachers.
- DIT has set up **50 ICT Vocational centres across the country for students with disabilities with special IT assistive tools and technologies**. Further, 50 more schools have been identified and the setting up of suitable ICT infrastructure is in progress.
- **Sanyog is a multilingual Augmentative & Alternative Communication system**, developed at the Media Lab Asia research hub at IIT Kharagpur, to serve individuals with speech impairment and neuromotor disorders. It allows individuals to form and vocalize their own messages. The system has been deployed at Indian Institute of Cerebral Palsy in Kolkata, Action for Ability Development and Inclusion in New Delhi, National Institute for Mentally Handicapped in Hyderabad and Manovikas Kendra again in Kolkata, where it is being used by a number of students with special needs, facilitating improved communication with teachers and parents.
- **Sambhav, a National Resource Centre on Disability**, provides the facilities for demonstration and practical use of the displayed items by persons with disabilities. The centre will have information about the price, availability and usage of devices.

These are very small steps. Most of these initiatives have largely been due to advocacy by the disability activists. **There has hardly been any proactive initiative on the part of the Government to develop various forms of communication. There is hardly any work undertaken to developing alternative/augmentative communication and to facilitate the use of technology to communicate.** Media Lab Asia, which aims to bring the benefits of ICT to daily lives of common man has really not done much in the area of disability. There is so much more that needs to be done and can be done by the organisation.

Most tools available for communication are imported and are quite expensive. Some NGOs are working on creating certain indigenous communication technologies but they are not being adequately supported to expand their

research and for making them available at lower costs. NGOs also do not have the necessary capacity to market them well to reach large numbers. Corporates in India have not taken any initiatives in this area.

2. Providing Information in Accessible Formats

The Ministries concerned with information and communication in the country are the Ministry of Communications and Information Technology (Department of Telecommunications and Department of Information Technology) and Ministry of Information and Broadcasting.

The **Department of Telecommunications (DoT)** is working to ensure affordable and effective communication facilities to all citizens. It is not clear if there is any focus on ensuring effective communication for persons with disabilities, based on the information available on their website and Annual Reports. **There seem to be no programmes for making telephones accessible to people, particularly those with sensory impairments. For example, providing screen reading software for mobile phones or for making phones accessible to hearing impaired people.**

The mandate of the **Ministry of Information and Broadcasting** is to ensure people have access to free flow of information through the mass communication media consisting of radio, television, films, press and print publications, advertising and traditional modes of communication such as dance and drama. The Ministry is involved in catering to the entertainment needs of various age groups and focusing attention of the people on issues of national integration, environmental protection, health care and family welfare, eradication of illiteracy and issues relating to women, children, minority and other disadvantaged sections of the society. **It is not clear from their website and Annual Report as to how these are being made accessible and inclusive to persons with disabilities in order to ensure free flow of information for them.**

The Ministry has undertaken some initiatives to promote awareness on disability. According to its Annual Report 2010-11, a special campaign regarding implementation of the provisions of the CRPD was launched. Programmes highlighting the provisions covered under Articles 8,9,21,27 and 30 of the CRPD were broadcast creating social awareness on the issues of persons with disabilities. An advertisement was released by the Ministry on the International Day of Disabled Persons.¹³⁹

The media is definitely underutilised as far as disability is concerned. One, information in most cases is difficult to access for persons with disabilities. Second, there is hardly any media space given to opinions and issues of persons with disabilities in the print media, visual media or the radio. The advertisements are often related to prevention of disability and highlight stereotypical images of persons with disabilities. They are also not part of issues of regular debates like corruption, politics, social issues, health, education, employment, entertainment etc. Community Radio can be an effective medium for taking up the rights issues

¹³⁹ Annual Report, Ministry of Information and Broadcasting, 2010-11.

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of persons with disabilities. Children's programmes have also not taken up the issue of diversity, inclusion and making friends with other children with disabilities as a natural process.

The **Department of Information Technology is working on** the e-Development of India. Some of its functions are:

- Policy matters relating to Information Technology, Electronics and Internet.
- Initiatives for development of Hardware/Software industry including knowledge based enterprises.
- Promotion of Information Technology and Information Technology enabled services and Internet.
- Assistance to other departments in the promotion of E-Governance, E-Infrastructure, E-Medicine, E-Commerce etc.
- Promotion of Information Technology education and Information Technology-based education, Initiative on bridging the Digital Divide and Matters relating to Media Lab Asia.

Some of its initiatives related to providing access to information by the Department of Information Technology are:

- **Adoption of Guidelines for Web Accessibility** by the Department of Information and Technology for all the Government websites (Mentioned in detail in Chapter on Article 9)
- **CBTS (Computerized Braille Transcription System)** has been installed in 40 schools where 80 teachers have been trained and around 3000 students have been benefited.
- **ABCD (Audio Books Content Delivery) for visually impaired**, an indigenously developed Daisy audio books player, 'Buddy', along with complete curriculum of secondary and senior secondary level have been test deployed at NAB (National Association of Blind) New Delhi and Gangtok branch.
- **Content Generation for Capacity Building of Persons with Blindness or Low Vision:** The project aims supporting graduate/post graduate level visually impaired students by facilitating content in accessible formats like e-text, Braille, Daisy, large print and audio books as per requirement. For Inclusive Education, 4473 hours (515 in number) of Audio Daisy Books have been generated. 454 books have been converted into e-Text. 69 books (900 Hours) have been generated in synthesized voice. Benefiting a large cross section of Visually Impaired students, more than 20,000 copies of CDs of these books have been distributed. Media Lab Asia is a member of DAISY Forum of India, which is a network of more than 80+ organizations working for digital books.

The **Ministry of Culture, which preserves historical monuments, museums and libraries** have taken a few initiatives in their heritage sites, museums and libraries accessible (detailed in chapter on Article 30).

The **Ministry of Social Justice and Empowerment**, the nodal Ministry for disability, has introduced a new category of national awards from the Year 2010 for the best disabled-friendly website in Government, public sector and private sector. The Chief Ministers of all States and Union Ministers were requested vide

D.O. letter dated 31st January 2010 of Minister, Social Justice and Empowerment, to make their office buildings and websites accessible for persons with disabilities, preferably by 2010-11. The Apex Chambers of Industries were also requested vide D.O. letter dated 7th March 2011 to urge their members to make all their industrial and business premises as well as websites accessible for persons with disabilities.¹⁴⁰

The **Department of Information Technology** is working on large scale computerisation in areas like information dissemination, education, health, livelihood and for various other services. Some of their initiatives are listed below:

- National e-governance Plan, consisting of 27 mission mode projects, out of which 15 have gone live and are delivering services electronically.
- State Wide Area Networks (SWAN), which is operational in 23 States and UTs.
- State Data Centres, which are being set up in 14 States.
- Common Services Centres, which has the Government's approval for 1 lakh Centres in 6 lakh villages in 31 States.
- National Knowledge Network - 104 institutions have been connected and 15 virtual classrooms have been set up.
- e-Galla- an affordable retail management system to address the needs of the unorganised retail sector.
- Multi-media Resource Kit for pre-primary teachers.
- Mobile and Internet based maths preparation application.
- Virtual Laboratories for life science experiments for higher secondary education.
- Programmes for ICT for health care and e-hospitals.
- Smart card based applications.
- e-Library services

It is not clear from the Annual Report or their websites if these initiatives are accessible to persons with disabilities.

There are many issues that people with disabilities face in accessing information. Some of the concerns have been listed below.

- **Many Forms are only in print form and would have to be filled by hand.** For example, for getting disability certificates or other identity cards, medical test reports, school admission forms are mostly available in print form and many persons with disabilities are not able to fill them without the help of another person.
- **Information boards, brochures, booklets, signages, kiosks, enquiry counters, announcements and media are mostly inaccessible** - Awareness raising posters and advertisements; display of Information of train or flight timings are not in accessible format for people with vision impairment/reading difficulties. Announcements about arrival/departures of train and flights; emergency numbers/warnings are inaccessible for persons with hearing impairment; many instructions on forms related to health,

¹⁴⁰ Status Paper, Working Group on Empowerment of Persons with Disabilities for Formulation of XII Plan (2012-17), 2011.

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banking, billing etc., are not available in alternate formats and are in complicated language and not accessible for persons with intellectual impairment. In the absence of Auditory Description, visual media is inaccessible for persons with visual impairment. Many of the news sites on the Internet are not accessible for them. Sometimes the place where forms are available or information is provided or bills are to be paid are inaccessible for people with mobility difficulties.

The Information kiosk installed in Bangalore Cantonment Station was not accessible for persons with mobility impairment and persons with visual impairment. It was too high for people on wheelchairs and it did not have voice inputs for visually impaired people”

-A person with disability

- There is no support available for people who need assistance in communicating. **No sign language interpreters, transcribers, readers and assistance are provided in public places.**

In this country, we have 18 million hearing impaired people but only 250 certified interpreters by a conservative estimate. If we are having dearth of sign language interpreters, then how would we deploy them at public places?

-From 'Official Language Status for Sign Language Demanded', The Hindu, 4th December 2011.¹⁴¹

- **Currently, most Indian films and television programmes do not have captions and audio description.** Some Hindi films have audio descriptions, like 'My name is Khan'. However, not many people are aware of this. No cinema hall in India provides same language captions or audio descriptions.
- **Books are not available in accessible formats.** Only about 0.5% of the books are available in accessible format. There is also the issue of copyright legislation which prevents books to be converted in other formats without permission. There is also a lack of infrastructure for Braille transcription. For those who are not familiar with Braille, there aren't any audio books or books in soft copy that are available for them. There is no facility for persons with disabilities who require help in reading out notes/books. One has to depend on volunteers or family members for reading out books.
- Most of the initiatives (which are also not too many) of the Government in this area are focused on persons with visual impairment. The information needs of person with **other disabilities**, like persons with hearing impairment, intellectual impairment, Autism, learning disabilities, are not being addressed. Moreover, the initiatives are 'project based' and are hence, limited in their coverage and application.
- India seems to be on fast track for **e-governance**. However, their usability for persons with disability is not clear. The concept of Universal Design has

¹⁴¹ Accessed at <http://www.thehindu.com/news/national/article2684848.ece>. on 6th December 2011.

to be promoted and ensured while formulating and implementing these plans.

- There are hardly any mandates for the **private sector** with respect to accessibility of websites or media. As a result, most of the private websites (used by public) are inaccessible in the country. There are many private television channels which have been approved and running that have no mandate to ensure accessibility for persons with disabilities.

Opportunities are generally not given to people with disabilities to express their opinions. Though the concept of 'nothing about us, without us' is being promoted by the disability rights movement in the country, it is yet to be understood and implemented by policy makers in the country. There are hardly any forums for hearing the voices of persons with disabilities or involving them in policy making and implementation of various programmes. They are still seen as recipients of charity, who do not have any voice. People with certain disabilities, like mental impairment, do not have any voice, as per many laws in our country.

Recommendations

- 1) Disability laws should ensure provisions for freedom of expression and opinion, and access to information.
- 2) Other related laws should be reviewed and amended in the light of the CRPD.
- 3) All related Ministries (Information and Broadcasting and Communications and Information Technology) should have a disability cell with a clear cut mandate so that funds, human resources and implementation and monitoring mechanisms reach every village of the country.
- 4) Persons with various disabilities should be included in decision making and monitoring committees in various Ministries at the Central, State, District and Village levels.
- 5) Conferences, public speeches, rallies, debates should ensure that persons with disabilities are equal participants by providing sign language interpreters, material in CDs or Braille and other accessible formats etc.
- 6) The National Centres for Universal Design and for Sign Language need to be developed as very dynamic and visionary institutions.
- 7) Accessibility for persons with disabilities should be ensured as part of various programmes of the relevant Ministries, in addition to initiating separate focussed programmes.
- 8) All e governance programmes should be audited to ensure accessibility for people with all disabilities.
- 9) Training of existing professionals like website developers, software engineers and bureaucrats should be conducted regularly.
- 10) In order to provide various services such as sign language/tactile communication interpreters, transcribers, readers, scribes, personal assistants to ensure effective communication, there should be focus on training of personnel. These services would have to be provided at no extra cost to persons with disabilities.

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- 11) Various forms of media should ensure that disability issues are highlighted on the rights based model through articles, reports, discussions, documentaries, films, theatre, dance-drama and so on.
- 12) A conscious effort should be made to provide media space for persons with disabilities to express their opinions on various issues and not just disability issues.
- 13) Promote and facilitate research and development in the area of modes and means of communication and access to information.

Article 22: Respect for Privacy

The text of Article 22 in the CRPD is given below.

1. *No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.*
2. *States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.*

Survey Findings

1. The findings with respect to the efforts made by the Government to ensure respect for privacy of persons with disabilities is given below.

Rating	Percentage of Respondents
Extremely dissatisfied	61%
Dissatisfied	23%
Satisfied	10%
Extremely satisfied	0%
Do not know much about the issue	6%

84% people are dissatisfied with the State's effort in protecting the right to privacy for persons with disabilities. This shows that the right is quite often violated in the country. Privacy as a rights issue is not well understood by many people in the country.

Laws and Policies

Neither **The Disability Act, 1995**, nor **The National Trust Act, 1999**, cover anything on privacy or confidentiality.

The Mental Health Act, 1987 provides for confidentiality of the personal records of a patient. It also mentions that "No letter or other communication sent by or to a mentally ill person under treatment shall be intercepted, detained or destroyed". The Act has only a cursory mention about privacy in certain situations but does not mention it as an absolute right.

As per Government Policy, **the Census data and NSSO data** is confidential. Though individual data on disability is taken, only aggregates are used and

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publicised. The individual respondents are assured of confidentiality of the information shared.

In India, the **Constitution** does not expressly recognise the right to privacy. The concept of privacy as a fundamental right first evolved in 1964 in the case of *Kharak Singh v the State of Uttar Pradesh*. The Supreme Court of India, for the first time, recognised that there is a right of privacy implicit in the Constitution under Article 21. The Court held that the Right to Privacy is an integral part of the Right to Life, but without any clear cut laws it still remains a grey area.¹⁴²

Professional Conduct, Etiquette and Ethics Regulations, 2002,¹⁴³ states under Clause 2.2, Patience, Delicacy and Secrecy, that "Confidences concerning individual or domestic life entrusted by patients to a physician and defects in the disposition or character of patients observed during medical attendance should never be revealed unless their revelation is required by the laws of the State."

Privacy data protection laws in general are not very strong in India. There are various bills and propositions in the pipeline for the same. These policies/laws/guidelines, when they are framed, should ensure that they have strong provisions to ensure confidentiality of disability related information.

Progress and Concerns

1. Personal Privacy

Most institutions/organisations do not have a policy on matters related to privacy.

Many residential institutions lack even the basic amenities to protect peoples' privacy. There are many instances that have been reported particularly with respect to people with high support needs that their privacy is not even considered.

Banyan, an organisation working in the area of mental health, had conducted an audit of the Institute of Mental Health (IMH) in Chennai on 3rd October 2008 to measure specifics like availability of basic amenities to evaluate living conditions of people with mental illness who are residing there. Now, IMH is the nodal agency for implementation of the District Mental Health Programme (DMHP). The auditors reported that "toilets lack basic privacy".¹⁴⁴

Most NGOs that are mainly into service delivery are not aware of rights of people with disabilities. Activities of Daily Living/Self-care are taught without maintaining much privacy. Sometimes the need for ensuring privacy does not

¹⁴² Does right to privacy exempt right to know? A case study in the Indian Context, Devmalya Chakraborty, December, 2010, Global Media Journal – Indian Edition.

¹⁴³ Accessed at www.mciindia.org on 15th November 2011.

¹⁴⁴ "Institute of Mental Health (IMH) - Intention versus Reality?'1Dial 100 Mental Health Helpline - Evolution in Institute of Mental Health (IMH), The Banyan received by E-mail from Disability Law Unit, South on 19th January 2009.

even occur to staff working there who consider them as children even after they have become older and attained puberty and adulthood.

People with disabilities when they are making the Disability Certificates are asked to submit photos "showing the disability". People with disability in their leg have to take photos with their pants/skirts/sarees pulled up showing the disability. Such a practice is a violation of their right to privacy.

2. Confidentiality of information shared in schools and offices

The Government also do not have clear cut policies on protecting personal information. **The Social Justice Department, Government of Himachal Pradesh, has a website that gives the list of people with disabilities who have taken Disability Certificate. It mentions their name, age, type of impairment, severity of impairment, Tehsil and District name.**¹⁴⁵

NGOs take an in depth case history of individuals, including their family, marital relationships, etc. Most NGOs do not have data protection policy. Information is shared with employers, educators etc. without taking appropriate permissions. Information about 'clients'/'students' is shared openly with other staff members, trainees, visitors, employers, etc. They are spoken about in the meetings, conferences and case studies with photos are presented in annual reports, proposals and media without taking permission. The personal problems of persons with disabilities are over emphasised to gather funds. Even doctors openly advertise 'before' and 'after' photos of people with disabilities who underwent surgeries; etc. to attract more clients.

"I went to an NGO to join a training programme. I was asked all kinds of questions by their staff including my marital relationship. I was wondering would any other training or placement institution ask me all these questions or just because I am a person with disability that I am asked all these questions."
-A person with disability about his experience with an NGO.

"I shared information about my mental disability in a support group. The next day I saw the information was in a newspaper with my full name in it. I was not told there is a journalist sitting in that session".
- A person with disability

There is no **redress mechanism** for complaining against any breach of personal privacy or attacks on personal reputation.

¹⁴⁵ The Website is <http://india.gov.in/outerwin.php?id=http%3A%2F%2Fhimachal.gov.in%2Fwelfare%2FSe archDCIS.asp> accessed on 17th November 2011.

Recommendations

- 1) All the disability and other relevant laws and guidelines should explicitly mention the right to privacy of persons with disabilities. It should apply to privacy of personal, health and rehabilitation information.
- 2) There should be redress mechanism to ensure protection of people with disabilities for complaining against any breach of privacy.
- 3) Training of rehabilitation and medical professionals should include right to privacy of the client in the curriculum.

Article 23: Respect for Home and the Family

The text of Article 23 in the CRPD is given below.

1. *States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:*
 - a) *The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;*
 - b) *The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognised, and the means necessary to enable them to exercise these rights are provided;*
 - c) *Persons with disabilities, including children, retain their fertility on an equal basis with others.*
2. *States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.*
3. *States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realising these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.*
4. *States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.*
5. *States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.*

Survey Findings

1. The findings with respect to the efforts made by the government to ensure that persons with disabilities have a right to home and family and have adequate respect and support for the same are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	61%
Dissatisfied	24%
Satisfied	13%
Extremely Satisfied	0%
Do not know much about the issue	2%

There is considerable dissatisfaction (85%) among people with disabilities, as these are not rights recognised by disability laws in our country. Moreover, this is an area where people with disabilities are discriminated against in the family and by the society, due to many myths surrounding disability. In India, there is a strong bonding within family, which has provided good support to some people with disabilities to come up in life in spite of barriers in the society. However, there have been many instances, where due to familial, social and economical pressures; people with disabilities have been denied their right to home and family.

Laws and Policies

The Disability Act, 1995 and The Mental Health Act, 1987, do not make any specific mention about right to home and family.

The National Trust Act 1999, in Chapter 3, 'Objects of the Trust', states the following points which has some relevance to this Article:

- To strengthen facilities to provide support to persons with disability to live within their own families.
- To extend support to registered organisation to provide need based services during the period of crises in the family of persons with disability.
- To deal with problems of persons with disability who do not have family support.
- To promote measures for the care and protraction of persons with disability in the event of death of their parent or guardian.

Many of the **marriage/family/adoption laws**, such as, Special Marriage Act, 1954, Dissolution of Muslim Marriage Act, 1939, Hindu Marriage Act, 1955, Hindu Adoption and Maintenance Act, 1956, Indian Divorce Act, 1869, have certain aspects which are not in line with CRPD. For instance, some legislations allow for divorce on the grounds of leprosy and mental impairment. Any person with so called "unsound mind" cannot adopt a child.

Progress and Concerns

1. Non-discrimination in matters related to Marriage, Parenthood and Relationships

There seems to be no focused initiative on the part of the Government (Ministry of Social Justice and Empowerment, Ministry of Women and Child Development) to promote and protect the right of persons with disabilities to marry and be parents.

However, the landmark judgment of the Supreme Court, which upheld the right to motherhood to a person with intellectual impairment and which obligated the State to provide necessary support to the woman for bringing up the child, was a huge step forward in this regard.

In July 2009, by way of an interim order, the Supreme Court of India upheld the right to motherhood of a mentally retarded girl who was raped at a government run shelter.

DNIS had earlier reported about the case which made headlines in July and had forced the judiciary and the country to sit up and take notice of the State's apathy towards people with mental disabilities. Not only did the State fail to protect the girl, it also tried to terminate the pregnancy against her wishes. It was only because of determined efforts of a young lawyer, Tanu Bedi and support from the disability sector that justice was finally delivered.

However, the society at large still has not woken up to recognise the sexual and reproductive rights of people with mental retardation. There was plenty of outrage at the Supreme Court's decision. Many questioned whether courts were the place to decide such moral and ethical cases. They also speculated about the future of the child. The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Mental Disabilities has offered to take care of the girl and her baby. They have offered to put her in an independent home, either in Bangalore or closer to Chandigarh.

"The biggest obstacle that a disabled person faces is not the disability but society's perception towards it," said Bedi. "In fact when this case made headlines, everybody was talking about retardation, disability and abortion but no one even bothered about what the girl wanted," she added. Recently, when Tinku Ray, a journalist from BBC went to meet the girl, who now stays in a different government shelter home in Chandigarh, she appeared to be looking forward to her baby due in December.¹⁴⁶

In Maharashtra, the State Government announced an incentive scheme for encouraging non-disabled people to marry disabled people! The move has been opposed by many disability activists strongly saying it is like paying dowry!

¹⁴⁶ Supreme Court judgement out on Right to Motherhood of mentally retarded, 15th September, 2009, Disability News and Information Service.

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Some have said that it is a good amount for people from lower socio-economic background and that this money would help in setting up a house.

It's a bitter pill to swallow, but in India, the physically challenged have not been integrated into mainstream society. And marriage is the one institution where the stigma of being differently-abled is starkly highlighted. Now, the State Government has decided to rectify this and is planning to launch a scheme where anyone marrying a disabled person will be awarded Rs 50,000. Social Justice Minister Shivajirao Moghe said the idea is to encourage marriages between the "disabled and the able-bodied". Any person who marries a person with 40% or above disability—one who is certified as disabled—will be eligible. The Government is of the opinion that the reward scheme will promote greater integration of physically challenged people into mainstream society, and will be implemented across Maharashtra.¹⁴⁷

Many people with disabilities have difficulty finding a partner, as there are many myths related to disability.

In India, most marriages are “arranged” by families. Sometimes, the person who is marrying or for whom a life partner is being sought may not have a say about whom to marry and when to marry. When it comes to person with disabilities the issue gets compounded. The person is not given the choice to decide. The parents may have to pay huge sums of money to get their daughter/son with disability married. There are also instances where siblings with persons with disabilities are not able to get married because prospective families are sceptical that the disability would be genetic or that they would have to take care of the sibling who has a disability.

There has not been much awareness created in the society to project people with disabilities in a positive manner. There are a few people who have been able to find a match for themselves.

Sometimes there are also societal and administrative barriers imposed on people with disabilities who want to marry.

“According to the CRPD, any person with disability is allowed to have a family. I was not allowed to have a registered marriage in Delhi Court just because I am a person with Cerebral Palsy. As per some strange provisions of the Marriage Act, persons with Cerebral Disorders are not legally entitled to have a marriage. The concerned Magistrate, even refused to acknowledge my 10th Class Certificate because in the column of school name it read ‘The Spastics Society of Northern India’. Today, I feel that was an infringement to my right to home and family, and adequate respect and support for the same.”
-Alok Sikka shared the following in the CRPD Questionnaire.

¹⁴⁷ Wed a disabled person, get Rs 50,000 from state; Sandeep Ashar, TNN 9th October, 2010, accessed at http://articles.timesofindia.indiatimes.com/2010-10-09/mumbai/28244825_1_disabled-person-scheme-bitter-pill on 16th November, 2011.

"I am now 32 years of age. My family is not even thinking of my marriage! My younger sister and brother are married. I do not know how to approach this topic with my family."

-A girl with orthopaedic disability.

There are many instances where **hysterectomy and forced sterilisation are carried out on persons with disabilities**, particularly on persons with intellectual and mental impairment, by their families or institutions where they are residing. The consent is taken from parents and guardians and not from persons with disabilities.

The family planning or reproductive health education provided by the Ministry of Women and Child Development or by NGOs working with women, do not include the needs and rights of women with disabilities. The health officials providing these services sometimes assume that persons with disabilities do not need this information. Families in India generally do not talk about these matters and when it comes to persons with disabilities, they sometimes completely avoid this topic. Sometimes, it is assumed that the person with disability would not understand what is being talked about. **Information in alternate and accessible formats may not be available.** As a result, persons with disabilities may remain with many misconceptions about family planning, reproductive health, child health and rearing practices etc.

2. Right to be a Guardian, Trustee, Right to Adoption of Children

There are restrictions in the law for certain persons with disabilities to be a guardian, trustee, warden and to adopt children. People with so-called "unsound mind" are excluded from these rights. There are also certain mindsets and perception in the society about capabilities of persons to take up such responsibilities and hence, these rights are denied to them.

The Government has not taken up any specific measures to promote or protect these rights of persons with disabilities.

The Central Adoption Resource Authority (CARA), Ministry of Women & Child Development has mentioned in eligibility for adoption, "Prospective Adoptive Parents (PAPs) should have good health and should not be suffering from any contagious or terminal disease or any such mental or physical condition which may prevent them from taking care of the child."¹⁴⁸

Persons with disabilities could be denied adoption on this ground. There seems to be no data or information available of cases where people with disabilities have adopted children or have been denied adoption.

¹⁴⁸ Accessed at <http://adoptioninda.nic.in/Parents/Eligibility-Criteria-for-Adoption.html> on 31st October 2011.

3. Right of Children to Family Life - Protection from Abandonment, Separation, Concealment and Segregation

There are certain initiatives of The National Trust, particularly Sahyogi (Care Givers Training & Deployment) and Niramya (Health Insurance Scheme), which provide support to families of children with disabilities. Under the Sahyogi scheme, Care Givers Cells (CGCs) have been set up in selected NGO Centers across the country. So far, 40 CGCs have been set up in the country and 184 caregivers have been trained so far till 2009. **Niramaya is the first Health Insurance Scheme where people with Developmental Disabilities have been covered. So far, enrolment of 85,041 beneficiaries has been done and Health Card issued to 71,595 beneficiaries.**¹⁴⁹

The schemes in general aim to protect persons with disabilities from abandonment and aims to provide the necessary support in terms of homes, medical insurance, personal attendants, etc. to ensure care and living independently. In terms of impact, the reach of these schemes seems to be very limited and definitely not enough to meet the needs of the large population of persons with disabilities. **These schemes also do not cater to ALL persons with disabilities** and are meant only for persons with "Mental Retardation, Autism, Cerebral Palsy and Multiple Disabilities".

The stigma related to disability, lack of support services (like social security, health and rehabilitation services etc.) and lack of awareness about the few existing support services leads to many families either **concealing or abandoning** persons with disabilities. In some instances, cases of killing newborns with disabilities have also come to light when rehabilitation workers gain the trust of community members. But these are not reported or recorded.

There are a few reports of families not disclosing that they have a child with disability even to their relatives and friends. Abandonment need not be the act of leaving the infant/child at the railway station or at an orphanage; it can be as subtly done as leaving the child in a hostel/home. A girl with disability from a village recently shared her story with one of authors of this document. She was admitted to a hostel at the age of 4 years. The parents never shared with anyone that they has a child with disability. They would come and visit her and give her money on a regular basis but she was never taken to her home and was not invited to any family functions. She shared that one of her wishes from the childhood was that her parents should acknowledge her as one their daughters.

There are also reports of families abandoning persons with mental impairment. In fact, analysis of reports of abandonment, particularly of people with mental impairment, seems to indicate that abandonment and abuse of persons with disabilities is a racket and the Government seems to turn a blind eye to it!

¹⁴⁹ Annual Report, Ministry of Social Justice and Empowerment, 2009 -10.

Some families have found a shocking way of getting rid of their mentally challenged members. They pay truckers to dump them on a forlorn stretch of road running through Karnataka's Bandipur National Park, a tiger reserve 220 km southwest of Bangalore. The hapless victims, many of whom can't even utter their own names coherently, hail mostly from West Bengal, Orissa, Maharashtra, Uttar Pradesh, Tamil Nadu and Kerala. Left to the mercy of the elements, many have either been killed by wild animals or sexually abused by truckers. Lacking basic survival skills, some of them have even set alight forest fires. Apart from families, police in neighbouring states of Tamil Nadu and Kerala are also alleged to have paid truckers to get rid of mentally ill people whom they have apprehended off the streets, NGOs working in the region said. Some of those who survive have landed up in a hospital run by Catholic missionaries.

A few like the Marathi-speaking, middle-aged Vijay (name given by locals) do petty chores to earn food from tourists and forest officials. "One or two such people are brought to us every week," said Sister Hillary, doctor-in-charge of Karunalaya Hospital of Nanjangud town on the edges of the park. Of the 57 currently being treated at the hospital, 32 are women, six of them pregnant and five HIV positive. "They are being treated for a range of ailments from advanced schizophrenia to delusion to paranoia, apart from being provided food and shelter," said another doctor at the hospital. The trend of dumping the mentally ill began in 2007, locals said. The victims are unaware that their kin preferred to pay for abandoning them rather than spend on their treatment. Some like 20-something Savitri (real name unknown) ended up being raped during her transportation and getting pregnant, Sister Hillary said.

"Long-distance truckers are known to pick up the mentally ill, especially women, and rape them before dumping them," said B Renuka Prasad, in-charge of the Gundulpet police station in the region.

Checkpoints along the stretch have done little to curb the menace. Police attribute it to their inability to understand what the victims are saying. Sometimes the truckers are known to drug the victim with opium, making it impossible to question him or her. Besides, policemen normally check the papers of vehicles and what they are carrying, not the cabin or passengers in it.

The Karnataka Government hasn't been able to curb the racket. "We are aware of the problem. The administration is conducting a survey of such persons. They will be treated and rehabilitated," said Karnataka State Mental Health Authority Member Secretary H Chandrashekhar.¹⁵⁰

Many children who are abandoned have disability. As per data available between 2007 and 2008 with Child Line in Lucknow, out of the 27 new born abandoned children, 21 were females and had disability either mentally or physically. While

¹⁵⁰ Families dump mentally ill in tiger reserve; [Salil Mekaad, Hindustan Times](http://www.hindustantimes.com/Families-dump-mentally-ill-in-tiger-reserve/Article1-552379.aspx); New Delhi, June 03, 2010, accessed at <http://www.hindustantimes.com/Families-dump-mentally-ill-in-tiger-reserve/Article1-552379.aspx> on 30th October 2011.

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out of 19 boys abandoned, 10 were with disabilities and out the total 50 found abandoned in one year, 31 were females with disability.¹⁵¹

Children with disabilities, in general, do not get adopted and are sometimes not even put on adoption rolls. One couple had recently adopted two children from an institution in Bangalore. They did not make any specific demand with respect to the physical conditions of the child. They were willing to adopt any child who was there for adoption at that time. They adopted two children who had certain medical condition. Later, they got to know that there were three infants in the institution with disabilities (cerebral palsy and mental impairment) who were not on the adoption rolls!

There are reports that many a times, couples from other countries are more open to adopting children with disabilities from India.

4. Alternative care within the wider family or the community in a family setting

There are some efforts by NGOs to reunite people with disabilities with their families. However, such initiatives are very few. People who have been abandoned either end up in a state-run institution or remain on the streets, begging.

The National Trust has a Scheme called 'Samarth', under which, there are 120 short term and long term stay facilities for adults and destitute children, catering to about 30 residents in each home. However, these are in an institution setting and not in a family setting as per Article 23 (5) of CRPD.

With the increase in breaking down of the joint family system in India, the cases of reduction in community support and resulting abandonment of persons with disabilities is only going to rise in number. It is certainly a long way to go for India to provide alternate care within wider family and in the community for persons with disabilities.

Recommendations

- 1) The disability laws should be amended to ensure that the right to home and family is explicitly mentioned.
- 2) The other laws related to marriage, family, adoption, guardianship, etc. have to be reviewed and suitably amended, as per CRPD.
- 3) Large scale awareness should be created among the public regarding disability. Stories of successful people with disabilities should be highlighted.
- 4) Government should establish systems and networks to ensure that appropriate information and support are provided to the parents of children with disabilities.

¹⁵¹ Children of a lesser God? Abandoned and stricken too! Anjali Singh, 10th February, 2009, NI Newstrack India, accessed at <http://www.newstrackindia.com/newsdetails/66829> on 19th November, 2011.

- 5) There should be adequate monetary support (social security, insurance, disability allowance, etc.) to ensure that the financial “burden” on the families due to disability is reduced.
- 6) Hospitals and doctors should not only be made aware of disability rights and facilities but they should be encouraged to play a more proactive role in terms of referring parents to these support systems.
- 7) The course curriculum of social workers, rehabilitation workers, psychologists, etc. should include counselling for marriage, parenthood, family planning, reproductive health etc. of persons with disabilities. Information on the same should be made available in accessible formats.
- 8) The Ministry of Women and Child Development should ensure inclusion of women and children with disabilities in all their programmes and also ensure data is collected and maintained with regard to number of beneficiaries with disabilities for all their programmes.

Article 24: Education

The text of the article is given below.

1. *States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:*
 - a) *The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;*
 - b) *The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;*
 - c) *Enabling persons with disabilities to participate effectively in a free society.*
2. *In realizing this right, States Parties shall ensure that:*
 - a) *Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;*
 - b) *Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;*
 - c) *Reasonable accommodation of the individual's requirements is provided;*
 - d) *Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;*
 - e) *Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.*
3. *States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:*
 - a) *Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;*
 - b) *Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;*
 - c) *Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.*

4. *In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.*
5. *States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.*

Survey Results

The results of the CRPD survey are given below. Two questions were asked. The first was on access to education at the primary and secondary levels and the second was on access to higher education and vocational training.

1. The findings with respect to the efforts made by the government to ensure that persons with disabilities have access to education on an equal basis at the primary and secondary levels are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	40%
Dissatisfied	40%
Satisfied	20%
Extremely satisfied	0%
Do not know much about the issue	0%

2. The findings on what steps the Government has taken to ensure that persons with disabilities have access to education on an equal basis for higher education, vocational training, adult education etc. are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	44%
Dissatisfied	37%
Satisfied	18%
Extremely satisfied	0%
Do not know much about the issue	1%

For Primary and Secondary education, the dissatisfaction level of respondents was 80%. Compared to other Articles of CRPD, the satisfaction level of 20% is high, which may be a reflection of people's perception of the effort being made

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by the Government under various Schemes to promote inclusive education. The satisfaction level of respondents of the survey for higher education, vocational training, adult education etc. is 18%. It could be because of reservations provided in Universities, which have benefited a few people. However, the dissatisfaction level of about 80% in education indicates that there are still a lot of issues. The majority of people with disabilities still do not have access to equal opportunities in education.

Laws and Policies

As per the **Constitution** of India (Article 21A), "the State shall provide free and compulsory education to all children of the age of six to fourteen years in such manner as the State may, by law, determine."

Chapter 5 (Clauses 26 - 30) and Chapter 6 (Clause 39) of **The Disability Act, 1995**, are on education. The Act mandates that every child with a disability should have access to free education in an appropriate environment till the age of eighteen years. It provides for a comprehensive education scheme, which should cover transport facilities; removal of architectural barriers from schools, colleges or other institutions; supply of books, uniforms, etc; scholarships and setting up of a forum for the redress of grievances. It also mandates restructuring of curriculum for the benefit of children with disabilities. It mandates the Government to set up an adequate number of teachers' training institutions and to assist the national institutes and other voluntary organisations to develop teachers' training programmes so that requisite trained manpower is available for special schools and integrated schools for children with disabilities. It also provides for research for designing and developing new assistive devices, teaching aids and special teaching materials. It also mentions provision of non-formal education. It also mandates 3% reservation for persons with disabilities in all educational institutions and other educational institutions receiving aid from the Government.

Under **The Rehabilitation Council of India Act, 1992**, the term 'Rehabilitation professionals', include "special teacher for educating and training the handicapped". The Act focuses on recognising rehabilitation courses, setting standards for curriculum and ethics for rehabilitation professionals and registering of these professionals.

Post ratification of the CRPD, in August 2009, India enacted **The Right of Children to Free and Compulsory Education Act (RTE)**. In Chapter 2, RTE says that "a child suffering from disability as defined in The Disability Act, 1995, shall have the right to pursue free and compulsory elementary education in accordance with the provisions of Chapter 5 of the said Act". It didn't make any reference to the CRPD. Due to strong opposition and advocacy at the highest level by the disability sector, amendments have been tabled in the Parliament. The proposed amendments are that (1) children with disability should be included in 'children belonging to disadvantaged group', thus entitled for the 25% reservation in neighbourhood schools; and (2) the provisions would be extended to children with disabilities as defined by both The Disability Act, 1995 and The National Trust Act, 1999.

There are more wrongs than rights in the Right to Education Bill

“Some major flaws include children in the age group 0-6 years not covered, bill does not promote a common school system and legitimises inequality through a multi-layered system. The Bill has detailed the norms required of a school (teacher-pupil ratio, buildings, etc.), it is silent on the facilities needed to enable children with disabilities to attend school. In this Bill, ‘disability’ has the meaning assigned by the Persons with Disabilities Act, 1995, which does not include such other disabilities as defined by the National Trust Act, 1999 (autism and cerebral palsy)”.

-Renu Singh, ‘The wrongs in the Right to Education Bill’, 6th July 2009.¹⁵²

Progress and Concerns

There have not been any specific initiatives by the Government for implementing Article 24 of the CRPD. However, the education of persons with disabilities has been a focus for quite some time in the country, dating back to the 1960s.

1. Brief Background of Education of Persons with Disabilities in India

The Kothari Commission in 1966 recommended education of children with disabilities in regular schools. Based on the recommendations, in 1974, the Department of Social Welfare launched the scheme of Integrated Education for the Disabled Children (IEDC). The implementation of this scheme was transferred to the Department of Education in 1982. The National Education Policy, announced in 1986, reiterated that “physically and mentally handicapped children should be integrated with the general community as equal partners, to prepare them for normal growth and to enable them to face life with courage and confidence”. The Disability Act, 1995 reinforced it by making it a right of children with disabilities to get free and compulsory education. The Sarva Shiksha Abhiyan (SSA), the flagship Programme of the Government of India, which was launched in 2001 to facilitate free and compulsory elementary education has a clear focus on inclusion, with a “zero rejection” policy. **In spite of all these measures, there have been many issues in the implementation of these schemes and policies. Moreover, these mandates/schemes have covered only Government institutions so far and the discrimination in private institutions has not been addressed.**

In India, **there is a parallel existence of both inclusive and special education systems.** The systemic changes that are required to make the regular education system truly inclusive seem a distant dream. The special schooling system has been quite ad hoc in its approach and extremely limited in its reach. The fact remains that both the systems have not been effective in

¹⁵²Accessed at <http://nsingit.wordpress.com/2009/07/06/the-wrongs-in-the-right-to-education-bill/> on 10th October 2011.

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delivering the desired result, which is quality education for persons with disabilities.

The following sections analyse the current scenario with respect to various provisions in Article 24 of the CRPD and identify the gaps that are existing.

2. Education Status of Persons with Disabilities

The latest data that is available in the country on disability are from the Census 2001 and National Sample Survey (NSS), 2002. (The disability data from Census 2011 has not been announced yet). Even the data available from Census and NSS is NOT accurate as most people with disabilities remained uncounted in these surveys. Only 2% of the population with disabilities were enumerated.

According to Census 2001 literacy is 49% across all persons with disability versus 65% in the general population. According to the National Sample Survey of India, 58th Round (2002), 50% of persons with disabilities are literate (28% of children with severe disability, 57% of children with moderate disability and 65% of children with a mild disability).

The percentage drops very steeply, when one looks at the figures of children with disability studying beyond primary school. As per the NSS Report, about 95.5% drop out after primary school. Only about 4.5% of students with disabilities pursue education beyond the primary level. (Source: People with Disabilities in India – From Commitments to Outcome, The World Bank, 2007).

As with the general population, there are strong gender differences in educational attainment among people with disabilities, with the literacy rate of females with disabilities pegged at 36% against literacy of 57% amongst males with disabilities.

Further, NSS found that, out of children with disabilities going to school, only 5.7% were in special schools and 94.3% were in regular schools, in the age group 5 -14 years.¹⁵³

In the case of enrolment in the special schools, about 11 percent enrolled in the special schools in the urban areas as compared to even less than 1 percent in the rural areas.¹⁵⁴

3. Inclusion and Non-discrimination in Primary and Secondary Education

One of the major initiatives of the Government of India to promote universalisation of elementary education in a time-bound manner was the **Sarva**

¹⁵³ World Bank Report, 'People with Disabilities in India: From Commitments to Outcomes', May 2007.

¹⁵⁴ Punarbhava Website accessed at

http://punarbhava.in/index.php?option=com_content&task=view&id=734&Itemid=540&limit=1&limitstart=7 on 14th August 2011.

Shiksha Abhiyan (SSA). SSA had “zero rejection policy”, meaning, no children should be excluded from receiving education. The scheme also had “inclusive education” as a component.

The enrolment of children with disabilities in the schools has increased due to the focused initiative under SSA. According to the Annual Report of Ministry of Human Resource Development (MHRD), 2010-11 (page 293),

- 29.72 lakh Children with Special Needs (CWSN) have been identified and that 24.59 lakh children with Special Needs (82.74% of those identified) are enrolled in schools till September 2010.
- 71,453 Children with Special Needs are being covered through Education Guarantee Scheme (EGS)/Alternative and Innovative Education (AIE) in 18 States/UTs.
- 164,002 Children with Special Needs are being provided home based education in 29 States/UT.

In all, 90.47% of the identified children with special needs have been covered through various strategies.

This is certainly an achievement. However, it requires to be seen in the larger context with respect to the total population of children with disability in order to analyse its coverage.

The total population of children in the age group 6 to 14 years is (as per SSA figure of 2009-10), is 202,600,799. Therefore, even if we take the conservative estimate of 5% of population as being persons with disability, the number would be 10,130,039, which is about 10 million or 1 crore (Table: Progress of Inclusive Education on SSA - SSA website¹⁵⁵). However, the total number of Children with Special Needs identified under SSA is only about 30 lakhs, which is only 30% of the total number of children with disabilities! **Hence, about 70% of children have still not been identified even after more than 10 years of implementation of SSA.**

More than enrolment, which sometimes is just a name in a register, it is important to analyse the attendance and dropout rates. Unfortunately, such data is not maintained under SSA. The Report of the survey conducted by Social & Rural Research Institute, Indian Market Research Bureau, published by Educational Consultants India Limited (EdCIL) in 2010, states that **34.8% children with disabilities are amongst ‘out of school children’ (6 to 13 years).**

Moreover, there is no information available in terms of outcomes/quality of education being provided to children with disabilities.

There seems to a proposal from the Ministry of Human Resource Development to exclude children with severe or multiple disabilities from compulsory elementary education, which if enforced, would be contrary to the provisions given in the CRPD.

¹⁵⁵ http://ssa.nic.in/page_portletlinks?foldername=inclusive-education accessed on 3rd September 2011

The 223rd Report by the Department Related Parliamentary Standing Committee on Human Resource Development on the Right of Children to Free and Compulsory Education (Amendment) Bill 2010, presented in the Rajya Sabha on 28th June, 2010 stated the following: "The Committee understands that children with multiple disabilities need to be part of the compulsory education process. However, there may be cases where in such a situation, a view needs to be taken about the viability of invoking the component of compulsory education in schools. In this connection, the Committee would like to point out that under SSA, 75,099 children with multiple disabilities are being provided education in regular schools. This has been made possible by these children being first provided some school preparation programmes before being mainstreamed in regular schools. The Committee understands that the strategy of Home Based Education under SSA is at present being evaluated. The Committee is of the view that this strategy needs to be vigorously pursued for children in the 0-6 years age-group for Early Intervention and School Readiness followed by their induction in the mainstream schools. The Committee, therefore, believes that elementary education should not be made compulsory for children with severe or multiple disabilities and the relevant provision in the Act may accordingly be modified." -E-mail from Radhika Alkazi, AARTH ASTHA to DEOC, dated 14th November, 2011).

4. Physical Accessibility

In the Annual Report of Ministry of Human Resource Development (MHRD), 2010-11, it has been stated that **7.27 lakh (727,000) (58.02%) schools have been made barrier-free.** The term '**barrier-free**' used in SSA seems **to be very restrictive.** The Manual for Planning & Implementation of Inclusive Education in SSA has a small paragraph on Architectural Barriers. It says, "**All new school buildings being constructed under SSA should have ramps, handrails and other such modifications to provide easy access**". **Moreover, no standards have been indicated.**

The fact that "barrier-free" does not include anything beyond the limited definition (as stated above) is also evident from the District Information System for Education (DISE) (2009-2010) projects where the sole indicators for barrier-free access were taken as ramps and rails! Further, only 15 out of the 35 States do not even have 50% of their school made barrier-free¹⁵⁶.

Lack of accessible **transport** prevents many children with disabilities from coming to schools. Another issue is the **pathway** to schools. For example, a child in the rural area may find it extremely difficult to go through a field to go to school even though the school may not be very "far".

¹⁵⁶ Elementary Education in India Progress towards UEE, National University of Educational Planning and Administration, 2008-2009, E-mail from Radhika Alkazi, AARTH ASTHA to DEOC, dated 14th November, 2011.

5. Curriculum Accommodations

Clause 30 (g) of The Disability Act of 1995 mandates that the curriculum will be restructured for the benefit of children with disabilities. However, much progress has not been made in this area. The National Curriculum Framework for School Education, 2005, developed by NCERT has recommended inclusive schools for learners with special educational needs by making appropriate modifications in the content, presentation and transaction strategies, preparing teachers and developing learning friendly evaluation procedures. Clause 29 of the RTE Act mentions that curriculum and evaluation procedures shall be laid down (though it does not specifically mention disability).

According to the Annual Report of MHRD, 2010-11, page 33, "14 States so far have renewed their curriculum based on NCF, 2005 and seven States have completed the revision of textbooks accordingly to make them more activity-based, child-friendly and sensitive to gender and marginalised groups." However, there is no mention about changes undertaken with respect to disability or the flexibility/accommodations that may be required in the curriculum.

Article 24 (3) in the CRPD provides for development of life and social skills within the inclusive education system. It would include teaching communication (augmentative communication, sign language, speech therapy, etc.), mobility training, skills of activity of daily living, social skills, etc. These need to be part of the curriculum for children with disabilities. The resource teacher therefore needs to play a proactive role to ensure holistic development of children with disabilities at each stage of development.

There are two aspects related to curriculum that requires to be addressed for children with disabilities in inclusive schools. One, additional skills, which may be required to be taught to children with disabilities to increase their access to a learning environment, like Braille, mobility for children with blindness, use of assistive devices, speech, language and communication skills for children with hearing impairment, multiple disabilities, etc. and the other, adjustment to the general curriculum to address the diverse needs arising out of disability and use of additional resources and classroom management to improve access of children to learning. This may include, (1) same curriculum but provided in accessible formats; (2) adjustment/modification in areas which cannot be accessed despite assistive aids (3) substitution of curriculum content by alternative content (4) deletion of specific curricular content¹⁵⁷.

6. Examination System

In India, the **general examination system is rigid**. Each student needs to study the same set of subjects (subject options are limited) in the same manner and duly reproduce them during exams. The rote method of learning is all

¹⁵⁷ World Bank Report, 'People with Disabilities in India: From Commitments to Outcomes', May 2007).

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prevalent! The examination system is highly stressful. By and large, there seems only one kind of system to judge success and failure. In the stipulated three hours time, a child is supposed to write the right answers.

At best, students with disabilities (with dyslexia, hearing impairment, blindness etc.) are asked to study not two but one language or not attempt certain questions in certain subjects or given extra time. The curriculum, subject content, teaching methods remains the same. If a student is unable to cope up, she/he fails.

There are many other accommodations that may be required for people with certain disabilities in order for them to appear in the exam on an equal footing with others. This may include flexible assessment systems, alternate questions, alternate methods of evaluation, etc.

7. Individualised Reasonable Accommodation and Support

Apart from general accessibility and changes in the policy and systems, reasonable accommodation is individualised. It could range from request for assistive devices, to moving of classroom from upper floor to ground floor, to providing a reader/writer, sign language interpreter or giving frequent breaks, based on individual need and circumstance.

Assistive devices and technologies play a crucial role in enhancing independence, learning, communication and productivity. SSA has a component to provide aids/appliances to children with disabilities. 18.37 lakhs (72.49%) children with special needs who require have been provided with assistive devices¹⁵⁸. **The range of assistive devices that are provided under the Government scheme is quite limited and does not include more expensive technologies** (the price limit for the grant scheme for an assistive device is Rs. 6000/- per equipment in ADIP). **Moreover, teaching aids, like tactile diagrams, visual aids, etc. are required to make the teaching effective. Teachers may not have access to such aids. There are not many resource centres/libraries for such materials.**

There are some **reasonable accommodations that are allowed as a policy, like scribes and extra time for writing exams. Since they are not flexible or individualised, sometimes they do not serve the purpose.** For example, students with disabilities are given a certain extra time to write their answers. Sometimes, the extra time given may not be sufficient, particularly for a person with writing difficulties and their requests for more time is generally not entertained by examination authorities. Several students have faced difficulties with respect to the rules related to using of scribes. Sometimes, scribe is provided only to blind students and not to persons with cerebral palsy or to persons with writing difficulties. The rigid rules like the qualification/marks of scribes pose considerable problems, particularly, when writing technical exams. Sometimes the authorities insist on students using the scribe provided by them who may not be skilled.

¹⁵⁸ Annual Report, Ministry of Human Resource Development, 2010-11, page 294

Most of the schools or institutions do not have an Office for Disability Services or Equal Opportunity Office or Resource Teachers who can understand the needs and coordinate reasonable accommodation of students with disabilities. A student with disability is expected to 'adjust' herself/himself to learn from the classroom teaching.

"I wanted to take the UPSC paper in 2008. Two days before, the officials said, if you are a blind person, only then would you be allowed to use a scribe".
-Divya Arora, Response to CRPD Questionnaire

Reasonable accommodation in **extra-curricular activities** is seldom looked into.

Some schools are developing **Individualised Education Plan (IEP)** in collaboration with NGOs/Resource Teachers. This requires a very intensive involvement on the part of Resource Teachers, whose availability seems to be a major problem.

8. Training of Teachers and Other Professionals

Teachers play a very important role (perhaps the most important) in educating children whether they have a disability or not. **When it comes to disability, two categories of teachers cater to the needs of children with disabilities - one, regular school teachers who have children with disabilities in their classrooms and the other, 'special' educators, who work as resource teachers or teach in 'special' schools.**

With 90% of children with disabilities studying in regular schools, it is crucial that teachers are well equipped to cater to the needs of children with disabilities. Most teachers in the country (particularly in the Government schools) have gone through some formal teachers training courses, such as Bachelor of Education, etc. before joining as teachers. However, these training courses do not equip teachers with skills required to teach children with different disabilities! Hence, teachers need training in inclusive education after they join the job. Under SSA, there is a component of training regular school teachers. According to the Annual Report of MHRD 2010-11 (Page 294), 26.24 lakh teachers have been covered through regular teacher training Programmes, which include a 2-3 day capsule on inclusive education; 19.40 lakh teachers have been provided 3-5 days additional training for better orientation to inclusive education.

There is a provision for the appointment of **Resource Teachers for inclusive education** in the SSA. Resource Teachers are specially trained teachers for teaching children with disabilities in all settings. Their main role is to provide remedial assistance to a child in those content areas in which she/he is having comprehension problems in a regular classroom. A Resource Teacher also advises the general teacher on how to cater to the needs of children with disabilities in the classroom. These Resource Teachers can either be appointed by the State and District authorities to function at the block level or their support can be obtained through 'special' schools, competent NGOs or the Integrated

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Education for Disabled Children IEDC Scheme of MHRD. **1.38 lakh teacher have been trained in 26 States with Rehabilitation Council of India for 90 days and act as Resource Persons in Districts/Blocks.** (Source: SSA Portal).

About 28 States have appointed 12,629 resource teachers and 1075 NGOs are involved in the programme in 30 States (Page 294, Annual Report, Ministry of HRD, 2010-11). If 26.94 lakh children have been covered under various strategies and there are only 12,629 resource teachers, then, **on an average 213 children with special needs will be under each resource teacher, which is highly inadequate!**

There is certainly a huge shortage of Resource Teachers. In SSA's inclusive education model, the role of Resource Teachers is very crucial. They provide the necessary support to children and to the regular school teachers. There is an urgent need for a concerted effort in the area of building up manpower.

Moreover, there would be children with different needs coming to regular schools like those requiring physiotherapy, those requiring to learn Braille/sign language/augmentative communication, those requiring speech therapy and medical/surgical intervention. Each school should be linked up with these services and the Resource Teacher should have knowledge on these issues and should be able to refer students for these services.

The current situation in India is that about 11% of urban children with disabilities and 1% of rural children are studying in **special schools** (NSS). There are no exact figures as to how many special schools are there in the country. Most of them are located in metropolitan cities. **There is a huge shortage of human resources in Special Schools as well, especially those trained in education. Moreover, their salaries are not at par and in fact, very low.**

There are limited number of trained personnel. There are currently only three training centres in the country, which train 60 teachers every year for an estimated deaf-blind population of 450,000.

-E-mail sent on 14th November 2011 by Zamir Dhale, Sense International.

"According to the Planning Commission's Institute of Applied Manpower Research (IAMR), India has 5265 professionals for the hearing impaired people while the requirement is for 58,000."

-Deepa Suryanarayan, 'In desperate need of special educators', DNA (Daily News & Analysis) 23rd March 2009.¹⁵⁹

¹⁵⁹http://www.dnaindia.com/mumbai/report_in-desperate-need-of-special-educators_1241600, accessed on 21st November 2011.

“Differently abled students of Municipal Corporation of Delhi (MCD) schools across the city will have to wait for special educators for some more time. In spite of the High Court order in 2009 asking for at least two special educators in all MCD schools for differently abled children, two years down the line there still are not any recruitments.”

-Disabled kids wait for special educators in MCD schools; indianexpress.com, 7th June 2011.¹⁶⁰

9. Tertiary, Vocational and Life Long Learning

There is no compressive data on the total number students with disabilities taking up higher education in the country. 3% reservation (as mandated by The Disability Act, 1995) has helped a few people with disabilities to join universities, including premier institutions. According to the data given in the Annual Report of Ministry of Human Resource Development, 2010-11, in the 19 Central Educational Institutions, 182 students with disabilities have been admitted (Page 298). This data does not give information about the total number of central institutions, nor does it give the percentage of students with disabilities as compared to the overall student strength. Informal surveys conducted by certain organisations indicate a very low number of enrolments of persons with disabilities in higher/professional education.

The University Grants Commission (UGC) announced schemes in 1998 for promoting education of students with disabilities. The Scheme that was specifically focussed on higher education was called Higher Education for Persons with Special Needs (HEPSN). The Scheme has three components – (1) setting up of Disability Units; (2) providing access and (3) provision of assistive devices and services to disabled students. The number of colleges that were assisted under the scheme during 2009-10 were 618. The amount paid is Rs. 80,913,000/- (Page 296, Annual Report, Ministry of Human Resource Development, 2010 -11). There are many other apex bodies in the education sector that are responsible for recognising various professional courses, such as the All India Council for Technical Education (AICTE), the Medical Council of India, the Bar Council of India, the Nursing Council of India, etc. None of these councils have Schemes like HEPSN to promote education of students with disabilities.

The Ministry of Social Justice and Empowerment has a **Scholarship Scheme** under which, every year 500 new scholarships are awarded for pursuing post-matric professional and technical courses of duration more than one year. However, in respect of students with cerebral palsy, mental retardation, multiple disabilities and profound or severe hearing impairment, scholarship are awarded for pursuing studies from IX Standard onwards.¹⁶¹ The National Handicapped Finance Development Corporation (NHFD) also has a

¹⁶⁰<http://www.indianexpress.com/news/disabled-kids-wait-for-special-educators-in/800177/>, accessed on 21st November 2011.

¹⁶¹ MSJE website, Scheme and programmes, accessed at <http://socialjustice.nic.in/schemespro3.php#a4> on 12th November 2011.

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similar scholarship scheme under which 284 persons with disabilities were given scholarship in the academic year 2009-10.¹⁶²

Many institutions (Government or Government-aided) are providing 3% reservation (as mandated by the law). However, there are a lot of barriers that students are facing in pursuing education on an equal basis with others, like availability of books in accessible formats, sign language interpreter, option of taking up subject of their choice, etc.

No Sign language Interpreters in Colleges

"Adarsh College in Chamarajpet, Bengaluru has over 10 deaf students and initially provided interpreters for all of these - who ran from class to class. Now she has left as a result of feeling frustrated about not being able to provide good services and the low pay, and so the students have no interpreters. What was especially egregious is that the parents were required to chip in Rs. 2000/- towards the interpreters' pay.

I have also met one deaf student in Delhi University (DU) who is in her second year of B.Com. DU has agreed to provide an interpreter but has told her that she needs to find the person herself. She has spent the last two years searching and banging on doors, pleading with people who know sign language to leave their jobs or to help her out. It's pretty insane to watch."

-E-Mail dated 28th January 2009 from Michele Friedner, Ph.D. Candidate, Medical Anthropology, to Rama Chari, one of the authors of this document.

I applied and got through the entrance test for studying doctorate in a premier institute in Bengaluru. At the interview the Head the Department asked me why I wanted to pursue a Ph.D. when I had so many health problems. At that time I was stunned and didn't know how to react. I let it go but now I realise I should have taken this up seriously."

-A student who has Thalaesemia

Many students enrol in **correspondence courses**, where one gets the course material in printed form through post and contact classes are held during the weekends/evenings. **One does not hear of these reading materials being available in accessible formats for those with difficulty in reading printed material.** Distance and Online education are options for persons with and without disabilities to enrol in courses and study from home. However, a lot of audio-visuals are used in these, which may not be accessible for some persons with disabilities. The Government does not provide any guidelines to the institutions that run these courses to make their teaching materials in accessible formats.

In the last 5 years, there has been a huge focus of the country on Skill Development. In the Eleventh Five Year Plan (2007-2012), an ambitious Skill Development Mission was initiated by the Government with a target of creating 500 million skilled workers by 2022. The **National Policy on Skill**

¹⁶² Page 135, Annual Report, Ministry of Social Justice and Empowerment, 2009-10.

Development clearly mandated 3% reservation, accessibility and reasonable accommodation for persons with disabilities. However, its implementation at the end of five years has been very poor. There is no centralised data on how many people with disabilities benefited from this programme.

There are 20 **Vocational Rehabilitation Centres (VRCs)** for Persons with Disabilities in the country. According to one of the reports received from the Ministry of Labour & Employment, during 2010-11, only 1077 persons with disability were trained in VRCs and 4696 persons with disabilities trained outside VRCs. 3675 were placed in “wage paid” and 3211 were placed in self employment. **On an average, only about 50 students were trained in one VRC in one full year!** This seems to be a huge underutilisation of infrastructure and resources. Moreover, the courses that run there are archaic and not market oriented.

Article 24 of the CRPD mentions equal opportunities for **lifelong learning**. **Early childhood** (the first six years) is the most crucial period, when the foundations are laid for cognitive, social, emotional, physical/motor development and cumulative life-long learning. The Right to Education Act, 2009 is applicable to children in the age group 6 to 14 years. The Ministry of Women and Child Development administers a scheme, **‘Integrated Child Development Service (ICDS)’**, which aims at holistic child development (6 months to 6 years). A package of following six services is provided under the ICDS scheme: Supplementary nutrition; Non-formal pre-school education; Immunization; Health check-up; Referral services and Nutrition and Health education. The Ministry does not have data on the number of children with disabilities who have benefited from the scheme. In response to an RTI filed in October 2011 by NCPEDP, the Ministry has mentioned **“The existing MIS (Management Information Systems) does not capture information of disabled children”**.

There are many instances of persons with disabilities who have stagnated in their career and not given opportunities to get trained and grow. There are age restrictions for joining many courses; the breaks in education or work due to disability is not given relaxation; and inaccessibility in general further reduces the opportunities for exposure and learning.

Though the Government has programmes for **adult education**, which focuses on women and persons belonging to the Scheduled Caste, Scheduled Tribes, Minority groups and other disadvantaged groups, it does not seem to specifically mention persons with disabilities. **The data is given for beneficiaries belonging to the above groups but not for persons with disabilities.** (Page 173, Annual Report, Ministry of Human Resource Development, 2010-11).

10. Lack of Strategy or Road Map for Educating Children with Disabilities

The Government seems to be having no clear vision/policy/strategy/road map for educating all children with disabilities in India. **There is a debate in the country with respect to Inclusive/Special Education.** Even the disability

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sector does not have a unanimous view on the subject. While some are of the opinion that the special schools should be phased out and all resources should be put in for strengthening inclusive education and there are others who believe that both the systems should coexist and resources should be invested in expanding and strengthening special schools as well.

Another issue of confusion is that education of children with disabilities in India is the **responsibility of both the Ministry of Human Resource Development (MHRD) and the Ministry of Social Justice and Empowerment (MSJE)**. Inclusive Education falls under MHRD and special schools are funded by MSJE.

With the Government playing little role in the early days in the education of persons with disabilities, NGOs, *Madarsas* and concerned individuals took on the role of teaching. MSJE began to give grants to these initiatives, without really taking on the responsibility directly. MHRD that looks into the education of the entire country, then started talking about integration and inclusion of persons with disabilities in the regular education system. This led to a division, where the two Ministries, at the national level, were unclear as to whose responsibility it was ultimately and started passing on the responsibility onto each other. One can see this trend not only at the national level, policy level, budget allocation level, but also in the day to day struggles of students with disabilities, where teachers/principals of regular schools 'counsel' them to go to special schools and the special schools 'counsel' them to get admission in regular schools.

Recommendations

- 1) The disability laws should be amended to bring them in line with Article 24 of the CRPD.
- 2) Right to Education Act should be amended to include provisions of the CRPD.
- 3) The subject of 'education for persons with disabilities' should be placed entirely under Ministry of Human Resource Development (MHRD) without any further delay.
- 4) At least 3% of the MHRD's resources should be allocated for disability, as given in the Eleventh Plan and its utilisation should be mentioned in the Annual Report.
- 5) A Disability Cell should be set up in MHRD to not only ensure that disability is included in all educational policies and schemes, but also to have targeted programmes for educating people with disabilities.
- 6) The plan of the Government to make education "not compulsory" for students with severe disability should be strongly opposed and concerted effort should be made to address issues that prevent their inclusion in schools.
- 7) The regular teachers training programmes, like nursery teachers training, Diplomas, Bachelors and Masters programmes in Education should have 'education of persons with disabilities' as a compulsory subject.
- 8) The training programme in inclusive education for regular school teachers should be evaluated and refresher trainings should be provided on a

regular basis to make them more competent and aware of latest developments, including use of assistive devices, technologies and different modes of communication.

- 9) The curriculum of training of Resource Teachers should be reviewed and modified to equip them with knowledge and skills to work with students with different disabilities.
- 10) Accessibility is vaguely mentioned in the SSA Manual. RTE has also mandated 'barrier-free access' to buildings under the norms and standards for schools. Accessibility standards have to be specified for school buildings and should include needs of children with all disabilities.
- 11) Hostels should also be made accessible for students with disabilities.
- 12) Provision of reasonable accommodation should be adopted as a policy in our education and examination system, so that support/adjustment based on individual's need is provided.
- 13) Access to books, learning materials and inclusion in extra-curricular activities should be ensured.
- 14) There are many children with disabilities who are still "out of school". A focused effort should be made to bring them to schools. The drop out data should be maintained with respect to students with disability under the SSA.
- 15) The curriculum and evaluation system which would be framed as per RTE, should take into account needs of children with disabilities. Further, the school curriculum should include sensitisation module on disability, sign language and Braille for all children to learn.
- 16) The ADIP scheme should be revised to ensure people with disabilities get appropriate devices suitable to their individual needs.
- 17) The Government should either strengthen the ICDS through a focused Programme or launch a targeted mission for holistic development of young children with disabilities.
- 18) All the schemes/programmes to promote higher/technical/vocational education should have a disability focus not just in terms of reservation but also in providing equal opportunities and accommodations for students with disabilities.
- 19) Disability Units should be set up in every university/institution. Disability Units should also be set up in the University Grants Commission (UGC), All India Council for Technical Education (AICTE), National Council of Educational Research and Training (NCERT), Kendriya Vidyalaya Sangathan (KVS), and all other apex education bodies.
- 20) There should be a special literacy drive targeting people with disabilities (age of 16 and above) in the country. The initiative should impart literacy and vocational skills in tandem.
- 21) Distance Education/Open Schooling systems should make a proactive initiative to ensure that their methodology of teaching/evaluation is inclusive.

Article 25: Health

The text of Article 25 in the CRPD is given below.

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- (a) *Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;*
- (b) *Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;*
- (c) *Provide these health services as close as possible to people's own communities, including in rural areas;*
- (d) *Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;*
- (e) *Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;*
- (f) *Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.*

Survey findings

- The findings with respect to the efforts made by the Government to ensure that persons with disabilities have access to adequate health services are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	54%
Dissatisfied	39%
Satisfied	6%
Extremely satisfied	0%
Do not know much about the issue	1%

A whopping 93% were 'dissatisfied' with the efforts made by the Government to ensure that persons with disabilities have access to adequate health services. Only 6% were satisfied with Government efforts on this issue. The high level of dissatisfaction could be because none of the major health programmes initiated by Government of India like the National Rural Health Mission (NRHM), Janani Suraksha Yojna and other schemes explicitly mention or address the needs of people with disabilities. Basic health services remain inaccessible for persons with disabilities due to distance; lack of knowledge regarding disability issues amongst medical professionals; lack of accessibility of hospitals and clinics, cost of consultation, surgeries, medicines and rehabilitation equipment; lack of coordination between health and rehabilitation professionals and institutions etc.

Laws and Policies

Article 47 of the **Constitution of India** imposes on the Government a primary duty to raise the level of nutrition, the standard of living of its people and improve public health.

The Disability Act, 1995 states that the Central and State Co-ordination Committee shall consist of Secretaries to the Government of India and State Government who are in-charge of the Departments of Welfare, Health, Woman and Child Development. The Central Executive Committee shall include the Director-General for Health Services as a member. The Act also provides for appropriate Governments and local authorities to take certain steps for the early detection of disabilities. Clause 25 states that the appropriate Government shall screen all the children at least once a year for the purpose of identifying "at-risk" cases, provide facilities for training to the staff at the primary health centres, take measures for post-natal care of mother and child, educate the public through pre-schools, schools, primary health centres, village level workers and anganwadi workers. Under the provisions for employment, we have the following clauses that discuss aspects of health.

- Clause 38 states that the appropriate Governments and local authorities shall, by notification, formulate schemes for ensuring employment of persons with disabilities and such schemes may provide for health and safety measures where persons with disabilities are employed.
- Clause 46 mentions ramps in hospitals, primary health centres and other medical care and rehabilitation institutions.
- Clause 48(b) mentions that the Government shall promote and sponsor research in the area of rehabilitation, including community based rehabilitation.
- Clause 66 mandates Governments to undertake rehabilitation of all persons with disabilities; grant financial assistance to non-governmental organisations and consult the non-governmental organisations working for the cause of persons with disabilities.
- Clause 67 mandates framing of an insurance scheme for the benefit of its employees with disabilities.

The National Trust Act, 1999, states that the Board of the National Trust should consist of officials (not below the rank of Joint Secretary to the Government of India) to represent Ministries including the Ministries or

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Departments of Social Justice and Empowerment, Women and Child Development, and Health and Family Welfare. Under the rules prescribed for appointing a guardian, this Act states that the application for guardianship for personal care and maintenance shall be accepted to cover the following areas including health care needs, nutrition and medical & surgical needs.

The Rehabilitation Council of India (RCI) Act, 1992, was enacted to regulate and monitor services given to persons with disability, standardise syllabi and to maintain a Central Rehabilitation Register of all qualified professionals and personnel working in the field of Rehabilitation and Special Education. The Act also prescribes punitive action against unqualified persons delivering services to persons with disability. It also mandates that the Council shall consist of the members representing the Ministries dealing with welfare and health.

Mental Health Act 1987 empowers the Union Government or the State Government to establish or maintain psychiatric hospitals/nursing homes. The Act prohibits the establishment or maintenance of any psychiatric hospital or psychiatric nursing home by any person unless she/he holds a valid licence granted to her/him under the Act. It provides for Central/State Authority for Mental Health Services to supervise the psychiatric hospitals and psychiatric nursing homes and other Mental Health Service Agencies (observation wards, day-care centers, inpatient treatment in general hospitals, ambulatory treatment facilities and other facilities, convalescent homes and half-way-homes for mentally ill persons) under the control of the Central/State Governments respectively.

There are **other health related legislations** like the Medical Termination of Pregnancy Act, The Pharmacy Act, The Transplantation of Human Organs Act, Consumer Protection Act, Maternity Benefit Act, Life Insurance Corporation Act, 1956, Insurance Regulatory and Development Act, 1999 etc. and State laws related to health which need to be reviewed in the light of provisions given in CRPD.

Progress and Concerns

1. Non-discrimination in Health Services-Availability, Accessibility, Affordability and Quality

There are hardly any initiatives by the Government to promote accessibility of health services to persons with disabilities. The Ministry of Health and Family Welfare does not have any focus on access to health for persons with disabilities. **This is clear from the fact that the Flagship programme, National Rural Health Mission (NRHM), which was initiated in 2005 to provide accessible, affordable and accountable quality health services to the poorest household in the remotest rural regions does not include disability.** This is quite unfortunate, because a lot of resources are being spent on setting up and upgrading infrastructure, building human resources and strengthening delivery of health services at the community level.

Designed on similar lines is another flagship programme, the National Urban Health Mission (NUHM), which is yet to take off, that aims to provide quality

healthcare to the country's urban poor. Based on the information available on the internet about the programmes, there is no mention of disability.

There is no data available on how many people with disabilities are benefiting from the health services that are being provided.

There is a **huge gap in terms of health services available for disabled and non-disabled people in the country**. Issues vary from inaccessible buildings and diagnostic equipments, negative/stereotypical attitude of health professionals or their ignorance, lack of training to communicate with people with hearing/speech impairment or intellectual disability, inaccessible transport to reach the health centre or sheer expense of treatment/rehabilitation.

"A very young child of about 1 year had come to a Primary Health Centre (PHC) in the village. The child had not developed head control and all the milestones were delayed. The doctor wrote that the child has nutrition deficiency. He did not even refer the child to the rehabilitation centre which was right opposite the PHC".

- Community worker shared this information with DEOC.

"On the topic of Health, we are not treated and are often told that we are making things up when our physical symptoms could be something very serious. We are not given the right treatment and often always put back on psychiatric medications."

-Reshma V, Red Door, E-mail to Rama Chari, on 13th November 2011.

"A person with Cerebral Palsy had once narrated his experience of trying to find a dentist in his area. He could not find a single dental clinic which was accessible. Some dentists also refused to treat him saying they do not have necessary equipments! It is a fact that most local clinics, health centres and pathological labs are inaccessible to people with disabilities."

-Sakshi Broota, DEOC.

"I live in Bengaluru. There are no Government hospitals nearby. I go to a private clinic of an MBBS doctor for any ailment. I have to take a taxi to reach there, as it is about 1 km from my house plus have to shell out Rs. 200/- for a simple consultation."

-Person with disability who uses crutches belonging to a lower middle class family.

2. Support Groups

There are hardly any support groups for persons with disabilities in the country. Doctors sometimes do not have answers to the queries of health

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issues of persons with disabilities. And it would help to know other people who are having similar issues and how they are handling it.

"I went to a disability rehabilitation organisation to check if they could help me learn activities of daily living after I had paralysis of my lower limbs. The therapist there told me that they do not have much knowledge in this area and that there are no organisations that could help. The best option would be to learn from peers. Where do I find peers?"

-A wheelchair user.

"I have been seeing flashes of strange images which I have not been able to articulate to my doctor or family. I tried many times to search on the internet to find a support group of people who could be having similar experiences. And believe me, when I finally found a support group of people who were able to write about these experiences, half my anxiety was gone. I knew, here was a group I could share my anxieties with and they would understand what I was talking about."

-A person who has neurological medical condition.

"I am deaf and wanted to meet a doctor to share certain problems that I was having. I am not very articulate in writing. I was not comfortable sharing it with my family. None of the hospitals have sign language interpreters. I somehow managed to communicate with my doctor. But I realise this is a huge problem for deaf people who have communication difficulties."

-A deaf person shared this with DEOC.

3. Awareness

There is **lack of awareness among persons with disabilities** and their families about their right to access to health facilities. Majority of people in the country (disabled or non-disabled) have little awareness about the facilities that are available. For persons with disabilities, access to this information becomes even more difficult, as the media through which the information may be disseminated may not be accessible. For instance, TV/Radio advertisement on various health aspects like vaccinations, family planning, health issues etc. are not accessible for people with sensory impairments.

"Government has not been taken health campaign for deaf people and are not raising awareness."

-T.K.M. Sandeep, Response to the CRPD Questionnaire

4. Health Governance

The health of persons with disabilities seems to be nobody's responsibility. The Ministry of Health and Family Welfare has no focus on disability, except mental health. The Ministry of Social Justice and Empowerment is not working in the area of access to health. There is passing of responsibility and no convergence between the two Ministries. Lack of data as to how many people with disabilities are using the public and private health care services is also a key problem. There is no data on health conditions of persons with disabilities, due to which disability budgeting and evaluation of programmes gets affected. There is a lack of participation of the disabled population in all health-related decision-making at the community and national levels.

Under Integrated Child Development Services (ICDS), 781.71 lakh children (6 months to 6 years) received supplementary nutrition. The existing MIS (Management Information Systems) does not capture information on disabled children.

-Response to RTI filed by NCPEDP on the status of implementation of XI Five Year Plan, October, 2011.

5. Mental Health Programmes

One of the major areas of work of the Ministry of Health and Family Welfare is 'Mental Health'. The National Mental Health Programme (NMHP) was started in 1982 and the District Mental Health Programme (DMHP) in 1996 with the objective to ensure availability and accessibility of minimum mental health care for all, to encourage mental health knowledge and skills and to promote community participation in mental health service development and to stimulate self-help in the community.

The issues related to implementation of the programmes as per the evaluation undertaken in 2008 were, lack of dedicated monitoring and implementing mechanism; shortage of skilled manpower in mental health; lack of coordination between implementing departments; lack of community involvement, etc. The allocation of funds was substantially increased to Rs. 1000/- crores in the XI Plan for mental health programmes.

Some of the progress as mentioned in the Annual Report of Ministry of Health and Family Welfare (2010-11) are given below.¹⁶³

- At present DMHP is covering 123 districts in 30 States and Union Territories
- As of now, 9 Mental Health Institutes have been funded for developing as centres of excellence in Mental Health.
- 23 Post Graduate departments have started Post Graduate courses and/or increased the intake.
- A total of 29 mental hospitals/institutes have been supported for modernisation.

¹⁶³ Page 150-152, Annual Report of Ministry of Health and Family Welfare, 2010-11.

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- A total of 88 psychiatry wings have availed grant for upgrading facilities and equipment.
- Funds were provided for research to institutes and organisations in the field of mental health in the country.
- Efforts are being made to mainstream the components of NMHP under the overall umbrella of National Rural Health Mission so that the States are able to plan requirements concerning mental health services as part of their respective Programme Implementation Plans (PIPs).

Though there has been some progress, however, the impact at the ground level has been minimal even after about 30 years of implementation of NMHP and 15 years of DMHP.

Some of the basic issues relate to the kind of treatment given, the human rights of persons with psycho-social impairment, the archaic provisions of the Mental Health Act that allow for involuntary admission and detention, the state of "mental hospitals" in the country, lack of human resources in the field and lack of awareness about mental health are the major road blocks and the efforts undertaken to address any of these are inadequate.

Shock treatment

Banyan (an NGO) conducted an audit of the Institute of Mental Health (IMH) on 3rd October 2008 to measure specifics like availability of basic amenities to evaluate living conditions of people with mental illness who are residing there. Its findings are shocking. The report states that people live in appalling conditions – wards have inadequate ventilation and are built like prison cells; roofs leak in many wards; toilets lack basic privacy; drinking water available only in open water containers kept under trees and there are not enough mats and blankets.

There have been shocking instances of gross violations of human rights. Wardens move around with *lathis* and have been seen to use it to intimidate. In the visitor's committee meeting held on 31st October, a woman was found with pus oozing from her badly injured head. It was revealed that earlier that week she was masked with a cloth and mercilessly beaten on the head by many wardens because she had tried to escape.

- 'Dial 100 Mental Health Helpline - Evolution in Institute of Mental Health (IMH)', The Banyan, received by E-mail from Disability Law Unit, South on 19th January 2009.

"I am yet to meet a medical practitioner who does not treat you like another 'subject'- another specimen on whom they can carry out their drug trials and tests. We are never forewarned about contra-indications and side-effects of any medicine we are given, because it is assumed that we are incapable of thinking for ourselves and that the medical fraternity knows best. Even if a drug or procedure is banned or internationally forbidden the information regarding the ban never comes to the fore in India. I only know that one

needs to go to a doctor, irrespective of whether they can treat you or not - at least they will sedate you; sometimes for months and months.

I do not know of any place, where I can go and register the fact that I have a psychiatric illness and I should be given any special benefits, doles, grants, support or concessions- nowhere. Nobody would even tell someone they went to meet a psychiatrist; what to mention of seeking support outside the four walls of their homes, except for when they need hospitalisation or institutionalisation."

-A Respondent to the CRPD Questionnaire.

"The reason for the failure of NMHP is that "the how of it" is missing in the programme. There is no clear strategy or mechanism to implement the programme. NMHP is under Central Government and the implementer is the State Government. Monies are not being released on time for the States to implement the programme. There are several initiatives mentioned in NMHP, which have not been implemented. For instance, there is a School Programme mentioned in NMHP which is yet to take off in many States. There is no well established monitoring system, including civil society or affected persons."

Late D.M. Naidu, Base Line Report on Health, NCPEDP, 2009.

"Awareness about mental illness among the community members were recorded through door to door survey in the District of Sikar, Rajasthan and also discussion with common people at very informal level. Most of the community members contacted during the survey were of the opinion that no health awareness camp had been held in their village at all. Only 4% reported attending a health camp."

-Section: 2.5.2.1; Evaluation of DMHP, ICMR Report, E-Mail sent to yahoo groups by Vaishnavi Jayakumar, dated 24th October 2011.

With the vision/paradigm shift brought about by CRPD combined with strong self advocacy by people with mental illness, one can hope for a larger change in the years to come. **The legislative changes; community based programmes, support network and large scale awareness creation would be required to effectively address mental health issues.**

6. Disability Certificates

For availing benefits/entitlements provided by the Government, persons with disabilities require a Disability Certificate. **Only 31.47% of persons with disabilities have been issued Disability Certificates in the country.** The certification process was amended vide notification no. 16-02/2007-DD.III dated 30.12.2009. (Page 107, Annual Report of Ministry of Social Justice and Empowerment, 2009-10). The process of issuance of Disability Certificates has been simplified and decentralised. The guidelines provide for issuance of medical certificates at Primary Health Centres (PHCs), Community Health Centres (CHCs) and Hospitals at the Sub-Divisional level, in case of obvious disabilities. For

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disabilities that are not obvious, certificate can be issued by a specialist and in case of multiple disabilities; a multi-member board is to issue the certificate¹⁶⁴. This is a step forward. However, the reach, even after the simplification process, has not increased much.

About 65% of people with disabilities do not have disability certificates in the country. Only two States, Gujarat and Bihar, have adopted this simplified process¹⁶⁵. The percentage coverage is based on the population of Census 2001, which is not only dated but also not very authentic. **Hence, in reality, the percentage of people who do not have Disability Certificates would be much more.**

Most of the States have not simplified the procedure yet. **Moreover, people with hearing impairment, low vision, mental, intellectual and other impairments are continuing to get referred to District or State Hospitals for certification.** There is no information available as to where one could go and the dates in which the certification would be done in these Hospitals. The District Hospitals, most of time, do not have specialised doctors to assess certain disabilities, particularly intellectual and mental impairments. Hence, **most people with intellectual and mental impairment remain without certification in the country.**

The 'simplification of the procedure' has not really helped most people with disabilities. **People who may have difficulty to reach Primary Health Centre,** due to severity of their disability, they also remain without certificate, as there is no system to send doctors to homes to issue disability certificates.

There is also lack of knowledge and sensitivity among doctors regarding disability. Most doctors do not assess disability percentage properly and give an arbitrary number. The doctors are also unable to advice people who come for certification regarding any rehabilitation aspect or give any other information (such as availability of pension, reservations, etc.), as they themselves are not aware of the provisions/schemes. Many doctors are not motivated to do the certification work as they perceive it as an additional work and not part of their regular work.

The Health Ministry has not made any mention of Disability Certification on their website or Annual Report. This work is seen as the work of Ministry of Social Justice and Empowerment. There is lack of coordination between the two Ministries on this issue.

Most people with disabilities are not even aware of Disability Certificates or regarding the benefits of having a certificate. There seems to be no effort made by the Government to disseminate this information. Moreover, there is no measure in the amended rules to reach people with disabilities who have difficulty reaching the medical centres for getting disability certificates. **People with disabilities who are not covered under The Disability Act, 1995 are not issued any disability certificate.**

¹⁶⁴ Page 107, Annual Report 2009-10, Ministry of Social Justice and Empowerment

¹⁶⁵ The Status Paper, 'Working Group on Empowerment of Persons with Disabilities for formulation of XII Plan')

7. Awareness and Training of Medical Professionals

There is no mention in the Annual Reports of MSJE and MHFW about any training and sensitisation programmes of doctors and community workers of NRHM on disability.

There is a huge of shortage of trained medical/rehabilitation professionals to cater to the needs of people with disabilities in the country. It is an irony that for ages, disability and people with disabilities have been seen as a medical concern (disabled people seen as patients) and yet hospitals and other medical institutions across the country are not disabled-friendly.

The medical courses cover diagnosis and 'treatment' of various disabling conditions, however, and not much on the rights of persons with disabilities, their rehabilitation and the linkages between rehabilitation and medicine. As a result, the medical fraternity has very little information and knowledge and are unable to advice and refer people with disabilities for rehabilitation.

Medical Professionals actively discourage families from seeking health support for children with severe disability. In a study conducted by AARTH-ASTHA, parents of children with Cerebral Palsy in Delhi reported that they were told by the doctors that nothing could be done for their child. Therefore, rehabilitation measures were not taken and the families gave up on their children. Thus, starts the devaluation of the child, which is closely related to neglect and abuse.

8. Health Insurance

People with disabilities are generally **excluded from health insurance on the grounds of their disability or asked to pay huge premiums.** Most of the health insurance is under the private sector.

The Ministry of Health and Family Welfare (Page 34, Annual Report 2010-11) has advised the State/Union Territory (UT) Governments to prepare health Insurance models as per their local needs to be run on pilot basis and so certain guidelines were sent to all States/UTs for preparation for pilot projects on Health Insurance. The support from the Government of India, for paying premium for the Health Insurance Scheme for the BPL families has been fixed as per Universal Health Insurance Scheme of the Ministry of Finance, at Rs. 300/- for a family of five.

Rashtriya Swasthya Bima Yojana (RSBY) was launched in 2008 to provide health insurance cover to families Below Poverty Line (BPL). It covers hospitalisation charges upto Rs. 30,000/- and provides the option of taking treatment either in a public or private hospital. **The exclusions mentioned in RSBY are congenital external diseases or defects or anomalies,**

intentional self-injury/suicide, all psychiatric and psychosomatic and related disorders.¹⁶⁶

Niramaya, a Health Insurance Scheme, is a pioneering initiative of the National Trust, to provide health insurance for people with Autism, Cerebral Palsy, Mental Retardation & Multiple Disabilities. The scheme has some path-breaking features like - no age bar, no exclusion of pre-existing medical conditions and no pre-insurance medical test.

According to the Annual Report, 85,041 beneficiaries have been enrolled under the Niramaya Scheme and Health Card have been issued to 71,595 beneficiaries. Claim settlement amounting to Rs. 1.05 crore of 1035 cases have been made so far. This includes Rs. 76.49 lakh for 480 cases under cashless and Rs. 28.77 lakh for 555 cases under reimbursement.¹⁶⁷

The cashless facility has been recently withdrawn due to misuse of funds by certain hospitals. This is a major setback, as it would directly affect poor people who may not have immediate cash to pay. There are also apprehensions about the continuation of the scheme. In the words of its Joint Secretary and Chief Executive Officer, National Trust, "though these figures appear impressive, there was also a serious cause for concern as only 8950 beneficiaries applied for renewal. **Since it is a group health insurance scheme, hence its continuity and effectiveness depends on group dynamics and in the absence of a sizeable group, Niramaya may itself become sick and even die down.**"¹⁶⁸

Niramaya is the only health insurance scheme specifically for persons with disabilities and this also does not cover all disabilities. As a result, people with disabilities have to shell out large amounts of money on their health needs. This is also because of increased privatisation of health services in India. While the general population has probably benefited from the private health insurance policies, the impact of it has been adverse on people with disabilities. **The cost of medical services has substantially gone up due to availability of insurance. Thus, persons with disabilities who are not covered under insurance end up spending more money than before.**

"No insurance policy covers our case conveniently"

- Anjali Sardana (representing persons with Thalassemia), Response to the CRPD Questionnaire.

"I had a fall and had a nose fracture and was admitted in the hospital for treatment. I mentioned about epilepsy in the hospital so that doctors are aware. My epilepsy has been in control for some years now. Even then,

¹⁶⁶ RSBY website, http://www.rsby.gov.in/about_rsby.aspx accessed on 25th November 2011.

¹⁶⁷ Page 147, Annual Report, Ministry of Social Justice and Empowerment, 2009-10.

¹⁶⁸ Annual Report, 2010-11, National Trust.

because of doctor's noting about my epilepsy in the record, my insurance was denied. "

-A person with Epilepsy

9. Health of Women, Children and Older Persons with Disabilities

CRPD provides for gender sensitive health services, sexual and reproductive health and services to children and older persons. **There is nothing specific in the Government of India's health schemes that focuses on the needs of women, children and older persons with disabilities.** The concerns relating to reproductive and child health needs are covered in detail in the section, Women with Disabilities, in the chapter on Article 6 and in the section, Children with Disabilities, in the chapter on Article 7. There are hardly any schemes for the health of older persons in the country in general. A lot of older people may have disability. Their needs and concerns are totally ignored.

Recommendations

- 1) The disability legislations and other health related legislations should specifically mention access to health for persons with disabilities and should cover private practitioners and hospitals.
- 2) The Draft National Health Bill has to be reviewed and amended to ensure its compliance with CRPD.
- 3) The Ministry of Health should take under its purview health and rehabilitation of people with disabilities.
- 4) The NMHP and DMHP should be reviewed on the basis of various provisions in CRPD, including aspects of ensuring community involvement, setting up of support networks, creating awareness, etc.
- 5) Persons with disabilities should be included under "vulnerable/targeted sections" in all health schemes of the country.
- 6) The Insurance schemes should be reviewed and amended to ensure non discrimination against persons with disabilities.
- 7) The Niramaya insurance scheme should be strengthened and should cover all people with disabilities.
- 8) The Government should provide subsidies to manufactures/distributors in order to reduce the costs of various medicines, medical equipments (catheter, diapers etc.), used by persons with disabilities on a regular basis to make them affordable.
- 9) Home based services should be introduced to persons with disabilities who have difficulty reaching clinics/hospitals.
- 10) The Government of India should make disability-specific provisions that can address the needs of children, the elderly persons and women with disabilities.
- 11) The Government should subsidise healthcare services for people with disabilities, irrespective of whether it is public or private.
- 12) There is an urgent need for sensitisation of healthcare professionals on disability and the staff working in health programmes, right from

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community workers to medical professionals and officials in charge of various schemes.

- 13) The Medical Courses (Bachelor of Medicine, Nursing, and other Paramedical Courses) should cover disability not just in terms of diagnosis and treatment but also in terms of rehabilitation and rights, which would enable doctors to provide the right information and advice to families and persons with disabilities.
- 14) Better convergence is required between the various Ministries - Ministry of Health and Family Welfare, Ministry of Social Justice and Empowerment and Ministry of Women and Child Development, to ensure a more coordinated effort in this area
- 15) Accessibility norms should be strictly implemented in all hospitals, Primary Health Centres (PHCs), medical clinics, testing labs etc. including the ones that are privately owned. Those found not following the norms should be severely penalised.

Article 26: Habilitation and Rehabilitation

The text of Article 26 in the CRPD is given below.

1. *States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:*
 - a) *Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;*
 - b) *Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.*
2. *States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.*
3. *States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.*

Survey Findings

1. The findings with respect to the efforts made by the Government to ensure that persons with disabilities have access to habilitation and rehabilitation services close to their communities are given below.

Rating	Percentage of Respondents
Extremely Dissatisfied	53%
Dissatisfied	33%
Satisfied	11%
Extremely satisfied	0%
Do not know much about the issue	2%

About 11% of the respondents have expressed 'satisfaction' with the efforts made by the Government to provide rehabilitation services. However, the majority (86%) have expressed 'dissatisfaction'. Considering the medical model that is being followed in the country for dealing with disabilities, one would have expected a slightly better score in this aspect compared to other aspects. But it

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is not that surprising either, as it is a known fact that habilitation and rehabilitation services are almost non-existent in many parts of the country.

Laws and Policies

India's disability legislations do mention rehabilitation of persons with disabilities.

The Disability Act, 1995, has clauses for early detection and rehabilitation of disabilities. It also mentions research in the area of rehabilitation, including community based rehabilitation. Section 66 (2) states that rehabilitation shall be undertaken by non-governmental organisations with financial assistance from Government and local authorities. It also states that Governments and local authorities shall consult the non-governmental organisations working for the cause of persons with disabilities while formulating rehabilitation policies.

The **National Trust Act, 1999**, provides for need based services (through guardians and caregivers) to only persons with particular disabilities and not all disabilities. However, the terms, habilitation and rehabilitation, are not mentioned in the National Trust Act, 1999!

The **Rehabilitation Council of India (RCI), 1992, amended in 2000**, was enacted to regulate and monitor services given to persons with disability, standardise syllabi and to maintain a Central Rehabilitation Register of all qualified professionals and personnel working in the field of Rehabilitation and Special Education. The Act also prescribes punitive action against unqualified persons delivering services to persons with disability. It has been often felt by the disability sector that the punitive clause is restricting because while developing human resources for habilitation and rehabilitation is crucial. ensuring that disability knowledge spreads to all other professionals, doctors, teachers, architects, lawyers, etc. is also extremely important to promote inclusion.¹⁶⁹

The **Mental Health Act 1987**, which is quite archaic, allows for the institutionalisation of a person with mental illness. It talks more of treatment and less of rights. It mentions that "Mental Health Services" include, in addition to psychiatric hospitals and psychiatric nursing homes, observation wards, day-care centres, inpatient treatment in general hospitals, ambulatory treatment facilities and other facilities, convalescent homes and half-way-homes for mentally ill persons. It does not talk about how services need to reach the remote corners of the country or about the need for more trained manpower for rehabilitation of persons with mental illness. It also does not mention the need for early identification and treatment/support.

The provisions are quite weak and inadequate in The Disability Act and The National Trust Act and quite regressive in The Mental Health Act.

¹⁶⁹ Rehabilitation Council of India website

Progress and Concerns

1. Availability of Habilitation and Rehabilitation Services

There has not been any specific measure taken post ratification of CRPD to provide/strengthen habilitation and rehabilitation services in the country.

The approach that is being followed towards providing these services and the **infrastructure that is currently available are far from adequate**. The following paragraphs briefly state the current scenario and the concerns that exist.

The rehabilitation of people with disabilities is under the Ministry of Social Justice and Empowerment (MSJE) which, however, does not seem to include services for persons with mental illness. 'Medical treatment' of mental illness falls under the Ministry of Health. However, there seems to be no work being done in the area of rehabilitation (employment, education and social services). The Ministry of Health, in general, seems to be doing nothing much about rehabilitation of persons with any disability.

As per the Annual Report of Ministry of Social Justice and Empowerment, 2009-10, some of the main components of rehabilitation of persons with disabilities are:

- provision of assistive aids and appliances
- education
- vocational training
- assistance for employment
- training in or assistance for independent living

Under the MSJE, there are **eight autonomous National Institutes** for different types of disabilities. These are involved in early identification, therapy, counselling, outreach, vocational training, training of manpower, research, information dissemination, rehabilitation, etc. Then there are **Composite Regional Centres (CRCs)** whose function is to speed up the process of establishing, strengthening and upgrading rehabilitation services to reach every person with disability in the country. The centres also facilitate capacity building. At present, **there are six CRCs**. To facilitate the creation of infrastructure and capacity building at the district level for awareness generation, rehabilitation, training and guiding rehabilitation professionals, the Ministry, with the active support of the State Governments, is providing services to the persons with disabilities by way of setting up of **District Disability Rehabilitation Centres (DDRCs)** in all those districts of the country that do not have them. This initiative was launched in 1999-2000. At present, **199 DDRCs have been sanctioned, out of which, 179 DDRCs are functional and are providing rehabilitation services to persons with disabilities.**¹⁷⁰ There are 640 Districts in India (from Census 2011). The reach of DDRCs is only 28%, i.e. **72% of the Districts do not have DDRCs.**

¹⁷⁰ Page 130, Annual Report, Ministry of Social Justice and Empowerment, 2009-10.

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The Ministry of Social Justice and Empowerment also provides grants to NGOs under the Deendayal Rehabilitation Scheme. Under the Deendayal Disabled Rehabilitation Scheme (DDRS), in 2007-08, 687 NGOs with 1.9 lakh beneficiaries were assisted. In 2010-11, 530 NGOs with 2.3 lakh beneficiaries were assisted. **Instead of increasing the support to NGOs that are providing rehabilitation in various districts and villages of India, the support from the Government seems to be decreasing. The average number of beneficiaries benefiting from the programme is only about 1.5 lakhs per year. This is again substantially low compared to what the need is.**¹⁷¹

The National Trust has the following programmes/projects which is aimed at rehabilitation. '**Samarth**' is a programme under which there are **120 short and long term stay facilities** for adults and destitute children. Each facility caters to 30 residents at any time. Another is '**Aspiration**', which are Day Care Centres that work with infants of 0-6 years with developmental disabilities in order to make them ready for schooling. **At present, 79 Centres have been sanctioned, providing services to 1520 beneficiaries.** The National Trust is also supporting a few innovative projects leading to the development of new technologies and devices for betterment of persons with developmental disabilities.¹⁷² The initiatives of the National Trust may be providing the much needed services for people with developmental disabilities. **However, these services are highly inadequate and the reach is quite limited looking at the number of beneficiaries under each of its programmes.**

As mentioned before, the focus of mental health programmes of the Government are focused on diagnosis and cure and not on rehabilitation.

Based on the information gathered with regard to the number of beneficiaries assisted through various programmes, it is quite obvious that majority of persons with disabilities do not have access to rehabilitation services. One of the studies conducted by Handicap International indicated that **only about 15% of the people living in urban areas and 3% of the people living in rural areas can avail of rehabilitation services in India. The total coverage is only 5.7%!**¹⁷³

The Disability Act, 1995, provides for early detection of disabilities. However, the measures that are being taken to promote **early intervention** has not been adequate. The Ministry of Women & Child Development (MWCD) runs the **Integrated Child Development Services (ICDS) Scheme** that focuses on children below six years of age in order to lay a foundation for the proper psychological, physical and social development of the child, to reduce the incidence of mortality, malnutrition and school drop outs and to achieve effective coordination of policy & implementation among various departments to promote child development; etc. The Annual Report (2007-08) of the Ministry has stated that sensitisation programmes for ICDS functionaries and trainers on Early

¹⁷¹ Status paper, Working Paper on Empowerment of Persons with Disabilities for Formulation of XII Plan.

¹⁷² Page 147, Annual Report, Ministry of Social Justice and Empowerment, 2009-10.

¹⁷³ Rehabilitation Professionals in Public Health Systems - An Initiative to Reduce Vulnerabilities for Disadvantaged Communities by Satish Mishra, Handicap International.

Detection and Prevention of Disabilities were conducted.¹⁷⁴ **The data of children with disabilities under the programme is not captured and hence, it is not possible to measure the impact.**

One of the biggest issues in the provision of rehabilitation services in the country lies in its delivery mechanism! Apart from the setting up of National Institutes for different disabilities and about six CRCs, the entire delivery mechanism for rehabilitation services across the country is through NGOs. This has resulted in a very haphazard distribution of services in the country with NGOs in certain States/UTs being given more grants than others.

The **quality of services** provided by organisations is also highly inconsistent. The NGOs and DDRCs face a lot of constraints, particularly with respect to manpower, infrastructure, equipments, etc. DDRCs in many places are non functional. The ones that are functioning are facing a lot of issues with regard to resources. The salaries of the professionals given in the DDRC scheme are very low; funds from the Centre are not reaching on time and the funding is only for 3 years.

The District Disability Rehabilitation Centre (DDRC) at Sir Sayajirao General (SSG) Hospital has been treating over thousands of persons with disabilities annually for the past seven years. But with the irregular funding by the Central Government, the rehabilitation centre is now almost on the verge of getting closed. The centre, which should have at least ten working employees, is functioning with only five of them, who have not received their salary for the last eight months.

-Debarati Basu, 'DDRC on crutches as Central government forgets to send funds', Vadodary, Express India, 6th August, 2008.¹⁷⁵

There are no programmes of the Government for providing rehabilitation services below the District level. A few NGOs have Community Based Programmes and outreach. However, their reach is quite limited.

There are few **private practitioners** in the market today, particularly in the metropolitan cities. Their charges are quite exorbitant. The cost of travel, personal attendants, equipments, aids and assistive devices, materials for daily activities, diapers, catheters, etc. further adds to the expense. **There is no Scheme of the Government to subsidise these services/items or provide any disability allowance or insurance coverage to those requiring long term habilitation and rehabilitation.**

At many places, **the reference system**, from the primary health centre to the secondary and then to the tertiary level at the State capital hospital has worked to meet the needs of health of people. The doctor refers the patient depending on the seriousness of the medical condition of the person and the kind of intervention required. A similar system of intervention options at primary,

¹⁷⁴ Base line study on Health of Persons with Disabilities, NCPEDP, February, 2009.

¹⁷⁵ Accessed at <http://www.expressindia.com/latest-news/ddrc-on-crutches-as-central-government-forgets-to-send-funds/345302/> on May 13th 2011.

secondary and tertiary levels can work in rehabilitation. Most people come to the health centres for rehabilitation and therefore it could be linked to the health delivery system.

2. Rehabilitation Professionals

The reach and the quality of rehabilitation services are directly related to availability and the skills of people providing the services. According to the Rehabilitation Council of India (RCI), which regulates and monitors services given to persons with disabilities, the total number of registrations of professionals and personnel involved in rehabilitation is only 43,675 as on 31st March 2009! Only 6092 registrations have been added in a year. With over 100 million people with disabilities in the country, the numbers given here are terribly low. There would be some who are involved in rehabilitation and may not have registered with RCI but those numbers would not be very high.

RCI has also set up a dedicated satellite channel on disability which is the Education Satellite Channel 'NAVSHIKHAR'. More than 500 study centres/institutions have been connected through this station for the benefits of the students, trainees and parents of the persons with disabilities.¹⁷⁶

The availability of rehabilitation professionals for mental health is also low. According to a Study conducted by the National Human Rights Commission (NHRC) and the National Institute of Mental Health and Neuro Sciences (NIMHANS), the gap between the resources – human, material and financial needed on account of the growing demand for mental health services and the available resources is a major concern.¹⁷⁷

The Government has not taken any steps to make the rehabilitation profession attractive for youngsters to join. Many studies have indicated that the field of rehabilitation is less preferred for various reasons. Salaries are low; posts are few; and working conditions are difficult. With increased job opportunities and increased salaries in other sectors like Information Technology, hospitality etc. very few people take up rehabilitation as a career option. There is also greater burn out faced by professionals due to poor working conditions. Rehabilitation involves labour-intensive processes. This leads to rapid turnover of staff engaged in rehabilitation.

3. Appropriate, Affordable Aids and Assistive Devices and Technologies

There are hardly any assistive technologies which are manufactured in the country, except for some basic ones like the wheelchair, etc. Even these are not of very good quality. Hence, many persons with disabilities prefer (those who can afford) to use aids and assistive devices that are imported from other countries.

¹⁷⁶ Page 148, Annual Report, Ministry of Social Justice and Empowerment, 2009-10.

¹⁷⁷ Mental Health Care & Human Rights; National Human Rights Commission; and National Institute of Mental Health & Neuro Sciences; Editors: D Nagaraja; Pratima Murthy

One of the major manufacturers of assistive devices, set up in 1972 by the Government of India, is the Artificial Limbs Manufacturing Corporation (ALIMCO) which is a non-profit company. The Government has a scheme, Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances (ADIP), through which aids and appliances are distributed to people with disabilities. The Mid Term Report of XI Five Year Plan itself says that **“ALIMCO products are believed to be costly and also have low acceptability among users.** As such, there is an urgent need to enhance the production capacity of assistive devices that are affordable, culture-specific, and repairable within a 5 km distance. **Manufacturing of assistive devices in the private sector should also be promoted.”** The Report adds that about 2 lakh needy persons with disabilities are provided with assistive devices every year. **The procedures under the ADIP scheme need to be simplified so as to facilitate easy availability of the much-needed aids and appliances to persons with disabilities.** Rehabilitation professionals and persons with disabilities should be involved in designing appropriate and more viable aids and appliances. **There has been no progress in implementing the mandates of the XI Plan.**

4. Research in the Area of Rehabilitation

Research is crucial for development and provision of effective rehabilitation services. The initiatives undertaken in this area is quite limited.

There is a National Institute, Swami Vivekanand **National Institute for the Rehabilitation, Training and Research**¹⁷⁸ (SVNIRTAR) in Cuttack, Orissa. Its objective is training and research in the area of disability. According to its website, the completed Research Projects since its inception in 1984 are:

- Multipurpose Orthosis for paralysed children (Awarded the National Technology Award for the year 1993-1994.
- Use of synthetic materials in Prosthetic and Orthotic appliances.
- Low Cost Toilet Attachment to Wheel Chair for Rural Paraplegics.
- Tricycle-cum-standing frame for Children with Cerebral Palsy (5 to 12 years).
- Lawry Rotary attachment for paraplegics.

So, there are only five research projects completed in 27 years. The focus seems to be only on orthopaedic disability.

Media Lab Asia which has been promoted by Department of Information Technology, aims to bring the benefits of ICT to the common man. It has “empowerment of disabled” as one of its focus areas. However, based on the information given in the website, **only one project** - Shruti-Drishti (Text-to-Speech & Text-to-Braille) system integrated with Braille Embosser, Tactile Reader & Braille keyboard in 40 Girls/Co-Ed Blind Schools across the country has been undertaken.¹⁷⁹

¹⁷⁸ Accessed at <http://nirtar.nic.in/> on 26th October 2011.

¹⁷⁹ Accessed at <http://medialabasia.in/index.php/component/content/article/34-main-page/96-welcome-to-media-lab-asia> on 25th October 2011.

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All the other National Institutes and the Rehabilitation Council of India have research as one of their mandates. There is also the **Science and Technology Project in Mission Mode** which aims at the development of technologies that lead to availability of suitable devices of persons with disabilities. **However, no information could be found on the studies that they have undertaken in the Annual Report of the Ministry of Social Justice and Empowerment, 2009-10.**

The Department of Scientific and Industrial Research, under the Ministry of Science and Technology, has undertaken research to produce intelligent Prosthetic Devices such as a myoelectric arm with electrodes, a micro controlled spoon feeding robo system and a voice operated electronic hand.¹⁸⁰

The National Institute of Design (NID), the Indian Institutes of Technology (IITs) also take up research and development in the area of disability.

From the information gathered on the work undertaken, it appears that research and development in the field of disability is rather ad hoc, with no vision or direction. As a result, the impact of these researches has been negligible on the lives of persons with disabilities. There is very little fund available for it. The focus seems to be mainly on orthotics and prosthetics and in some cases on technologies for persons with visual impairment. Many innovations remain as prototypes with no marketing options to reach those who need these aids. There is hardly any research on other aspects like user surveys, needs, budget analyses, policy matters, disability audits, best practices in employment, education, etc. There also seems to be very little effort being made to disseminate the findings of research.

5. Access to Information Related to Rehabilitation

Some efforts seem to have been made by the Government in creating awareness or in disseminating information. Some examples are the Punarbhava website, National Trust's Help line or the Badhte Kadam Campaign. However, these initiatives are insufficient. **Most of the awareness campaigns on disability in the media focus on prevention.** Persons with disabilities and their families usually go from pillar to post for their various needs. Many a times, they do not even know what is available and where. Lack of information on rehabilitation and the possibilities that exist only reinforces the stereotypical attitude that persons with disabilities are dependent and/or a burden on society. Delay in interventions lead to secondary impairments. There are very few Indian websites that provide information on products, services and on understanding disabilities. India is a vast country. There is no systematic system to reach the Districts and Villages across India. Moreover, information in accessible formats is hardly available anywhere. **There is no specific system and budget for compiling information on rehabilitation services and no system and budget for disseminating it.** There should be campaigns to promote rehabilitation services and how people can benefit from these services.

¹⁸⁰ Paragraph 6.18.10, Pg 155, Annual Report of Ministry of Social Justice and Empowerment, 2009-10.

Recommendations

- 1) All disability laws need to be reviewed and amended in the light of CRPD to include comprehensive habilitation and rehabilitation in the area of health, education, and employment.
- 2) There needs to be coordination between the various relevant Ministries to ensure rehabilitation services reaches every village of the country.
- 3) Primary, secondary and tertiary level rehabilitation model should be linked to the health system. There will have to be posts/jobs for rehabilitation services for various disabilities in primary, secondary and tertiary level hospitals/health centres and in NGOs.
- 4) The Government's initiative to give grants to NGOs that provide rehabilitation needs to be reviewed to ensure that NGOs working in remote and left-out areas get financial support. The Government needs to enhance its support to NGOs.
- 5) The Government needs to promote cross-disability institutes as well as specialised institutions and support groups for specific impairments.
- 6) The Government needs to take steps to promote rehabilitation as a lucrative career option.
- 7) The Government needs to introduce schemes for home-based rehabilitation services.
- 8) The Government needs to conduct courses for personal attendants across the country (also in local language) and maintain their District-wise data that is easily available in all hospitals and NGOs.
- 9) The Government should introduce schemes to subsidise items for rehabilitation and provide disability allowance or insurance coverage to those requiring long term habilitation and rehabilitation.
- 10) The Government needs to review the curriculum of various medical, rehabilitation and paramedical professionals to ensure that it includes updated and current knowledge of rehabilitation techniques and is rights based.

Article 27: Work and Employment

The text of Article 27 in the CRPD is given below.

1. *States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realisation of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:*
 - a) *Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;*
 - b) *Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;*
 - c) *Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;*
 - d) *Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;*
 - e) *Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;*
 - f) *Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;*
 - g) *Employ persons with disabilities in the public sector;*
 - h) *Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;*
 - i) *Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;*
 - j) *Promote the acquisition by persons with disabilities of work experience in the open labour market;*
 - k) *Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.*
2. *States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.*

SURVEY FINDINGS

- The findings with respect to the measures taken by the Government in promoting employment of persons with disabilities in the various sectors i.e. public, private, self employment and employment of persons with high support needs, is given below.

Public Sector

Rating	Percentage of Respondents
Extremely dissatisfied	44%
Dissatisfied	40%
Satisfied	14%
Extremely satisfied	2%
Do not know much about the issue	0%

Private Sector

Rating	Percentage of Respondents
Extremely dissatisfied	68%
Dissatisfied	25%
Satisfied	5%
Extremely satisfied	1%
Do not know much about the issue	1%

Self Employment

Rating	Percentage of Respondents
Extremely dissatisfied	45%
Dissatisfied	41%
Satisfied	11%
Extremely satisfied	2%
Do not know much about the issue	0%

Promotion of Employment of Persons with High Support Needs

Rating	Percentage of Respondents
Extremely dissatisfied	67%
Dissatisfied	23%
Satisfied	6%
Extremely satisfied	2%
Do not know much about the issue	2%

The findings show that the satisfaction levels vis-a-vis Public Sector employment is 16%, then comes Self Employment with 13% and the Private Sector employment is the lowest with just 6%. There is comparatively greater satisfaction with respect to Public Sector employment. The reason could be that there are legislative mandates, including reservations for persons with

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disabilities in Government and Public Sector jobs. However, there are no such mandates for the Private Sector. Hence, the jobs in the Private Sector continue to elude people with disabilities. There are also some Government and NGO initiatives for promoting Self Employment. However, those initiatives have not been very effective and their reach has been limited.

The dissatisfaction level of 90% in Employment for people with high support needs indicates that there are hardly any opportunities for them. Persons with high support needs were never considered part of labour force in the country. There are no focused programmes to promote their employment.

The dissatisfaction levels across all the sectors is quite high - Public Sector (84%), Private Sector (93%) and Self Employment (86%). This indicates that measures taken have been far from adequate. There is a very long way to go to achieve economic empowerment of persons with disabilities in the country.

Laws and policies

India has certain legislative measures that recognise some rights of persons with disabilities in the area of employment. However, there are several issues in these legislations which continue to restrict the rights of persons with disabilities.

Article 15 of the **Constitution of India** prohibits discrimination on grounds of religion, race, caste, sex or place of birth and Article 16 states equality of opportunity in matters related to public employment. However, disability has not been explicitly mentioned. As a result, specific issues related to disability equality have not been taken into account when the foundations for development were being laid in the country and disability continues to get left out in the programmes and policies for minorities/weaker/marginalised sections.

In 1977, the Government of India, through a **Government Order**, mandated a 3% reservation in C and D categories (low ranking - support staff, clerical, etc.) of Government and Public Sector jobs. The reservation was for people with visual, hearing and locomotor disabilities. The assumption was that people with disabilities cannot work in high level jobs. Another assumption was that people with other disabilities cannot work at all!

Later, with the passage of **The Disability Act, 1995**, the reservation was extended to A and B (higher ranking - officers, administrative/management etc.) category jobs in the Government and Public Sector jobs. Though the assumption that people with disabilities can only work in low ranking jobs had seemingly broken, but the clause that people with disabilities can work only in certain 'identified' jobs remains till date, as a result of which, people with disabilities are considered "unsuitable" for many jobs, which is mostly arbitrary. Further, the assumption that people with other disabilities cannot work continued! The Disability Act has about seven impairments included in the definition of disability, however, the reservation in jobs is only for the three categories - visual, hearing and locomotor disabilities.

In the Act, 3% reservation has been provided in all poverty alleviation schemes of the Government. However, it does not provide for accessibility and reasonable accommodation. Under the Chapter on 'Affirmative Action', it says that preferential allotment of land at concessional rate should be given to persons with disabilities for setting up business and establishment of factories. The chapter on 'Non-Discrimination' clearly mentions non-discrimination in Government employment to a person who acquires disability during service. The Act also provides for an incentive scheme to be formulated for employers in the Private and Public Sector to ensure that five percent of the workforce is composed of persons with disabilities. There is no other mention of Private Sector in the entire Act with respect to non-discrimination or affirmative action. (Clauses related to Employment in The Disability Act 1995 are Clauses 32 - 38, 40, 41, 43 (b, f) and 47).

The National Trust Act, 1999, which is specifically for people with developmental disabilities also had no provisions for employment!

The **Mahatma Gandhi National Rural Employment Guarantee Act (NREGA)** was enacted in 2005, which enhances livelihood security by guaranteeing 100 days of waged employment in a financial year to a rural household. A clear provision has been made in NREGA to ensure people with disabilities are not excluded. According to the NREGA Operational Guidelines 2008, "If a rural disabled person applies for work, work suitable to his/her ability and qualification will have to be given. This may also be in the form of services that are identified as integral to the programme."¹⁸¹

The various **Labour laws** in general do not include disability issues. For example, The All India Services Act, 1951; The Apprentices Act, 1961; Beedi and Cigar Workers (Conditions of Employment) Act, 1966; Employment Exchanges (Compulsory Notification of Vacancies) Act, 1959; Industrial Disputes Act, etc. need to be reviewed in the light of the CRPD.¹⁸² The Unorganised Workers' Social Security Act, 2008, also does not have provisions for persons with disabilities.

Progress and Concerns

There are **some legislative measures to recognise the rights of persons with disabilities, particularly in Government employment. However, the Government's effort in fulfilling these mandates leaves much to be desired.** Moreover, India's focus has not been much on mainstreaming disability in national programmes on skill development and livelihoods. Separate infrastructure like Special Employment Exchanges, Vocational Rehabilitation Centres (VRCs), etc. have been set up for promoting employment of people with disabilities, which have not been very effective. Where there have been legislative mandates for mainstreaming, like 3% reservation in poverty

¹⁸¹ NREGA Operational Guidelines 2008, 3rd Edition,, page 25, Section 5.5.10, accessed at <http://indiatoday.intoday.in/site/story/rml-hospital-head-holds-out-little-hope-for-thalassemic-ias-aspirant-sukhsohit-singh/1/141823.html>25 on 25th October 2011.

¹⁸² 'Harmonizing Laws with the UNCRPD', Edited by Dr. Amita Dhanda and Rajive Raturi, Human Rights Law Network, The Deaf Way Foundation, National Association of the Deaf, May, 2010.

alleviation programmes, etc., **there are no supportive measures, like 3% allocation of budget, reasonable accommodation, accessibility and manpower. Hence, these mandates only remain on paper.**

1. Public Sector Employment

There is 3% reservation in the public and Government Sectors. The Government has set up 42 Special Employment Exchanges and 38 special cells in regular employment exchanges across the country.

The **number of placements of people with disabilities by Employment Exchanges has declined** from 4,200 in 1999 to 3,700 in 2000, whereas the general employment has increased!¹⁸³

There **hasn't been any placement of persons with disabilities into jobs in 12 States and Union Territories** and less than 10 placements in 20 States and Union Territories in the year 2008.¹⁸⁴

While thousands of persons with disabilities are waiting to get a job, there is a **huge backlog of vacancies** in the Government sector. There are **6,611 vacancies unfilled**, based on the information received from 65 Ministries/Departments of the backlog vacancies for persons with disabilities, as on 15th November, 2009.¹⁸⁵ Similar is the situation with respect to backlog in all the States and Union Territories.

Almost 90% of the jobs remain 'unidentified' for persons with disabilities. Hence, many qualified people with disabilities are denied jobs in the Government due to this discriminatory policy. As per the data available (2003), only 10.2% of all posts in Ministries/Departments and Public Establishments have been identified as suitable for persons with disabilities.¹⁸⁶ According to The Disability Act, 1995, the review of the list had to be undertaken at least once every 3 years. However the Committee has met only twice in the last 15 years, that is, in 2001 and 2007.¹⁸⁷

"I have been trying to have existing legal provisions relating to reservation in employment and non-handicapping environment implemented with special reference to vacancies in universities/colleges/schools in Maharashtra. Have

¹⁸³ Page 44, Performance of Employment/Special Employment Exchanges for Physically Handicapped 1999-2008, Employment Exchange Statistics, 2010, Ministry of Labour and Employment.

¹⁸⁴ Annexure 3, State wise placement of physically handicapped during the last five years 2004-2008; Fax sent to NCPEDP by Bachchoo Sharma, Research Officer, Directorate General of Employment and Training (DGE&T), dated 20th June 2011.

¹⁸⁵ The total number of backlog vacancies identified was 7,628 and the number of backlog vacancies filled was only 1,017 as on 15.11.2010. (Page 28, Status Paper, Working Group on Empowerment of Persons with Disabilities for formulation of XII Plan 2012 -2017)

¹⁸⁶ People with Disabilities in India: From Commitments to Outcomes, World Bank, July 2009.

¹⁸⁷ Reply to an RTI filed by NCPEDP dated 10th June 2011.

met with limited success. In reply to RTI queries, Nagpur University has affirmed there is no reservation in Class I teaching jobs, and single or few posts in each college can not be brought within purview of reservation. Fight is on, and I hope for some positive results.”
-Respondent to the CRPD Questionnaire.

There is 3% reservation in promotions in the Government. However, people with disabilities face a lot of discrimination and road blocks in career advancement. Many a times, the promotion is denied because the next level of job is not identified. There have been some favourable judgments in this regard.

Another important aspect in ensuring non-discrimination in employment is to ensure provision for reasonable accommodation, as given in Article 27 (1) (i). **The Government has not made any policy or system to provide reasonable accommodation for persons with disabilities.** Recently, there was a judgment from the Bombay High Court, which upheld the Government’s obligation to provide assistive technologies as reasonable accommodation for employees with disabilities working with the Government (Articles 4 and 27 of CRPD).¹⁸⁸

There are a lot of jobs that are provided on contract basis in the Government. **Though all contract employees face issues of insecurity with no/little benefits and perks, it becomes more difficult for people with disabilities.**

“I was not given leave for my surgery. Such leave are given only to a person who is a permanent employee. My colleague with disability, working on Contract, was refused maternity leave.”
-Employee with disability on contractual employment with the Government

Article 27 (c) of the CRPD mandates Governments to take steps to ensure **persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others. No steps have been taken by the Government in this regard.**

“Trade Unions have not raised the disability related issues because employees with disability are not a vote bank. Employees with disabilities are not included in the decision making process and their voices are not heard by the trade union leaders and the appropriate Government authorities. There is no recognised Union/Association/Civil society/forum for the employees with disabilities in the Government establishment, from where they can raise their voice. The Northern Railways Employee Welfare Association, which is an Union of disabled employees working in Indian Railways, has not been recognised by the Government.”
-Mukesh Gupta, Northern Railways Employee Welfare Association.

¹⁸⁸ Bombay High Court Gadgets Matter; WP 3294 of 2010 Nileema Anant Surve V. State of Maharashtra & ors.

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Medical tests are conducted before recruitment for many jobs in the Public and Private Sectors. Medical doctors declare “fit” and “unfit” based on certain broad parameters. Most of the time, these decisions are quite arbitrary and are not based on actual requirements for the job.

Recently, in 2011, Sukhsohit Singh, with Thalassaemia, passed the Civil Services examination and interview. His dreams were shattered when the medical board declared him unfit to join any branch of the civil services. The medical superintendent of RML hospital said that someone with a 'pre-existing medical condition' couldn't be given admission into the civil services. He quoted government gazette guidelines to emphasise the diseases that require lifelong treatment could pose financial burden to government, which is not feasible.¹⁸⁹

He fought for justice and got back his job but many others may be succumbing to this archaic and discriminatory medical policy and accepting it.

2. Private Sector Employment

Jobs in the private sector have grown substantially in the last two decades or so post liberalisation. In the absence of any firm legislation/policy there has been hardly any initiative on the part of the Private Sector towards employing persons with disabilities. The CRPD, **Article 4 (1) mandates States to “take all appropriate measures to eliminate discrimination on the basis of disability by any person, organisation or private enterprise”.** **There has been no action on the part of the State to implement this Article.**

There are several industry associations and bodies like the Confederation of Indian Industry (CII), Federation of Indian Chamber of Commerce and Industry (FICCI), Associated Chambers of Commerce & Industry of India (ASSOCHAM), PHD Chamber of Commerce & Industry (PHDCCI), National Association of Software and Services Companies (NASSCOM) etc. These chambers/associations, though they have included disability on their agenda as a result of pressure from the civil society, have not been able to influence their member companies to employ persons with disabilities or to adopt any policy on non discrimination of persons with disabilities.

According to a Survey conducted by NCPEDP in 1999 on “top 100 companies”, the average **employment rate of people with disabilities in private and multinational companies were found to be 0.28% and 0.05% respectively.** There has not been any credible survey after this. Based on observations of the current scenario, it would not be totally wrong to assume that this situation would not have changed much.

To fulfil the incentives mandate of The Disability Act, 1995 in the Union Budget 2007-08, a Central Sector scheme, of providing one lakh jobs per annum to

¹⁸⁹ Indiatoday Website, accessed at <http://indiatoday.intoday.in/site/story/rml-hospital-head-holds-out-little-hope-for-thalassemic-ias-aspirant-sukhsohit-singh/1/141823.html> on 10th December 2011.

persons with disabilities with a proposed outlay of Rs. 1800 crore during the XI Five Year Plan, was announced. Under the scheme, the Government makes the payment of the employer's contribution to the Employees Provident Fund and Employees State Insurance for the first three years as an incentive in return for employment of persons with disabilities with monthly wage up to Rs. 25,000/- per month. However, these incentives have not resulted in increased employment of people with disabilities in the private sector. Based on the response received for an RTI filed by NCPEDP, the number of beneficiaries under the scheme by Employees State Insurance Corporation was only 457 as on 28th February, 2011, and by Employee Provident Fund Organisation was merely 186 as on 30th December 2010.

In absence of any policies, **the private sector blatantly discriminates against person with disabilities.**

A top Indian conglomerate abruptly terminated contact with Ankit Jindal, a visually impaired person, after he had managed to clear several rounds of the selection process, during campus recruitment of Master of Business Administration, Faculty of Management Studies.
-As shared with DEOC

3. Self Employment

The most important initiative in promoting self employment for persons with disabilities was the setting up of the **National Handicapped Finance and Development Corporation (NHFDC)** by the Government in 1997. It provides loans to persons with disabilities for setting up their business. However, people with disabilities face a lot of difficulty in accessing these loans. **The procedures are complicated. High collaterals and Government guarantors are required which become very difficult for many people with disabilities. Moreover, the State channelising agencies through which loans are to be disbursed are defunct in many States.** The data given below highlights the sorry state of affairs vis-à-vis NHFDC.

- Only **54,645 persons with disabilities have been provided loans** since its inception.¹⁹⁰
- The regional and disability distribution vis-à-vis the beneficiaries has been quite uneven. For instance, in the year 2009-10, out of 6,093 beneficiaries, **72% were from Tamil Nadu, Gujarat, Haryana and Andhra Pradesh.**¹⁹¹
- About **89% of the beneficiaries during the year 2009-10 were people with orthopaedic impairment and 'zero' people with mental illness.**¹⁹²

The Government has been focusing on **small and micro enterprises and entrepreneurship development** in the last few Five Year Plans. Several schemes have been announced in this regard. There are credit support schemes

¹⁹⁰ 'Annexure II, Scheme wise number of beneficiaries assisted by NHFDC since inception', given to NCPEDP by NHFDC on 21st June 2011.

¹⁹¹ Page 26, State wise distribution of loan; Thirteenth Annual Report, NHFDC, 2009-10.

¹⁹² Page 6, Disability wise distribution of Loans, Thirteenth Annual Report, NHFDC, 2009-10.

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which provide loans to people with no collaterals and the Government takes almost full guarantee for these loans. There are also entrepreneurship development programmes. **These programmes do not have specific focus on disability. As a result, most of these programmes remain unavailable to persons with disabilities.**

In the Swarna Jayanti Shahari Rozgar Yojana, which is a poverty alleviation programme focusing on the urban poor, **there is no disability reservation in 'Urban Wage Employment Programme'**. In the other programmes, namely, Urban Self Employment Programme (USEP), Urban Women Self-help Programme (UWSP) and Skill Training for Employment Promotion amongst Urban Poor (STEPUP), the number of beneficiaries with disabilities, cumulative since 1997 to March 2011, was only 26,909 (2.28%), 4836 (0.92%) and 24,341 (1.16%) under the three programmes respectively.¹⁹³

4. Rural Employment

Though the **Mahatma Gandhi National Rural Employment Guarantee Act (NREGA)** had included disability in the Operational Guidelines, the implementation of the scheme for people with disabilities leaves a lot to be desired. In the year 2011-12, though **999,211 persons with disabilities were registered only 16,436 were given work** under the scheme, creating 121,121 person days!¹⁹⁴ **The average person-days of work comes to only 7.37 days per person, whereas it has to be 100 days** of work as per the mandate of the Scheme! These are outright violation of the employment guarantee scheme.

The Government has a scheme for self employment for the rural areas. The guidelines of **Swarnjayanti Gram Swarozgar Yojana (SGSY)** stipulate that persons with disabilities will account for at least 3% of the total Swarozgaris. The groups formed should ideally be disability-specific wherever possible, however, in case sufficient number of people for formation of disability-specific groups are not available, a group may comprise persons with diverse disabilities or a group may comprise both disabled and non-disabled persons below poverty line. Total number of Swarozgaris assisted in this scheme during the year 2010-11 (upto December, 2010) were 1281221 out of which number of SHGs and Individual Swarozgaris achievement for persons with disabilities was 23718 (1.85%).¹⁹⁵ **The percentage is much below the 3% mandate.**

5. Unorganised Sector

More than 90% of the workforce in the country is in the unorganised sector. There is no specific data available on number of people with disabilities working in the unorganised sector. The Government had enacted 'The Unorganised

¹⁹³ Brief Note, Meeting of Empowerment of Persons with Disabilities and Social Welfare Groups Schedules for 15th July, 2011.

¹⁹⁴ Status Report, Working Group on Empowerment of Persons with Disabilities for formulation of XII Plan.

¹⁹⁵ Page 87, Annual Report, Ministry of Rural Development, 2010-11.

Workers Social Security Act' in 2008. There are quite a few provisions for providing security for people employed in the unorganised sector. **However, there are no specific provisions for people with disabilities. Moreover, there is very little awareness about the provisions under the scheme.**

"I work in a local beauty parlour. I am not aware of any such scheme".
-A deaf beautician.

There are many **vendors with disabilities who sell petty things at railway stations and other places for their living**. They are routinely harassed by police for '*hafta*' (weekly bribe). Many have taken to begging as they could not face the harassment.

"Kriparam from Gahal village of Harda district, Madhya Pradesh was a person with visual impairment, married and with a 6 months old daughter. His wife is also a person with disability and the entire family depended on the income of Kriparam who was selling books at the Harda railway station. He was killed by Railway Protection Force (RPF) staff of Harda station on 22nd September 2011. Few RPF staff had unnecessarily got into an argument with him and harassed him. He was arrested by RPF staff without any reasons at 10.00 p.m. from his house. He was treated with inhuman and degrading treatment. He was beaten up in the night badly and took him to hospital in the mid night where doctor declared him dead. Sir, this is not the first incident of inhuman and brutal act of railway administration but a routine activity. There were several incidents of this nature, which have been reported to the concerned authorities but there was no response."

-E-Mail on 28th September 2011 to Yahoo Group by Dr. Victor John Cordeiro President, RED-India.

6. Skill Development

Closely related to employment is skill development. Article 27 (1) (d) of the CRPD mentions that the Government should "enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training".

In the XI Five Year Plan (2007-12), an ambitious **Skill Development Mission** was initiated by the Government with a target of creating 500 million skilled workers by 2022. It also envisioned an increase in the capacity of the Government for skill development to 15 million persons annually. Section 3.7 of the National Policy on Skill Development, not only has 3% reservation but also mentions accessibility and reasonable accommodation for persons with disability.¹⁹⁶ However, four years since its launch, there has been no visible benefit from these programmes for people with disabilities.

Vocational Rehabilitation Centres (VRCs) for persons with disabilities, which

¹⁹⁶ Page 39, National Policy on Skill Development, Ministry of Labour and Employment

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are just 20 in number, have not been able to scale up to meet the industry needs. According to the report received from the Ministry of Labour and Employment, **only 1077 persons with disability were trained** in VRCs and 4696 persons with disabilities trained outside VRCs during 2010-11. 3675 were placed in 'wage paid' and 3211 were placed in self employment.¹⁹⁷ **Number of VRCs was to be doubled in the XI Five Year Plan. Not much progress has been made in this regard.**

Under the **Deendayal Disabled Rehabilitation Scheme (DDRS)**, there is a separate component for Vocational Training Centres and also for Sheltered Workshops. Several NGOs across the country are receiving grants under this programme. DDRS was revised in April 2009. 14 new courses like computer applications and programming, web designing and internet management, mobile repairing, etc. were added in addition to the trainings in 152 trades, which were already being provided by the Vocational Training Centres. **However, the number of people trained and the number of people who became self reliant due to these programmes was not available.**

A lot of private initiatives have come up recently for skill development under the Government's **Public-Private Partnership (PPP) programme**. Most of these programmes **are not inclusive for people with disabilities**. The various Chambers (CII, FICCI, NASSCOM) and many Corporates are conducting various training and affirmative action programmes targeting persons from the lower socio-economic background but are not including people with disabilities.

7. Employment of People with High Support Needs

People with more "severe impairment" or high support needs are left out in the job market whether in the Public or in the Private Sector. For instance, a person who is deaf loses out to a person who is hard of hearing, because employer assumes that it is easier to accommodate a hard of hearing person. Similarly, a blind person loses out to a person with low vision and person who is seen as more "severely disabled" against "mildly disabled person". The jobs continue to be given or not given based on disability and not the skills or qualification.

People with multiple disabilities, deaf-blindness, intellectual impairment, autism, mental impairment, who may need or "seem to need" more support/accommodation lose out to people who need less or no accommodation. The CRPD clearly mentions that non provision of reasonable accommodation is discrimination. There is no reasonable accommodation policy in the country. There is also no support to employers to encourage employment of persons with high support needs. There is also no concept of supported or assisted employment for people with intellectual impairment in the country.

¹⁹⁷ Booklet, Vocational Rehabilitation Centres for the Handicapped, Ministry of Labour & Employment; as on 1-10-2009

8. Forced Labour/Slavery

Article 27 (2) mandates that Governments ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour. **There have been no measures taken in this regard to implement this provision.** There may be children with disabilities working in the unorganised sector. There may be persons with disabilities who may be in bonded labour. There are certainly a lot of persons with disabilities who are beggars who can be seen begging in the streets, crossings and near places of worship in cities. There has been no proactive effort on the part of the Government to address their needs.

Recommendations

- 1) Review and modify Disability legislations and policies in the light of the CRPD. For example:
 - a) Disability legalisation to be amended to include employment mandates for all persons with disabilities.
 - b) A clear non-discrimination clause (including reasonable accommodation) to be added in all matters of employment.
 - c) Specific mandate for private sector, including NGOs, educational institutions for ensuring non-discrimination.
 - d) People with disabilities should have a choice to apply for jobs based on their interests and skills rather than their disabilities. They should be given the opportunity to demonstrate their ability to perform the job with or without accommodation.
- 2) Review and modify all relevant employment laws and policies in the light of CRPD.
- 3) Include persons with disabilities in various committees, policy-making bodies, forums, cells, Unions related to employment of persons with disabilities.
- 4) Have a Disability Audit of all existing schemes to identify gaps in implementation and ensure that the barriers are plugged.
- 5) Disability Cell in all relevant Ministries to ensure implementation and monitoring.
- 6) Redress mechanism to address issues of discrimination and harassment in the public and private sector.
- 7) More effective Incentives Policy for the Private Sector.
- 8) Specific schemes for promoting livelihood for persons with disabilities who are marginalised within the disability sector, including those with high support needs.
- 9) Sensitisation and awareness programmes for employers.
- 10) Inclusion of people with disabilities in all Skill Training and affirmative action programmes, including those conducted by the private sector.
- 11) Government to promote Research in the area of employment/livelihood.
- 12) Government to promote information dissemination. One of the ways could be to set up a National Portal on employment of persons with disabilities.
- 13) Inclusion of people with disabilities in Trade Unions not just as members but also as decision makers.

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- 14) Inclusion and specific provisions for persons with disabilities working in the unorganised sector, including providing safety and security to vendors with disabilities.
- 15) Focused programme for beggars with disability to provide rehabilitation.
- 16) Last but not the least, all related issues like accessibility, assistive devices, education, health, transport, hostels, etc. have to be addressed to ensure equal opportunities for persons with disabilities.

Article 28: Adequate Standard of Living and Social Protection

The text of Article 28 in the CRPD is given below.

1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.
2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:
 - a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;
 - b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;
 - c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;
 - d) To ensure access by persons with disabilities to public housing programmes;
 - e) To ensure equal access by persons with disabilities to retirement benefits and programmes.

Survey Findings

1. The findings with respect to the efforts made by the government to ensure that persons with disabilities have access to adequate standard of living and social protection are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	61%
Dissatisfied	29%
Satisfied	10%
Extremely satisfied	0%
Do not know much about the issue	0%

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While as many as 90% of the respondents were dissatisfied with the Government's efforts to ensure the right of persons with disabilities to an adequate standard of living for themselves and their families, 10% were satisfied with it. There is 3% reservation in poverty alleviation schemes and disability pension is provided in various States. However, these measures have benefited only a few people. These measures are not only highly inadequate but there are also several challenges in accessing these schemes. The inequality of income and opportunities has been increasing and majority of people with disabilities are among the poorest of the poor in the country, both in rural and in urban areas.

Laws and Policies

According to the **Constitution of India**, matters relating to Social Security are listed in the Directive Principles of State Policy and in the Concurrent List. According to Article 41 in the Directive Principles, "The State shall, within the limits of its economic capacity and development, make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement, and in other cases of undeserved want." In addition, the following social security issues are mentioned in the Concurrent List (List III in the Seventh Schedule of the Constitution of India) which are as follows:

- Item No. 23: Social Security and insurance, employment and unemployment and
- Item No. 24: Welfare of Labour including conditions of work, provident funds, employers' liability, workmen's compensation, invalidity and old age pension and maternity benefits.

The Disability Act, 1995, has Chapter XIII on Social Security. The relevant clauses are given below.

- Clause 67 mandates the Government to frame an insurance scheme for the benefit of its employees with disabilities.
- Clause 68 provides for unemployment allowance to persons with disabilities registered with the Special Employment Exchange for more than two years and who could not be placed in any gainful occupation.
- Clause 40 provides for reservation of not less than three per cent in all poverty alleviation schemes for the benefit of persons with disabilities.

The National Trust Act, 1999, provides for measures for the care and protection of persons with disabilities in the event of death of their parent or guardian.

The Mental Health Act, 1987, does not mention anything specific about Social Security.

Some of the **other laws** that are related to social security in India are given below.¹⁹⁸

- Employees' State Insurance Act, 1948.
- Workmen's Compensation Act, 1923.
- Employees' Provident Fund and Miscellaneous Provisions Act, 1952.
- Maternity Benefit Act, 196.
- Payment of Gratuity Act, 1972.
- National Rural Employment Guarantee Act, 2005.
- Unorganised Sector Workers' Social Security Act, 2008.
- Domestic Workers (Registration, social security and welfare) Act, 2008.

These have to be reviewed and amended to ensure that they are in line with the CRPD.

Progress and Concerns

1. Number of People with Disabilities Below Poverty Line (BPL)

Poverty and disability are correlated. Though there is no exact count of number of people with disabilities below poverty line, we can assume that their number would be large. Among poor people, persons with disabilities would be the poorest of the poor.

The social security schemes in India mainly focus on families falling below the poverty line. Those who are not counted under the BPL are left out from most of the poverty alleviation schemes.

The **BPL Census** does not appropriately include persons with disabilities. Out of the seven deprivation indicators in the calculation of families under BPL, the one that relates to disability, says that "**Households with at least one disabled member and no able bodied adult would be considered as a BPL household.**" **The disability sector feels that such a criteria would exclude a lot of deserving people with disabilities.** For example, family having one or two children with disability with one non-disabled adult (parent), which could really be very poor and deserve the food security benefits for its survival, will be excluded.

2. Access to Food

Families below poverty line are provided food items at a highly subsidized cost through the Public Distribution System. The Public Distribution System (PDS) is an Indian **food security** system. Established by the Government of India under Ministry of Consumer Affairs, Food, and Public Distribution and managed jointly with State Governments in India, it distributes subsidised food and non-food items to India's poor. The Department of Food and Public Distribution runs the

¹⁹⁸Social Security Legislation in India; Palak Lotiya, accessed at <http://www.paycheck.in/main/work-and-pay/paycheck-articles-archives/social-security-legislations-in-india> on 29th November, 2011.

'Antyodaya Anna Yojana' (AAY) since 2000 for one crore poorest of the poor families. Foodgrains are also allocated under other welfare schemes like those listed below.

- Mid-Day Meal Scheme.
- Wheat Based Nutrition Programme
- Supply of Foodgrains to Hostels/ Welfare Institutions (5% of BPL allocation).
- Supply of Foodgrains for SC/ST/OBC Hostels.
- Annapurna Scheme.
- Nutritional Programme for Adolescent Girls (NPAG).
- Emergency Feeding Programme (EFP). This is a food-based intervention targeted for old, infirm and destitute persons belonging to BPL households to provide them food security in their distress conditions.
- Village Grain Banks Scheme: The grain banks are set up in food scarce areas like the drought prone areas, the hot and cold desert areas, tribal areas and the inaccessible hilly areas which remain cut off because of natural calamities like floods etc. Village Panchayats/Gram Sabhas, Self-Help Groups, NGOs etc. identified by the State Government are eligible for running the Grain Banks.

People with disabilities are often unable to access these food security programmes for various reasons. They may not be included in the BPL category or children with disabilities may not be going to schools to access the Mid-Day meal programme. The Nutritional programmes for women and children may not be reaching those with disabilities due to lack of any proactive measures for ensuring their inclusion or coverage. Most people with disabilities remain unaware of these programmes. Accessing these provisions becomes even more difficult for persons with disabilities who belong to, say, a "lower" caste or who have multiple disability or who do not have another family member to go out and get these provisions or those with more than one person with disability in the family.

3. Right to Clothing

The Government does not seem to have any programme to cover adequate clothing for persons living in poverty and those with disabilities.

Persons with disabilities, especially those who are homeless, living on the streets of cities, do not have access to adequate clothing. They also may not have a place to keep their extra set of clothing. Extreme changes in weather raise the need for woollens and quilt which are not available for those living on streets, especially for men, women, children and elderly persons with disabilities. Some NGOs make an effort to provide clothing, but their reach is very limited. Persons with disabilities often do not get to know if there is any place where they can get appropriate clothing. Similar is the condition of other people living in poverty, be it in rural or in urban slums.

Many persons with disabilities living in institutions are also not provided adequate clothing. There have been many reports which have mentioned that people with disabilities, particularly women, were not well covered.

4. Right to Shelter

Access to shelter is an important aspect for leading a life with protection, safety, security and dignity. Land prices are skyrocketing. Land/house has become unaffordable to most people in the country. **For people with disabilities whose earning and saving capacities are lower than others, it becomes even more difficult to purchase or rent a house.** There are also a higher number of people with disabilities below the poverty line and homeless people. There initiatives taken on the part of the Government does not adequately address the magnitude of the problem that exists.

There is reservation for persons with disabilities in the Government housing schemes. Housing is a State subject and the implementation varies from State to State. Some States are providing 3% reservation for persons with disabilities, some are providing 1% and some are providing none. Some States provide reservation to people with only certain disabilities. There have been court cases to implement the scheme by aware citizens and have received favourable orders.

The Ministry of Rural Development started implementing its major housing scheme of **Indira Awaas Yojana** (IAY) as an independent scheme from 1 January 1996. The role of the State Government is confined to mere facilitating use of local, low cost, environment-friendly, and disaster resistant technology and also in encouraging construction of sanitary latrine and smokeless *chulha*. There is no prescribed design or technology and no contractors are involved. Funds are released in instalments directly to the beneficiaries and there is no credit portion as part of the assistance which enable timely release of funds. There is 3% reservation for persons with disabilities under the scheme. **Only beneficiaries who have house-sites are selected and thus, the very poor who do not have a plot of land are kept out of the purview of the scheme. This is a serious problem, since these are the people who are the most vulnerable.**¹⁹⁹

The Annual Report of Ministry of Rural Development states that the total number of Dwelling Units completed under IAY during the period 2010-11 (upto December 2010) was 26,86,117 out of which **33,118 (1.23%) houses were allotted in the name of persons with disabilities. This is way below the 3% which is mandated by the law.**

There is increased migration and the slums are growing in the cities. A very high number of people live in slums and squatter settlements (estimated at 75.2 million in 2001), in inhuman conditions that deny them dignity, shelter, security, and the right to basic civic amenities or social services. They live in an

¹⁹⁹ Eleventh Five Year Plan.

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environment in which crime, ill-health and disease frequently raise demands that draw them deeper into vulnerability and poverty.²⁰⁰

The Government has initiated the **Rajiv Awaas Yojana (RAY)** which aims at providing support to States that are willing to provide property rights to slum dwellers. The proposal of the Scheme has been submitted for consideration to the Cabinet Committee on Economic Affairs as on 10th February 2011. In the mean time, the preparatory phase of RAY has already commenced and the States are being assisted to draw up their Slum-free Plans of Action...Under the Scheme, a sum of Rs. 60 crore has been released to 20 States for preparing Slum free City Plans.²⁰¹ **Nothing specific has been mentioned about disability in the Scheme.**

The National Trust has a scheme **GHARAUNDA** (Group Home and Rehabilitation Activities Under National Trust Act for Disabled Adults). The objectives are to encourage assisted living with independence and dignity; to facilitate establishment of requisite infrastructure for the assured care system throughout the country and to provide the care services at an affordable price on a sustainable basis. The scheme is, at present, sanctioned to 7 places.²⁰²

Another Scheme of National Trust is '**Samarth**', a programme under which there are 120 short and long term stay facilities for adults and destitute children.

The **Night Shelters** and the **public toilets** are also inaccessible to most people with disabilities. People with disabilities are **sometimes harassed by the staff manning these places**. There is no access to clean drinking **water**, or even a place to take a bath or wash clothes. Infants, children, women and elderly people with disabilities find it extremely difficult. **Police also harasses people and asks for bribes for allowing them to sell/beg on the streets. There are no schemes and no protection from exploitation and abuse.**

Some **NGOs** try to provide temporary shelters during extreme weather conditions and during natural calamities. **Access to these shelters, their toilets and water for persons with disabilities is however, not taken into consideration while making them.** Some NGOs also run homes for homeless people. Some of them get a grant from the Government. In India, persons with disabilities many a times also get food, clothing and shelter at places of worship but there are reports that some temples do not allow persons with disabilities and hence this option may not be available to them.

For people who are thrown out of the house are completely lost with no options for them. There is hardly any information available regarding support services, including shelters. They become easy victims of abuse and exploitation. For people with disabilities the problems get compounded, due to inaccessibility of public transport, information, negative attitude of the society, etc. They may also not have access to basic health services.

²⁰⁰ Page 35, Annual Report, Ministry of Housing and Urban Poverty Alleviation, 2010-11.

²⁰¹ Page 36, Annual Report, Ministry of Housing and Urban Poverty Alleviation, 2010-11.

²⁰² Page 147, Ministry of Social Justice and Empowerment, Annual Report, 2009-10.

In the absence of food security and availability of basic amenities for survival, many persons with disabilities and their families are struggling to survive. There have been instances where persons with disabilities themselves have asked for permission to commit suicide from the President of India or their families have asked for “**mercy killing**” of their child/children with disability due to sheer desperation.

Access to Clean Water and Sanitation

Many places in the country have water scarcity. Sometimes, people have to go a certain distance to fetch water and carry heavy buckets/pots/vessels of water till their house. In slums, one has to stand in a queue for filling up a bucket of water. **Most of the drinking water facilities are not accessible for persons with disabilities. Accessing toilets is also difficult for people with disabilities.** Most houses in slums do not have toilets and common toilets are used. Again, they are at a distance; they are overcrowded and unhygienic. There are water and sanitation programmes in the country. However, access to persons with disabilities has not been taken into account.

There is a programme called the ‘**National Rural Drinking Water Programme**’ launched in April 2009 by the Ministry of Drinking Water and Sanitation, for assisting States in providing drinking water to the rural population of India.²⁰³ **There are no specific provisions in the programme for ensuring accessibility of drinking water availability to persons with disabilities.**

In absence of specific provisions with respect to accessibility of persons with disabilities, most of the wells, taps in public places, water outlets, tube wells are built in such a way that they may be inaccessible.

Integrated Low Cost Sanitation (ILCS) Scheme provides for converting/constructing low cost sanitation units through sanitary two pit pour flush latrines with superstructures and appropriate variations to suit local conditions (areas specific latrines) and for constructing new latrines where EWS (economically weaker sections) household have no latrines. (Page 52, Annual Report, Ministry of Housing and Urban Poverty Alleviation, 2010-11). **There is no mention of any support for designing/modification of latrines for persons with disabilities.**

Total Sanitation Campaign (TSC) was formulated in 1999 to provide rural sanitation. It aims to accelerate sanitation coverage in rural areas to access to toilets to all by 2017. **There is no specific mention about ensuring accessibility of the programme to persons with disabilities.**

5. Disability Pension

Disability pension is being given to persons with disabilities living below the poverty line across all states. The amount and the income ceiling of the family

²⁰³ Ministry of Drinking Water and Sanitation website accessed at <http://ddws.gov.in/> on 30th November, 2009.

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for eligibility vary from State to State. The disability pension in some States is as low as Rs 75/- and in some States it is Rs. 1000/-. There is no comprehensive data available (centrally) on the amount, the income ceiling and the beneficiaries.

Under the National Social Assistance Programme, the Government has the **Indira Gandhi National Disability Pension Scheme (IGNDPS)**. It came into existence in February 2009 for people in the age group 18-64 belonging to a household below the poverty line. It is for persons with severe or multiple disability. Rs. 200/- is provided by the Centre per month to the beneficiary and the State Government is urged to contribute at least equally to this amount. **The number of beneficiaries under the scheme is 766,000 till December 2010.**²⁰⁴

There are **several issues in accessing and in the delivery of the pension**. People with disabilities are not aware of the scheme and do not know the procedure for accessing it. There is also delay in the delivery of pension and many people have complained about postmen who ask for money to deliver the Money Order. This mal-practice is prevalent for getting other pensions too, like for old age or for widows. There are also informal "Brokers" or "Middle men" who help people access these schemes and take money for the service that they provide.

Disabled Await Their Pension

The disabled persons are yet to receive the pension of Rs. 400 per person, allotted by the state government. Their woes are increasing as the local bodies are passing the buck to the government. The pension scheme was even included in the Chief Minister's 100-day action plan and the authorities promised that the arrears would be paid to the beneficiaries before Onam. But it is learnt that no measures have been taken in this regard so far. During the term of the previous government, the pension amount was hiked from Rs. 300 to Rs. 400. But the then government hardly took measures to ensure that the amount was paid to the beneficiaries. "This is our only means of livelihood. We have been deprived of it," said V K Sasidharan, Treasurer, Differently Abled Persons Welfare Federation (DAWF). "Our pleas are falling on deaf ears," he said.

-From 'Disabled Await Their Pension', in Express News Service, The Indian Express, Cochi, posted on 12th September, 2007, IBN Live.²⁰⁵

In some States, the Disability Pension is higher than old age and other pensions, taking into account the disability costs, which is a positive measure. Karnataka gives higher disability pension of Rs. 1000 /- per month to a severely disabled person (above 75% disability) whereas only Rs. 400/- to a person with milder disability (40 to 75%). This is a well intended scheme. However, this has lead to several implementation issues.

²⁰⁴ Page 59, Annual Report, Ministry of Rural Development, 2010-11.

²⁰⁵ Accessed at <http://ibnlive.in.com/news/disabled-await-their-pension/183294-60-122.html> on 30th November, 2011.

Recommendations

- 1) The laws should be reviewed to ensure adequate standard of living for persons with disabilities on an equal basis with others.
- 2) The provision of social security to persons with disabilities should be reviewed and monitored very closely. Gender segregated disability data of beneficiaries (aggregates) of all the Schemes should be maintained and easily available in Annual Report/websites.
- 3) The definition of BPL should not just be based on income or spending. It should include the disability cost including the social discrimination costs (lack of opportunities, lack of accessible of transport etc.).
- 4) There is 3% reservation in poverty alleviation schemes which are seldom met. There has to be focused initiative to ensure people with disabilities benefit from these schemes. There has to be reasonable accommodation for persons with disabilities.
- 5) Regular dissemination of information on the various social security schemes in accessible formats and through various mediums.
- 6) Elderly people, women with disabilities and people with high support needs should have enhanced social security.
- 7) Disability pension should be revised to ensure it covers the basic costs. The delivery system should be improved. Greater awareness is required among people with disabilities and their families so that they can refuse to give bribe to the postman or any other public official to get the pension money. The age bar of maximum 64 years should be removed from the Indira Gandhi National Disability Pension Scheme (IGNDPS).
- 8) Water and Sanitation Programmes should take into account the needs of persons with disabilities and ensure their reach to them.

Article 29: Participation in Political and Public Life

The text of Article 29 in the CRPD is given below.

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake:

- (a) To ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:
 - (i) Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;*
 - (ii) Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;*
 - (iii) Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;**
- (b) To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:
 - (i) Participation in non-governmental organisations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;*
 - (ii) Forming and joining organisations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.**

Survey Findings

1. The findings with respect to the efforts made by the government to ensure that persons with disabilities have access to equal participation in political and public life are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	52%
Dissatisfied	33%
Satisfied	10%
Extremely satisfied	2%
Do not know much about the issue	2%

There is certainly some level of satisfaction with respect to political participation. A major movement led by the Disabled Right Group (DRG) in 2004 led to a Supreme Court Order for making voting accessible for persons with disabilities which led to the creation of ramps, Braille in Electronic Voting Machines (EVMs), separate queue for persons with disabilities etc. However, 85% of the respondents are still dissatisfied, which indicates there are still many issues with respect to participation in political and public life for persons with disabilities. At the ground level, these changes have not been implemented in many of the polling booths. People with certain disabilities are not even eligible to vote or hold public office or form associations. People with disabilities are still not seen as a vote bank in the country. There are hardly any representation of people with disabilities in the Parliament and local bodies.

Laws and Policies

Article 326 of the **Constitution of India** mentions that people with "unsoundness of mind" cannot be registered as a voter. Articles 102 (b) and 191 (b) states that a person would be disqualified for being chosen as, and for being, a member of either House of Parliament, Legislative Assembly or Legislative Council of a State "if he is of unsound mind".

The Disability Act, 1995, does not specifically mention 'political participation' of persons with disabilities. Clause 46 provides for 'Non-discrimination in the built environment' which would include polling booths also.

The National Trust Act, 1999 and **The Mental Health Act, 1987** has no mention of political participation.

Other laws like the Representation of Peoples' Act and some State laws bar people with disabilities from participating and holding public offices. The Panchayati Raj Act, 1994 of Tamil Nadu bars persons with "unsound mind" or "deaf mute" to contest in the elections. Persons with "unsound mind" are not allowed to form organisations/associations as per the Contract Act, 1872. And, according to The Indian Trusts Act, 1882, a trust may be created by every person "competent to contract". In addition, it says, "every person capable of holding property may be a trustee; but, where the trust involves the exercise of

discretion, he cannot execute it unless he is competent to contract." These laws have to be reviewed and amended to ensure its compliance with the CRPD.

Progress and Concerns

There have been no specific measures taken by the Government to implement this Article of the CRPD since the ratification in October 2007. However, it must be mentioned here that there has been some progress in this area since 2004, mainly due to the efforts of the disability rights movement in the country, which made the Government take up a few initiatives in making voting accessible to persons with disabilities, including ensuring secret ballot, for visually impaired voters who know Braille.

1. Accessibility of Voting Procedures

The voting procedures have been made accessible to an extent in India because of continuous advocacy by the disabled rights activists in the country. A sustained campaign was initiated by NCPEDP and the Disabled Rights Group (DRG) in 2004 before the General Elections. Several letters and faxes were sent to the Election Commissioner; rallies and protests were organised; the media was mobilised; petitions were sent to policy makers including the President of India. When these efforts didn't yield the desired result, Javed Abidi, Convenor DRG, sat on a fast-unto-death. The then Chief Justice of India took suo motu notice and converted a letter sent to him by DRG as a writ petition and issued a favourable Order to make voting accessible for persons with disabilities.

On 19th April 2004, the Supreme Court (SC) passed an Interim Order for the State Governments to provide wooden ramps in all polling booths across the country for the second phase of elections, and without fail in the last two phases on 5th May and 10th May. The SC took into account the difficulties faced by the physically challenged in approaching the polling booths to cast their votes. The Supreme Court also ordered that, for all future elections starting from September 2004, Braille labels giving the names and numbers of candidates should be on all Electronic Voting Machines (EVMs).²⁰⁶

In the General Elections 2009, there was a lot of proactive initiative on the part of disability activists and NGOs across the country to make it fully accessible. **There were positive reports about a few polling booths and not so positive reports about few others.**

²⁰⁶ Accessible General Elections in India Website, NCPEDP and DEOC, Supreme Court Order, accessed at <http://sites.google.com/site/accessibleelections/facilities-for/supreme-court-order> on 7th September 2011.

Experiences of Persons with Disability in Casting their Votes in the General Elections 2009

Delhi

I wish to share with you all, the fabulous experience I had yesterday while casting my vote, right from the entrance, the polling staff including the security personnel were very much cooperative and well trained, they all helped me a lot, the security personnel allowed me to enter in the booth and cast my vote out of turn despite there was a long queue outside. The presiding officer has offered me a seat and then gave me a dummy ballot paper in Braille to read, it was in both Hindi and English, then he himself took me to the other poll officials for another formalities and lastly he left me alone in the chamber where the EVMs were placed. As there were 40 candidates from my New Delhi constituency, there were 3 machines labelled with serial numbers in Braille, after casting my vote successfully, the presiding officer took me to my friend, accompanying me who was waiting outside.

In short, I can say that it was a very nice experience, which I did never imagine, it was my first independent voting in the last 10 years since I became blind, thanks to the Election Commission, Supreme Court and disability rights activists who have made it possible. Thanks and regards.

-Manoj

Karnataka

Nandini (35) was one among scores of visually impaired persons, who had been looking forward to this "historic election", ever since the Supreme Court ordered in 2007 making it mandatory to make elections disabled-friendly. However, she was disappointed to find that at her polling booth in Laxmi Memorial School at Lingarajpuram there was no Braille-enabled stickers or dummy ballot papers. A dejected yet angry Ms. Nandini was forced to request her relative to vote on her behalf, as she had done in the past.

- 'Visually Challenged Person finds it tough', The Hindu, Bangalore 24th April 2009.²⁰⁷

Madhya Pradesh

Booths in Bhopal were completely accessible for blind people. All the 1078 booths of Bhopal had Braille stickers in the EVMs. The staff was thoroughly trained and were very polite. The list of all the candidates in Braille was also available. There was adequate coverage in television, radio and newspapers regarding the facilities for the blind in the election.

- Rohit Trivedi, 'Accessible General Elections in India', NCPEDP and DEOC.²⁰⁸

²⁰⁷ Accessed at

<http://www.hindu.com/2009/04/24/stories/2009042456920400.htm> on 7th September 2009.

²⁰⁸ Accessed at <http://sites.google.com/site/accessibleelections/experience> on 7th September 2011.

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People with disabilities have been demanding **postal ballots for those who have difficulty accessing the polling booths**. However, **this demand has not been fulfilled**.

The demand for making appropriate legislative changes for persons with intellectual/mental impairment to cast their votes in the country remains unfulfilled.

2. Inclusion of Disability in Manifestos of Political Parties

Disability activists have made an effort to create awareness amongst the political class about the rights and needs of persons with disabilities.

A major event, 'National Convention on Political Rights of Disabled People', in New Delhi was convened by the Disabled Rights Group (DRG) on 20th March 2004, where about 700 people from 17 States of India had participated. They demanded their share of attention from political parties by, for starters, including their needs in election manifestos.²⁰⁹

Major Political Parties have started mentioning disability in their Election Manifestos. **In General Elections 2004, there were one/two lines on disability in their manifestos. It increased to a paragraph to a full section on disability in the 2009 elections.**

Disability continues to **remain a separate issue** in these manifestos. **It is not included in other development issues and programmes meant for people from under-privileged, disadvantaged and minorities backgrounds.**

3. Accessibility of Election Materials and Campaigns

There has been some amount of advocacy on the part of the disability sector in **demanding accessibility of election materials and campaigns. However, there has not been much improvement in this regard.**

The election campaigns, particularly speeches, remain inaccessible for persons with hearing impairment and deafness, though there has been a demand for sign language interpreters during the election speeches. None of the visual media coverage of elections and the related debates has captioning in any of the channels and Government does not have any policy to provide for the same. The concerns of persons with disabilities are not discussed during elections by politicians as persons with disabilities are probably not seen as a vote bank.

The manifestos of major parties are available on the Internet. However, one is not sure if they are uploaded in accessible formats by the political parties. One could also not find any mention from their websites if the manifestos exist in Braille and other accessible formats.

²⁰⁹Accessible Elections Website, NCPEDP and DEOC, accessed at <http://sites.google.com/site/accessibleelections/history> on 7th September 2011.

4. Representation of Persons with Disabilities in the Gram Panchayat, Assemblies and Parliament

While there is 33% reservation for women in the Gram Panchayat and Municipal Elections, there **is no reservation for people with disabilities in the local bodies or in Assemblies and in the lower and upper houses of Parliament.** There are no mandates for nominating members for representing persons with disabilities, like it is in the case of Anglo Indian Community in the Lower House.²¹⁰ Twelve people are nominated by the President of India in the Upper House of Parliament, none of whom have been from the disability sector. In short, there has not been any proactive effort on the part of the Government to ensure representation of persons with disabilities in the Parliament or local bodies.

As mentioned in the Laws and Policies section, people with certain disabilities are not even allowed to stand in the elections.

The Tamil Nadu Panchayati Raj Act, 1994, Section 37, 'Disqualification of Candidates', states that a person with unsound mind or deaf mute can't contest in the elections. As per the above said Act, a person with hearing impairment's nomination for the upcoming elections has been rejected. We strongly condemn this act of the Election Commission.
-Rajiv Rajan, Facebook Update, 3rd October 2011.

It is also difficult for persons with disabilities to join a party and work as a party member due to various barriers. Even if a person stands for elections as an independent candidate, there are barriers in the campaigning and the need for a stable financial backing. The negative attitudes of people in general and the political parties towards persons with disabilities are major barriers to a successful political career for a person with disability.

In spite of the barriers, some people with disabilities have stood for elections at various levels and some of them have even won. Sudha Patel, age 24, was not only the first blind person but also the youngest Sarpanch to be elected to the office in 1999.²¹¹ Kamlesh Kumar Yadav, a person with orthopaedic disability, was elected as Sarpanch in the constituency of Paatan, Chattisgarh. He contested as an Independent Candidate in 2005.²¹²

There are a few others who stood in the elections to bring issues to the forefront. Javed Abidi, Convenor, Disabled Rights Group (DRG) stood as an

²¹⁰ In Lower House, no more than two members from Anglo-Indian community can be nominated by the President of India if he or she feels that the community is not adequately represented. Parliament of India, Wikipedia, http://en.wikipedia.org/wiki/Parliament_of_India accessed on 8th September 2011.

²¹¹ Sudha Patel, Helen Keller of Changa, Extract from The Week 14th March 1999 issue, accessed at <http://mahaanbharat.tripod.com/sudha.html> on 8th September, 2011.

²¹² DNIS, Managed by NCPEDP, Volume 3 Issue 5 - March 01, 2005; accessed at http://www.dnis.org/news.php?issue_id=5&volume_id=3&news_id=357&i=2 on 8th September 2011.

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Independent Candidate from the very prestigious New Delhi Constituency in 2004. The Network of Persons with Disabilities (NDPO), a DPO in Andhra Pradesh, fields candidates in almost all Municipal and State Elections to create visibility for disability issues. They are consciously working on building a cadre of leaders with disabilities.²¹³

The candidates face a lot of barriers, including financial constraints, inaccessible physical infrastructure, negative attitudes, lack of media support etc. in contesting elections on an equal basis with others. The State has taken no steps to address these barriers.

Recommendations

- 1) Disability laws should explicitly mention the right to participation in political and public life for persons with disabilities.
- 2) The laws that discriminate against persons with disabilities vis-a-vis political and public participation - for casting vote, standing for elections and holding public offices, forming associations should be suitably amended as per the CRPD.
- 3) All related laws (Contract Laws, Partnership Laws, Trust Laws, Representation of Peoples' Act, etc.) should be reviewed and amended.
- 4) There should be reservation for persons with disabilities in the Village Assembly, State Assembly and the Parliament of India.
- 5) A mandate should be introduced to nominate representatives of people with disabilities in both the Houses of the Parliament.
- 6) There should be a continuous effort on the part of the Election Commission to improve accessibility of voting procedures and close monitoring should be done. Postal voting, mobile booths, online voting, talking EVMs are some of the suggestions received from voters with disabilities.²¹⁴
- 7) Materials and information regarding election campaigns of various political parties should be available in accessible formats.

²¹³ 'If you vote for me, you will vote for equality and for development', Mallesh, Rama Chari, Disability News and Information Service (DNIS), Managed by NCPEDP, Volume 3 Issue 11 - June 01, 2005, accessed at http://www.dnis.org/index-2.php?issue_id=11&volume_id=3 on 8th September 2011.

²¹⁴ Accessible Elections Website, NCPEDP and DNIS, accessed at <http://sites.google.com/site/accessibleelections/suggestions/suggestions-received> on 8th September 2011.

Article 30: Participation in Cultural Life, Recreation, Leisure and Sport

The text of Article 30 in the CRPD is given below.

1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:
 - a) Enjoy access to cultural materials in accessible formats;
 - b) Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats;
 - c) Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.
2. States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.
3. States Parties shall take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials.
4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.
5. With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures:
 - a) To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;
 - b) To ensure that persons with disabilities have an opportunity to organise, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;
 - c) To ensure that persons with disabilities have access to sporting, recreational and tourism venues;
 - d) To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;
 - e) To ensure that persons with disabilities have access to services from those involved in the organisation of recreational, tourism, leisure and sporting activities.

Survey findings

1. The findings of the survey conducted with respect to the efforts made by the government to ensure that persons with disabilities have access to participation in cultural life, recreation, leisure and sports are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	52%
Dissatisfied	31%
Satisfied	15%
Extremely satisfied	1%
Do not know much about the issue	1%

The 15% satisfaction could be because of some efforts are being done to promote cultural life and sports like having exclusive sports events or enabling participation of sports persons with disabilities in Commonwealth Games 2010, or the fact that some historic monuments are being made disabled-friendly. The reason for such high dissatisfaction (83%) could be that there is no focused work being done in terms of promoting these aspects. They are done more as charity based work and not in a professional manner. Sports persons and artists with disabilities do not get the necessary recognition and support from the Government. There are several barriers for people with disabilities to equally participate in social life or to enjoy cultural rights.

Laws and Policies

The **Constitution of India** does not mention the participation of persons with disabilities in cultural life, recreation, leisure and sports.

The Disability Act, 1995, Clauses 44, 45 and 46 provides for 'non-discrimination' by removing physical barriers. It mentions making adaptations in rail, buses, and aircraft and in public buildings to make them accessible to persons with disabilities. The Clause 43(c) on Affirmative Action mentions preferential allotment of land at concessional rates for setting up of "special recreation centres".

The objectives of the **National Trust Act, 1999**, mentions, 'to facilitate the realisation of equal opportunities, protection of right and full participation of persons with disability'. However, there is no specific provision in the Act related to participation in cultural life, recreation, leisure and sport to ensure this objective.

The **Mental Health Act, 1987**, does not make any mention of right to culture, leisure, recreation or sports.

The **National Sports Development Board of India, 2011** makes a cursory mention of disability in terms of developing coaches for persons with disabilities and for increasing participation of people with disabilities (Sections 1.4.2 and 1.4.4). There is a Draft National Sports Bill, which is under discussion, that would have to be reviewed to see if it in line with the provisions given in the CRPD.

The **National Tourism Policy, 2002** does not include the concerns of persons with disabilities. However, the Strategic Action Plan as of February 2011, Ministry of Tourism, includes disabled friendliness of architectural sites and museums as the responsibility of Archaeological Survey of India (ASI) and the State Governments. There are a few legislations like The Ancient Monuments and Archaeological Sites and Remains Act, 1958.²¹⁵ These need to be reviewed in the light of the CRPD.

In the **National Youth Policy, 2003**, 'youth with disabilities' has been mentioned as one of the target groups.

The **Indian Copyright Act, 1957**, does not contain adequate exceptions and limitations for blind and other print impaired persons to feasibly convert printed matter into other formats.²¹⁶

Progress and Concerns

This Article is closely related to implementation of Article 9 on Accessibility. The Government needs to take steps to remove physical and communication barriers for full participation of people with disabilities. The various Ministries and departments responsible for implementation of the provisions of this Article include the Ministry of Youth Affairs and Sports, Ministry of Tourism, Ministry of Culture, Ministry of Human Resource Development and Ministry of Social Justice and Empowerment.

1. Right to Cultural Life and Recreation

Way back in 2001, Archaeological Survey of India (ASI) formulated a policy that all heritage sites and monuments would be made disabled-friendly²¹⁷. This year (2010-11), for the first time (almost 10 years after the policy announcement in 2001) a grant of Rs. 5 crore (Rs. 50 million) has been approved for the Archaeological Survey of India to make five of its World Heritage Sites and 25 other ticketed monuments accessible to persons with

²¹⁵ Archaeological Survey of India website accessed at http://asi.nic.in/asi_legislations.asp on 15th August, 2011.

²¹⁶ From 'Right to Read for the Print Impaired and Copyright Challenges', part of a letter written to the Director General of the World Intellectual Property Organisation by DAISY Forum of India comprising 65 organisations, accessed at http://www.visionip.org/news/en/vip_in_dg_09.html on 16th August, 2011.

²¹⁷ This policy decision was a direct result of the advocacy undertaken by NCPEDP when Prof. Stephen Hawking had expressed his wish to see four historical monuments (Jantar Mantar, Humayun's Tomb, Red Fort and Qutub Minar) during his visit to India in January 2001. NCPEDP took it up as a major campaign to bring this issue to the forefront, which was actively supported by the media. The Government hurriedly constructed temporary ramps to facilitate his visit to the four monuments in the country. A Stay Order was taken from the Delhi High Court when the ramps were removed by the authorities after the visit. ASI, which had earlier taken the view that not a brick will be moved, announced a policy to make all heritage buildings in the country accessible for persons with disabilities.

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disabilities. The World Heritage monuments for which accessibility-related works have been sanctioned are the Taj Mahal, Agra Fort, Fatehpur Sikri, Konark and Champaner-Pavagarh. Some of the other important ticketed monuments, for which such works have been sanctioned, include the Charminar, Golconda Fort, Nagarjunakonda, the Sun Temple at Modhera, and Bhubaneswar temples.²¹⁸

There have been a few ad hoc initiatives driven by certain NGOs across the country, which have led to some accessibility features being introduced in some monuments.

Buddhist sites in Sanchi from Sunday will become the first friendly world heritage monument in country for the visually challenged. Special tactile walkways, signages in Braille, beepers and a Braille map will make the famed Buddhist monuments, including the Stupa, come alive for the visually challenged who will also be also allowed to "feel" the grandeur in every sense. The Archaeological Survey of India Regional Director Simadri Bihari Ota said, "This is the first archaeological site in the country where we are taking a visually challenged person from the gate of the site to the monument. We are even allowing them to touch and feel the monuments."
-Prakash Hatvalne, 'Sanchi becomes first blind-friendly heritage site', The Times of India, Bhopal, 20th November, 2011.²¹⁹

The Annual Report of Ministry of Culture has mentioned that "Arrangements for disabled persons have been made in some of the Archaeological Site Museums. The facilities that are being introduced are Braille plaques, wheelchairs, specially designed toilet facilities at some Archaeological Site Museums, for example, Hazarduari Palace Museum." It is also mentioned that Archaeological Site Museums in Delhi have already finalised text details on museum objects and galleries in Braille and Braille plaques would be provided at the earliest.²²⁰

In the Nehru Memorial Museum & Library, 200 copies of Nehru's Letter from a Father to his Daughter, in Braille have been printed. The Museum, Planetarium, Library and Annexe buildings have also been made accessible to persons with disabilities through suitable ramps. Disabled-friendly toilets have been constructed in the Planetarium and Library buildings and a Cyber room for persons with disabilities in the Library has been made functional for Academic Activities.²²¹

In Khuda Bakhsh Oriental Public Library, the Library has established a separate Braille Section. and the Library is also getting constructed a ramp for readers on wheel chairs.²²²

²¹⁸ Status Paper, Working Group on Empowerment of Persons with Disabilities for Formulation of XII Plan (2012-17).

²¹⁹ Accessed at

<http://timesofindia.indiatimes.com/city/bhopal/Sanchi-becomes-first-blind-friendly-heritage-site/articleshow/10799990.cms> on 19th October, 2011.

²²⁰ Annual Report, Ministry of Culture, 2010-11.

²²¹ Page 309, Annual Report, Ministry of Culture, 2010-11.

²²² Page 310, Annual Report, Ministry of Culture, 2010-11.

The National Museum Institute has installed monograms, signs and Braille inscriptions to make objects in the museum blind-friendly. The main passages, ramps, and galleries have also been reworked so that they are barrier-free. They also held an art workshop for mentally challenged children.²²³

There have been numerous programmes such as workshops, exhibitions, competitions etc. for children with disabilities in the Science Centres of the National Council of Science Museums. It has also been reported that 20,146 visitors with disabilities visited the Science Centres during 2010-2011 (up to February 26, 2011).

There has been some effort in making the heritage sites, museums and libraries accessible to persons with disabilities. However, this information is not readily available in the Ministry of Culture's website or in any other information websites and publications. Hence, awareness about these initiatives is low amongst persons with disabilities. So majority of people with disabilities would not utilise the library services etc.

The **media** plays a crucial role in promoting culture. One gets knowledge about the various cultures through Books, Newspapers, Magazines, Television, Radio, Internet, Public Forums and Conferences and through other mass media. **There is no visible effort on the part of the Government to make these mediums accessible. The Government has adopted the Web Accessibility Guidelines and have said that all Govt websites would be made accessible. But no such policy guidelines have been adopted for Television and publications.** The national broadcaster, Doordarshan has a weekly sign language bulletin. Some other programmes on Doordarshan also have captioning.

The private channels do not have captioning or sign language interpretation. The 24 hour news channels have the news headlines scrolls but nothing more than that. Children's programmes/animation serials too do not have captioning. None of the films shown in the cinema halls/multiplexes have captions or audio descriptions. Access to performing arts, visual arts, dramas/plays etc. depends on the accessibility of cinema halls, galleries and auditoriums, clubs, community halls, which are often owned by private companies or individuals. Though these are places for public use, accessibility features are not looked into during the construction or renovation of these places.

In many areas, especially the rural, religious ceremonies, sports events, different forms of theatre, puppetry may be a source of recreation. **In many religious ceremonies, persons with disabilities may not be "allowed" to participate. The temporary structures for many plays and shows may have access barriers for persons with disabilities. Most of these programmes are organised by private enterprises. The programmes organised by the Government, for example, melas, do not look into the accessibility barriers** (infrastructure, toilets, water facility, entrance and exits,

²²³ National Museum Turns "disabled-friendly", Neha Alawadhi, The Hindu, 1st March 2011, accessed at <http://www.thehindu.com/todays-paper/tp-national/tp-newdelhi/article1499536.ece> on 19th October, 2011

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transport, parking, safety, emergency evacuation, information brochures, pamphlets, audio-visuals etc.)

Alka Arora, a woman using wheelchair was denied entry into a night club in Kolkata early on Sunday with the staff telling her that handicapped persons weren't entertained. Furious at the behaviour of the staff, Alka has filed a complaint with the State Human Rights Commission, alleging blatant discrimination. The management of the night club, Shisha, while acknowledging that the guest had been denied because she was in a wheelchair, reasoned that it was for her own safety as the newly-renovated club was extremely crowded at that hour.

- From 'Club denies entry to girl in wheelchair', The Times of India, Kolkata, 9th November, 2009.²²⁴

We had been to Bannerghatta National Park last Sunday (8th August 2010), with family and children. It was also an opportunity for me to relive my childhood memories. This time I was using a wheelchair. I was appalled by the total inaccessibility to all the facilities and services at the National Park. The bus stand and car park is more than a kilometre away from the main gate; all the routes outside and inside the park are extremely bumpy.

To reach the animal enclosures, seating area, drinking water and food counters one has to balance and cross-over rough granite slabs that act as culvers. Incidentally it started to rain and I had to fend for myself under the tree as I could not reach any of the shelters. The sign boards are totally inadequate. The public toilet in the park is situated on top of a mini hillock and you need trekking skills to reach the place. What happens to those who cannot climb? You can guess.

I missed the Butterfly Park, Reptile Park and the Safari too. All I can remember of my 'picnic' is being rooted under a tree near the main gate waiting to go back home. I leave the readers to decide...

-From 'My picnic to Bannerghatta National Park, Bengaluru', An experience narrated by C. Mahesh, Advocacy Coordinator, CBR Forum, Bengaluru.

Most **places of worship** are not accessible for persons with disabilities. Wheelchairs, callipers, crutches are all not allowed in most of the places of worship in India. The reason usually given is that any leather item is not allowed inside. A handful of places, however, keep their own wheelchairs and attendants. However, the main issue is the insensitive attitude and the exclusion of persons with disabilities.

A trip to a temple in Karnataka is going to remain etched in the minds of this Delhi-based family but for all the wrong reasons. The trip to the Sriranganathaswamy Temple in Srirangapatna near Mysore was a last minute

²²⁴ http://articles.timesofindia.indiatimes.com/2009-11-09/kolkata/28105581_1_wheelchair-night-club-shisha accessed on 23rd October 2011.

decision for Anikesh 's family. The decision however ended up causing them pain when their 23-year-old son Anikesh was not allowed to enter the temple on his wheelchair. Col. V. K. Kuber, Anikesh's father said, "I refused and said no, I would like to go with the wheelchair. To which he pushed the wheelchair aside and an old man in a khaki dress joined him in pushing it saying we don't allow wheelchairs. My son was sitting in the wheelchair and he was pushed around which is what actually hurt us. The priest left his job inside the sanctum sanctorum and he came and he joined them and said, take them out, take them out."

-From 'No Temple Entry for a Wheelchair', NDTV website, 27th June, 2010.²²⁵

Another important aspect related to cultural rights would be **accessible tourism**. People with disabilities generally find it extremely difficult to travel due to inaccessibility of transport to public places etc. There has not been much thought given to make tourism accessible in the country. This issue was brought to the light in 2001 when Prof. Stephen Hawking visited India. However, the issue still remains unaddressed or addressed in a very ad hoc way. Accessible transport, hotels, market places, places of tourism, safety and security, accessible ticketing mechanism, health insurance for travellers, information on accessible tourist places are all issues related to comfortable travel for persons with disabilities. Though there have been initiatives in making airports and hotels accessible by the Government, nothing much has been done in other related areas. It is especially very difficult for those who do not have much resources to spend.

The Ministry of **Tourism** came out with new Guidelines for classification of hotels, which also include making all hotels disabled friendly by September 2010. This not only includes 4 and 5 star hotels which were already accessible to an extent, but also 1, 2 and 3 star hotels.²²⁶

Though these guidelines were framed in 2009, one is not sure of its implementation and if there are any timelines for making the existing hotels accessible. Moreover, there seems to be no comprehensive information on the places and hotels that are disabled-friendly in different cities in India. The State Tourism services too may not know about accessible places in their own States.

2. Opportunities for Development and Utilisation of Creative and Intellectual Potential

The National Trust organises *melas* and exhibitions of crafts and other items made by persons with disabilities. Stalls in International Trade Fairs and Shilpottav are also given to display and sell their products.

²²⁵ Accessed at <http://www.ndtv.com/article/cities/no-temple-entry-for-a-wheelchair-34112> on 23rd October 2011

²²⁶ Disability News and Information Service (DNIS) News Network, India, August 15, 2009.

There are however hardly any opportunities for persons with disabilities to develop their creative potential. Those who have managed to develop and pursue their artistic talent have been able to do so due to their individual or family effort, in spite of the barriers and lack of support from the Government and the community.

Private event organisers generally do not take up such initiatives unless it is for charity or fund raising. To a certain extent, people with disabilities are being given a platform to showcase their talent through **various reality talent television shows**. This is a good means to bring about awareness amongst the people about disability. Here they are being given the opportunity to display their creative and artistic potential at a platform where non-disabled persons also perform.

There are many movies on the theme of persons with disabilities. However, **the role of a person with disability is played by non-disabled actors**. Persons with disabilities who are into theatre and films feel that persons with disabilities should be auditioned and given an equal opportunity to play the roles. "If people can accept Rani Mukherji in Black, then why not me," asks Divya Arora, a theatre actor-director-writer, a wheelchair user. After many years of struggle, she has finally played a small role in a Bollywood Commercial film 'Shaitan'.

There have been some **NGO** initiatives like film festivals of films on disability issues, exhibition of paintings by persons with disabilities, cultural events, sports events, competitions, dance-dramas, etc. with little or no support from the Government.

3. Recognising Deaf Culture and Linguistic Identity

Deaf Culture or Sign Language was not even considered or not seen as an issue for many years in the country. Deaf people hardly had/have any voice. It was mostly the speech therapists who ruled the sector of persons with hearing impairment or deafness. It is only in the last decade or so that there has been some amount of sustained self advocacy in this area, led by the National Association of the Deaf (NAD) and Disabled Rights Group (DRG). As a result of their hard struggle, consisting of several memorandums, press conferences and protests, that this demand was included in the XI Five Year Plan. Finally in 2011 (again after a lot of advocacy by NAD and DRG), **the Government made the announcement to set up the Indian Sign Language Research & Training Centre in New Delhi.**

There has also been a long standing demand by the disability sector to **recognise sign language as an official language** in the country. However, no action has been taken in this regard.

The need for developing an Indian Sign Language and the effort to create it has started only a few years back. It is at a very initial stage. Effort is being made create the Indian Sign Language corpus. Currently, some States are using the UK Sign Language and some others the American Sign Language but mostly it is the local gestures which are being used and understood by family and friends. With the setting up of the Indian Sign Language Research and Training Centre,

this effort could get the required push. Some persons have expressed that while children in schools are taught French/German/Spanish etc., it would be a good idea to introduce Sign Language as a language option for students, which would further promote the use of sign language and the inclusion of deaf people in the mainstream.

4. Equal Participation in Sports

'Disability sports' has been a hugely neglected issue.

There is no infrastructure for practice, no coaches, no support for building physical capacity and nutrition, no funding or sponsors for them to take sports as a career. Most of the initiatives in this area have been voluntary.

The Ministry of Youth Affairs and Sports formulated a scheme for promotion of sports and games for persons with disabilities in 2009.

The Scheme has the following components:²²⁷

- Grant for sports coaching and purchase of consumables & non-consumable sports equipment for Schools.
- Grant for Training of Coaches.
- Grant for holding District, State & National level competitions for the disabled.
- Grants to 56 schools/institutes were granted during 2010-11 up to 31st December 2010.

The international sports event, 'Commonwealth Games' has a few events for athletes with disability. There are three major exclusive international disability sports competitions - Special Olympics, Paralympics and Deaflympics. All these provide a forum for people with different disabilities to showcase their athletic talents.

Some **NGOs/associations** promote sporting activities within the country and also support individuals and teams to participate in international events. For example, chess for blind persons, cricket for blind persons, basketball for wheelchair users, adventure sports, marathons, and other sports. Funds, infrastructure, equipment and coaches are some of the constraints faced by these NGOs. Sponsors for sporting events for persons with disabilities are often a problem. Government support is negligible.

Commonwealth Games 2010

Disability sports comprising 15 events in the upcoming Commonwealth Games (CWG) in New Delhi will account for 45 medals - a gold, silver and a bronze medal for each event. Medals won in these events will be part of a country's final medal tally. Yet, in India, the host country, with just four months to go for the Games, the disability sports scene is in utter disarray.

²²⁷ Page 78, Scheme Relating to Participative Sports, Annual Report, Ministry of Youth Affairs and Sports, 2010-11.

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Not only does India seem ill prepared for most of the disability events, it won't even be participating in two of the events. This, after Rs 13.8 crore was allocated for disability sports events to train athletes and to buy equipment for them. With the CWG just a few months away, so far, the Sports Ministry has released just about Rs. 5 crore.

The two events India will not be participating in are the 1500m races for men and women. And why? Because there are no racing wheelchairs for athletes to train with. To make matters worse, wheelchairs for the women's table tennis event and for the 100-metre race are not available. Hence, the athletes are practising with wheelchairs they will not be using during actual competition. The cost of a racing wheelchair is about Rs 3-5 lakh, not really unaffordable with the crores allotted. However, the Sports Authority of India (SAI), which was supposed to procure them, never brought them in.

-Shaikh Mohammed Meraj, 'Disabled Athletes left high and dry, India may lose out on Medal', 7th June 2010, ²²⁸

Recommendations

- 1) The Disability laws should clearly mention cultural rights for persons with disabilities as per CRPD.
- 2) The Sports Bill which is being formulated should ensure disability sports is given due recognition and should ensure accessibility of sporting venues and services.
- 3) The other laws relating to media, copyright, etc. should be reviewed to ensure that they are compliant with the CRPD.
- 4) Measures should be taken to ensure sustained development of artistic and intellectual potential of persons with disabilities by having separate cells in the Ministries of Sports, Culture and Tourism with adequate human and financial resources.
- 5) Sports Infrastructure - venues, gymnasiums, swimming pools etc.- should be made disabled friendly so that sports persons with disabilities can also use them. Separate infrastructure should also be made, if required.
- 6) Cinema halls, theatres, galleries, exhibition grounds, parks, playgrounds, places of worship etc. including the ones owned by private and non-profit organisations should be made disabled-friendly.
- 7) Captions and audio descriptions should be mandated for all films produced in the country.
- 8) All television channels, including those privately owned should provide captions and audio descriptions.
- 9) News channels should have sign language interpretation throughout the day.
- 10) Scholarships to be provided to people with disabilities who want to pursue arts or sports as careers.

²²⁸ accessed at

<http://common-wealth-games-2010.blogspot.com/2010/06/disabled-athletes-left-high-dry-india.html> on 24th October 2011

- 11) Government funding should be provided for sportsperson and artists to participate in national and international events.
- 12) Exchange programmes should be organised for promoting disability sports and arts (for example, wheelchair dance).
- 13) Sports persons and artists who have achieved success should be rewarded and recognised and provided the same perks like providing them with jobs, house etc.
- 14) It is crucial to bring in transparency and involvement of people with disabilities in sports organisations.
- 15) Sign language should be recognised as an official language in the country.
- 16) Concerted effort should be made to develop the Indian Sign Language and to promote it widely so that even non-disabled people also learn and use the language.

Article 31: Statistics and Data Collection

The text of Article 31 in the CRPD is given below.

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:
 - a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;
 - b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.
2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.
3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Survey Findings

1. The findings with respect to the efforts made by the government to collect, maintain and disseminate data on persons with disabilities is given below.

Rating	Percentage of Respondents
Extremely dissatisfied	45%
Dissatisfied	33%
Satisfied	18%
Extremely satisfied	2%
Do not know much about the issue	1%

There is comparatively greater level of satisfaction (18%) with respect to the Government of India's effort to collect statistical data on disability, when compared to the satisfaction scores of other Articles in the CRPD. This could be because of the effort made by the Census Commission for collecting data on disability in Census 2011. However, it is also important to note that the majority of the respondents have still expressed dissatisfaction (78%). This shows that there is still a long way to go as far as collecting authentic data on disability is concerned. The resources and effort that should have been put in for creating awareness among the public regarding the disability question in Census was not done. The message didn't reach very far. Hence, the disability sector is not very optimistic about the data that would come out of Census 2011. Moreover, data

on disability is not collected or maintained by most Ministries for the various development programmes. Disability continues to be a non-issue for policy makers and persons with disabilities continue to be “invisible” in the country.

Laws and policies

Disability Laws do not specifically mention about data collection. However, the **Mental Health Act, 1987** has a mention regarding confidentiality of the information collected from the patients.

The Census Commission, under the Ministry of Home Affairs, and the National Sample Survey Organisation (NSSO) under the Ministry of Statistics and Programme Implementation, are the two main organisations that collect various kinds of data in the country for the propose of policy making and resource allocation. Both these organisations collect disability data. They have very clear norms for collecting data and disseminating information with respect to confidentiality. Only the aggregates are shared and individual data is kept confidential.

Progress and Concerns

1. Statistical Data on Disability

The efforts put in by the Census Commission to ensure better enumeration of persons with disabilities can be considered as a definite progress in this area post ratification of the CRPD. The disability sector approached the Census Commissioner, who gave his full support to ensure that the disability question is given due attention and priority in the latest Census of 2011. The role that the Ministry of Social Justice and Empowerment and Information and Broadcasting played was however quite negligible.

“We had almost missed the bus this time too, had Javed Abidi, Honorary Director, National Centre for Promotion of Employment for Disabled People (NCPEDP), not met the Registrar General and Census Commissioner of India, Dr. C. Chandramouli just in the nick of time. When Abidi met Dr. Chandramouli on 1st February 2010, the Pre- test of Census 2011 was already over and the question on disability had more or less been finalised. (The Pre-test question on disability was almost the same as it was in Census 2001). What was shocking for us was to learn that none of the other NGOs or activists of the disability sector had made any recommendation to the Census Commissioner until then.

NCPEDP made a request to the Census Commissioner to allow the disability sector to reframe the question on disability and to draft the guidelines of the enumerators’ manual for the same. Dr. Chandramouli very kindly agreed to this request.

Taking its vision of a cross disability movement forward, NCPEDP, along with the British High Commission, the Disabled Peoples' Organisation Denmark and Hans Foundation organised a two-day Round Table Consultation in New Delhi on 15th and 16th March 2010. More than 90 delegates representing various disabilities from across various geographic regions of the country were present at the meet.

Dr. C. Chandramouli inaugurated the Round Table. Dr. Chandramouli asked Abidi and other stakeholders present, as far as possible, to evolve a consensus on the disability question to be incorporated in Census 2011. A research on the disability question was conducted by Diversity and Equal Opportunity Centre (DEOC) on NCPEDP's behalf. It was based on the disability question asked in 11 countries including developing and developed countries, the question as suggested by the Washington Group and the question based on United Nations Convention on the Rights of Persons with Disabilities. After a day long discussion and a war of words and with options not to exceed more than nine, the participants of the Round Table were finally able to agree to a common question.- Rohinee Singh, 'Our Census, Our Future: Disability sector puts up a United Front', Disability News and Information Service (DNIS), April 01, 2010.²²⁹

The Disability Question in Census 2011 had seven impairment categories (1) Seeing (2) Hearing (3) Speech (4) Movement (5) Mental Retardation (6) Mental Illness (7) Any other and (8) Multiple Disabilities. Inclusion of the category 'Any other' was a big development, as it allowed anyone who had a disability, and so could not be included in other categories, to count themselves in. For example, persons with Autism, learning disability or persons with medical conditions could include themselves. The disability question was also moved up from Question 16 in Census 2001 to Question 9 this time for 2011 (before the question on Mother Tongue), which also increased the chances of the enumerator asking that question.

The Census Commission included a 45-minute Training Module developed by NCPEDP on disability for the Census Officials and Master Trainers at the National and State levels. The disability sector from across the country was actively involved in conducting and facilitating these training sessions. Though the Census enumeration took place in January - February 2011, the disability data has not yet been announced.

The awareness among the public about the disability question in the Census was not done at the scale that is required for a country as huge as India. Neither the Home Ministry, under which the Census Commission falls, nor the Ministry of Social Justice and Empowerment which is the nodal Ministry for disability, nor the Ministry of Information and Broadcasting which is in charge of publicity, had done enough to create awareness on the Census in general and the disability question in particular. There was just one advertisement which was shown a few

²²⁹ Accessed at http://www.dnis.org/features.php?issue_id=7&volume_id=7&features_id=173) on 21st October, 2011.

times on the national channels and it was missed by most people. Media coverage on Census was also very little.

There was mixed feedback from the people regarding the enumeration of persons with disabilities. Some enumerators asked the question and many had left it out.

"Our experience was pretty good. Both the teachers took time to explain the disability question and also the various codes associated to classify different types of disability. They had clear knowledge about this question and how by including all members in the family at a country wide level some policy changes could happen. I do hope the same level of awareness and interest exists in rural India as well."

-Annice Paul, Facebook

"Was given a form which had only six questions and disability was not included. The enumerator is a school teacher. Has limited time as her children are young. She gave this form to me about five days back, but she has not come back. I guess when she comes, she will ask about the other questions"

-Dr. Anita Ghai, Facebook

"Census enumerator came today. Incidentally I was at home. She never asked Question No. 9 which was on disability. Then I asked her about it and she said that she had just filled Question 9 as 'yes'. I told her to fill up 9 (b), which is on disability category! Well, looking at my experience, I don't think this census also we are going to have the right disability figures"

-Sowmya Simhan, Facebook

2. National Sample Survey Organisation (NSSO)

NSSO conducts sample surveys on various aspects, including disability. The last survey on disability (NSS 58th Round) was undertaken in 2002²³⁰. The result of the NSS Survey was worse than Census 2001. Only 1.8% of the population was found to have disability. The NSS, which also takes place every 10 years, should be happening any time now. One could not find much information on the Internet about the changes being made to improve the question and the data collection methodology to get more authentic results.

3. Disability Segregated data for Development Schemes

Disability segregated data is seldom available in the country. There are hardly any data available with respect to persons with disabilities utilising various

²³⁰ Punarbhava website; Accessed at http://punarbhava.in/index.php?option=com_content&task=view&id=734&Itemid=540 on 28th October 2011.

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services – health, legal, etc. The data is maintained by the Government for programmes where there is reservation for persons with disabilities, like in the case of employment or poverty alleviation schemes. Sometimes gender segregated data of disability is not maintained. Unless disability and gender segregated data of beneficiaries, allocation and utilisation of funds is collected, compiled, maintained, updated, shared and disseminated diligently and appropriately, it would be difficult to assess the impact of development programmes that should reach persons with disabilities.

4. Aadhar - Unique Identification (UID)

The **Unique Identification Authority of India (UIDAI)** is an agency of the Government responsible for implementing the **Aadhar Scheme**. It was established in February 2009. Aadhaar is a 12-digit unique number which the UIDAI will issue for all residents in India. The number will be stored in a centralised database and linked to the basic demographics and biometric information – photograph, ten fingerprints and iris – of each individual. (Wikipedia Unique Identification Authority of India).²³¹

The enrolment is currently going on in the country. There have been several complaints about the Aadhar venues not being disabled-friendly, of people with disability getting turned away, long hours of waiting to get registered and no facilities like washrooms etc.²³²

5. Confidentiality

The aspect of confidentiality has been dealt with in detail in the chapter on Article 22, Right to Privacy. The Census Commission and NSSO maintain confidentiality of the data collected, as they have clear cut norms for the same. Data is collected by various agencies - employment exchanges, employers, Vocational Rehabilitation Centres, NGOs, institutions and for various purposes - Disability Certification, Pensions, distributing aids and appliances, for training and employment etc. On one hand, there is lack of data in the country while on the other, there is a lot of much personal information that gets collected quite unnecessarily sometimes. For example, a person going to an NGO for joining a training programme gets probed about her/his family relationships, as they feel it is an important piece of information which might affect her/his training. Moreover, there are no norms for maintaining confidentiality of the information that is being collected there. The data is available in shared computers for all the staff to see; it gets shared with visitors and funding agencies. Stories are shared in conferences and are published in newspapers and on websites without taking any permission! Most of the violators of this right may not be even aware of the wrong they are doing and how it can affect an individual.

²³¹ http://en.wikipedia.org/wiki/Unique_Identification_Authority_of_India) accessed on 23rd October, 2011.

²³² TV 9, 10th September, 2011.

The Himachal Pradesh Government (Directorate of Social Justice and Empowerment) has published the entire list of persons with disabilities who have been issued Disability Certificates on their website, including their names, address, age, type of disability, which is available for anyone to see. This is clearly a violation of Right to Privacy for persons with disabilities.²³³

Recommendations

- 1) Disability laws should not only ensure collection of relevant data but also ensure the confidentiality of the information collected by the Government, private sector, NGOs and individuals.
- 2) Comprehensive disability data (gender segregated) should be collected and maintained by all relevant Ministries for all their development schemes and programmes. Aggregate data should be easily available for people to evaluate, analyse and assess so that the impact of various programmes can be determined and for future planning.
- 3) NSSO should ensure better enumeration of disability in the upcoming Survey. Involvement of leaders of disability is important to ensure an improved methodology and disability question.
- 4) Aadhar venues should be made disabled-friendly and people with disabilities should be given priority for registration. The officials should be sensitised to the needs of person with disabilities.
- 5) Greater awareness should be ensured for the next Census to ensure better enumeration.

²³³ District wise List of Issued Disability Identity Card, Directorate of Social Justice and Empowerment, Himachal Pradesh, <http://india.gov.in/outerwin.php?id=http%3A%2F%2Fhimachal.gov.in%2Fwelfare%2FSe archDCIS.asp> accessed on 6th December, 2011.

Article 32: International Cooperation

The text of Article 32 in the CRPD is given below.

1. *States Parties recognize the importance of international cooperation and its promotion, in support of national efforts for the realisation of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organisations and civil society, in particular organisations of persons with disabilities. Such measures could include, inter alia:*
 - a) *Ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities;*
 - b) *Facilitating and supporting capacity-building, including through the exchange and sharing of information, experiences, training programmes and best practices;*
 - c) *Facilitating cooperation in research and access to scientific and technical knowledge;*
 - d) *Providing, as appropriate, technical and economic assistance, including by facilitating access to and sharing of accessible and assistive technologies, and through the transfer of technologies.*
2. *The provisions of this article are without prejudice to the obligations of each State Party to fulfil its obligations under the present Convention.*

Survey Findings

1. The findings with respect to the efforts made by the government to promote international cooperation to complement national efforts to achieve the objectives of CRPD are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	59%
Dissatisfied	23%
Satisfied	7%
Extremely satisfied	0%
Do not know much about the issue	11%

According to the results of the survey, 82% of the respondents were dissatisfied with the efforts made by the Government to promote international cooperation to complement national efforts to achieve the objectives of the CRPD. It seems that persons with disabilities see a lot of potential in this area that has remained untapped. Sharing of funds, information, technology, research etc. seem to be

negligible. About 7% were satisfied with the Government's effort which could be a reflection of the international funds coming to some NGOs and to some Government programmes. About 11% respondents did not know much about the issue as some persons with disabilities may not be aware of what India is doing at an international or bilateral level with other countries in the area of disability.

Laws and Policies

The **Constitution of India**, under Directive Principles of State Policy, Section 51(c) states that "The State shall endeavour to foster respect for international law and treaty obligations in the dealings of organised peoples with one another". Section 253 states that "Parliament has power to make any law for the whole or any part of the territory of India for implementing any treaty, agreement or convention with any other country or countries or any decision made at any international conference, association or other body." Therefore, India is committed to giving effect to international agreements like the CRPD. India has ratified various international conventions for the protection of human rights and for the rights of women, children, and other vulnerable groups.

The Disability Act, 1995, states that one of the functions of the Central Coordination Committee, Section 8(2)(d), is to "take up the cause of persons with disabilities with the concerned authorities and the international organisations with a view to provide for schemes and projects for the disabled in the national plans and other programmes and policies evolved by the international agencies"

The National Trust Act, 1999, The Rehabilitation Council of India Act, 1992, and The Mental Health Act, 1987 do not mention international cooperation.

The Foreign (Contribution) Regulation Act, 2010 (FCRA) regulates the acceptance and utilisation of foreign contribution and foreign hospitality by persons and associations working in the important areas of national life.

Progress and Concerns

1. Contribution from International and Bilateral Organisations

International cooperation for India is in various areas like health, industry and commerce, infrastructure development etc. A few of the international and bilateral organisations work in the area of disability in India. The **World Health Organisation** works in the area of Injury, Disability and Rehabilitation and Mental Health, apart from other areas. It has prepared Guidelines for care of persons with Spinal Cord injury in the Community and Guidelines for Parents and Teachers for Early Identification & Disability Management in Children with Disability²³⁴.. The organisation also has programmes for providing psychological

²³⁴ WHO website, accessed at http://whoindia.org/en/Section20/Section385_1131.htm on 6th December, 2011.

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support for victims of disasters in India. The **World Bank** is assisting India in the areas of health, rural roads and water supply, urban development and many others. It did a detailed study on the Status of Persons with Disabilities in India which was published in 2009. It is supporting various States in the area of disability and trying to make existing systems work at the ground level. The **International Labour Organisation** protects working people who are discriminated on the basis of sex, age, origin, race, religion or health²³⁵.

Over an year ago, the **International Labour Organisation** came out with the idea of creating a Global Business and Disability Network - a platform for multinational companies, employers' organisations, N.G.O.s and disabled peoples' organisations etc. The idea is to facilitate the employment of people with disabilities. It recently held its Asian meeting in Bengaluru on February 17. Hosted by Wipro at its Sarjapur campus, the meeting saw participation from several Indian and multinational companies. Several presentations on best practices by companies worldwide were also made.²³⁶

In 2005, the **Asian Development Bank (ADB)** published 'Disabled People in Development: India Country Report'. It also funded poverty reduction programmes, including NGOs working in the area of disability, resulting in "increased educational assistance and rehabilitation support for deaf blind children; improved understanding and capacity of families and communities on rights, facilities, provisions related to the disability from low-income groups; and increased capacity of mothers of autistic children to effectively manage the progress of their children and support development of day-to-day skills in them."²³⁷

UNICEF works with socially excluded groups in the areas of health, nutrition, water, sanitation, HIV/AIDS, education and child protection. It has been helping in Braille production of Convention on the Rights of the Child (CRC). Copies of the Braille CRC are being distributed free of charge to schools for the visually impaired across West Bengal in Bengali and English.²³⁸

It is clear that many United Nations organisations fund various programmes in India as mentioned before. In addition, funds come from various countries for Government projects and to NGOs.

²³⁵ ILO website, accessed at <http://www.ilo.org/newdelhi/areasofwork/equality-and-discrimination/lang--en/index.htm> on 2nd November, 2011.

²³⁶ ILO's New Initiative to Promote Employment of Disabled People in the Private Sector, Disability News and Information Services (DNIS), 1st March, 2011, accessed at http://www.dnis.org/features.php?issue_id=5&volume_id=8&features_id=183 on 2nd November, 2011.

²³⁷ India: Integrating Poverty Reduction in Programs and Projects- Note on Poverty and Gender Component Financed by the Government of United Kingdom, Asian Development Bank, December, 2007.

²³⁸ A Braille version of the CRC spells out rights for the visually impaired in India, Angela Walker, 16th November, 2009 accessed at http://www.unicef.org/india/education_5911.htm on 7th December, 2011.

An analysis of the Home Ministry reports shows that the US, UK, Germany, Italy and Netherlands have been the top five donors to NGOs for the past several years, consistently giving over 50% of the total foreign contribution. Indian NGOs collectively received foreign contribution to the tune of over Rs. 49,968 crore during five years from 2005-06 to 2009-10. A total of 21,508 organisations received such funds in 2009-10. Some of the areas for which the funds are used are rural development, child welfare, environmental programmes, AIDS awareness and setting up religious schools.²³⁹

Information on how much of the money goes to disability rights related work is not available. There was also not much information available on international cooperation vis-a-vis research and technology related to disability.

The Ministry of Social Justice and Empowerment signed a Memorandum of Understanding with the Republic of Mauritius in various areas including disability in November 2007²⁴⁰. It includes

- Conducting training programmes in human resource development, viz. teachers and caregivers in inclusive education, special education, home based education, care services for disabled and senior citizens,
- Granting fellowships for training of scholars, caregivers and service providers from Mauritius for training in Prevention, Detection, Rehabilitation, Vocational Training, Assessment, fitting and production of Assistive Devices for all types of disabilities etc.,
- Pooling in resources for preparation of modules and manuals for training in the area of disability,
- Facilitating the exchange of Officers and experts between the two Governments in various fields of Social Defence and Disability,
- Holding joint workshops, seminars and symposia on human resource and programme development, curricula and modules, documentation etc.,
- Sharing of information and experience on best practices and mutual use of database between the two Governments,
- Undertaking documentation of information in the field of Disability for ensuring data support for intervention planning,
- Commissioning of joint research projects in the field of Disability to widen the scope of understanding and provide evidence based inputs for policy development and planning,
- Promoting networks and forums of civil society in the field of Disability.

The MoU between India and Mauritius seems to be covering a whole range of objectives to promote the rights of persons with disabilities. However, there was no information available on the progress made under this MoU.

The Ministry of Micro, Small and Medium Enterprises (MSME) has the Guidelines

²³⁹ In 5 Years, NGOs Got Rs. 49k Crore Foreign Funds, Vishwa Mohan, The Times of India, New Delhi, 7th December, 2011).

²⁴⁰ Ministry of Social Justice and Empowerment website, accessed at <http://socialjustice.nic.in/intercoop.php> on 7th December, 2011.

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of International Cooperation Scheme. However, it does not have focus on disability organisations, though it mentions that Registered Societies/Trusts and Organisations associated with the MSME are eligible for it.²⁴¹ Many more MoUs with other countries need to be undertaken in the area of rights of persons with disabilities. The scope of international cooperation is surely underutilised, as far as disability is concerned, for exchange of knowledge and funds.

There are many international organisations which are working on various issues like women rights, child rights, HIV/AIDS, poverty alleviation, education, health etc. Most of them are not addressing issues of persons with disabilities. Disability programmes remain exclusive.

2. Capacity Building and Information Sharing

Some international organisations are working in the area of capacity building and information sharing as mentioned above.

In addition, a few persons with disabilities have gone to various countries for higher studies. However, many of them find it difficult to avail scholarships for studying abroad. There are no international scholarships available exclusively for persons with disabilities nor is there any reservation for persons with disabilities in general scholarship schemes. The XI Five Year Plan (2007-11) proposed that “deserving persons with disabilities should be supported for training/education abroad, especially in studies relating to disability.” However, no action has been taken by the Government in this regard.²⁴²

There are often exchanges between national and international NGOs on a one to one basis. Many international volunteers come to India. For example, Voluntary Service Overseas (VSO) sends volunteers to many organisations working in the field of disability in India. Using their experience, the international volunteers work with their colleagues and members of the community sharing their skills and knowledge.²⁴³

Bureaucrats participate in various international meetings but seldom apply their knowledge or share the information with others. The same can be said even for some professionals in the disability sector. One example is the participation in The Washington Group on Disability Statistics, which was formed as a result of the United Nations International Seminar on Measurement of Disability that took place in June 2001. Even though there was some participation from India, the information acquired was never shared.

For decades, the Indian disability sector has been witness to a lobby of professionals who were happy with attending conferences and seminars

²⁴¹ Guidelines of International Cooperation Scheme, accessed at msme.gov.in/guidelines_schemes.pdf on 29th October, 2011.

²⁴² Page 32, Status Paper, Working Group on Empowerment of Persons with Disabilities for Formulation of XII Plan (2012-17), 2011.

²⁴³ VSO India website accessed at <http://www.vsoindia.org/> on 6th December, 2011.

abroad and writing books on their achievements and getting Government grants, land at posh locations and even awards. Then came the 90s and the entire sector saw a huge paradigm shift when disabled people themselves began taking charge of their movement... The Washington Group was set up in Washington in 2001. Since then, it has met 8 more times in various exotic locales across the world, namely Ottawa, Brussels, Bangkok, Rio de Janeiro, Kampala, Dublin, Manila, Dar es Salaam and the next meeting is scheduled in November 2010 in Luxembourg. If Mithu Alur or Sathi Alur or anyone else from their so-called 'Group' participated in these Washington Group deliberations, why then were the details of the meetings not ever intimated to the disability sector for all these years? Why these so-called champions of the Indian disability sector who represented us in those meetings, never felt the need to write a single letter, or an E-mail, or for that matter, why did they not 'approach the media' for all these years?

-Census 2011 and Disability – Mithu Alur's Publicity Stunt Enrages the Disability Sector, Dorodi Sharma, Disability News and Information Service (DNIS), 1st May, 2010.

In the area of capacity building through international cooperation, the Rehabilitation Council of India seems to have taken no initiative for exchange of expertise or for organising training programmes.

3. Persons with Disabilities as part of International Development Cooperation

Indian persons with disabilities have played an active role in international organisations and vice versa. Disabled People's International (DPI) has been active in India since the last many years and in December 2011, an Indian disability activist, Javed Abidi, was elected the Chairer of DPI. New Delhi also hosted the DPI meet in August 2011. However, there was little support in terms of disabled friendly infrastructure for the delegates.

The Government may be promoting Delhi as a disabled-friendly city, but a group of activists who want to hold an international workshop of Disabled Peoples International (DPI) is facing a huge problem. According to them, organising such an event in the capital is extremely difficult because even five-star hotels lack proper accommodation facilities for people with different needs and public transport poses another big hurdle.

Organisers said that they have spent a month looking for disabled-friendly accommodation facilities. Transportation is another area of concern for the delegates. There are no buses fitted with hydraulic lifts and the public transport system is not comfortable enough. "We are in talks with an NGO for such buses and have also requested the Chief Minister to rent us low-floor buses for four days so that the special guests can freely move around," said Javed Abidi.

- Durgesh Nandan Jha, 'No Room for Special Delegates', The Times of India, New Delhi, 12th June, 2011.

CRPD: Key Issues In India

Many other international disability organisations also work in India, for example the International Disability Alliance (IDA) has been playing an active role in training people with disabilities to understand the CRPD. There are other organisations like Sense International, Sight Savers and so on. Their focus varies from rehabilitation, education, formation of self help groups to capacity building and leadership training. The Royal National Institute for the Blind (RNIB) has undertaken the Bollywood Audio Description Project to enable audio description provision in both India and UK.²⁴⁴

The Government sends individuals and delegates from India to attend various conferences and training programmes in other sectors like health, women empowerment, child rights, infrastructure development, leadership of youth, entrepreneurship, education etc. However, the Government seldom thinks of including persons with disabilities in such delegations. Persons with disabilities would not only gain knowledge from such forums but also be able to contribute towards discussions and presentations. Persons with disabilities have varied experience and expertise. They can contribute to issues like formation of SHGs, DPOs, community based rehabilitation, indigenous low cost aids and so on.

4. Assistive Technologies

Bhagwan Mahaveer Viklang Sahayata Samiti conducts camps and exports various aids and artificial limbs like Jaipur Foot, calipers, modified footwear, hearing aids, special shoes for persons with different disabilities. "We have established several Jaipur foot centres abroad, for example in Manila, Nairobi, Nigeria, Rwanda, Uganda, Honduras, Panama, Trinidad & Tobago etc., through the help of Rotary Clubs, World Rehabilitation Fund and other agencies. We also provide training to the local technicians so that they can continue the work when our technicians come back to India. We are regularly exporting components and Jaipur Foot from India to these centres." So far 25 countries and nearly 20,000 beneficiaries have been benefited²⁴⁵.

It is an irony that while India has a huge market for many international goods and brands, the Government does little to promote international assistive devices and technologies for persons with disabilities. Some international brands are selling hearing aids in India but most of the assistive devices have to be imported by individuals or the NGOs. The maintenance of the aids thus becomes a problem.

There seems to be no information on international cooperation in the areas of research and development of aids and assistive devices which are being used and those that are appropriate for persons with disabilities living in various terrains and weather conditions of India. There are few non-governmental

²⁴⁴ RNIB website accessed at

<http://www.rnib.org.uk/livingwithsightloss/tvradiofilm/film/Pages/bollywood.aspx> on 7th December, 2011.

²⁴⁵ Bhagwan Mahaveer Viklang Sahayata Samiti, Jaipur website accessed at

http://www.jaipurfoot.org/05_fcamp.asp on 7th December, 2011

initiatives for exchange of knowledge on latest developments in this area. Techshare India has been organised since 2008 in India by BarrierBreak Technologies on assistive technologies. While it provides a platform for panel discussions and the exhibition of national and international aids and assistive devices, the Government seems to play little role in it or in taking up a similar initiative. The Organising committee of Techshare India features international bodies such as Royal National Institute of Blind People (RNIB), UK and Sight Savers International.

Recommendations

- 1) International Cooperation needs to be included in all disability and related laws in areas like capacity building, research, funds, science and technology, assistive aids and devices and so on as per the CRPD.
- 2) India should aim to be on the Committee of the CRPD.
- 3) Persons with disabilities need to be an integral part of international cooperation and exchange programmes not just in the disability field but also in all other development and human rights areas.
- 4) MoUs need to be signed with various countries for exchange of expertise in various aspects of disability.
- 5) Smaller NGOs, DPOs and SHGs need to be assisted in writing and sending proposals for international funding and exchange of expertise.
- 6) Rehabilitation Council of India should play an active role in bringing in disability experts for various capacity building programmes in the country.
- 7) Conferences on research, technology, assistive aids, information, best practices, employment, education etc. should be organised on a regular basis for exchange of ideas and information.
- 8) The Government should maintain data on how much international funding goes into the areas of disability rights.
- 9) Focus of international cooperation should include disability rights and the various provisions of CRPD.
- 10) Scholarships to be set up for persons with disabilities who wish to go for higher studies in disability related areas.

Article 35: Reports by States Parties

The text of Article 35 in the CRPD is given below.

1. *Each State Party shall submit to the Committee, through the Secretary-General of the United Nations, a comprehensive report on measures taken to give effect to its obligations under the present Convention and on the progress made in that regard, within two years after the entry into force of the present Convention for the State Party concerned.*
2. *Thereafter, States Parties shall submit subsequent reports at least every four years and further whenever the Committee so requests.*
3. *The Committee shall decide any guidelines applicable to the content of the reports.*
4. *A State Party which has submitted a comprehensive initial report to the Committee need not, in its subsequent reports, repeat information previously provided. When preparing reports to the Committee, States Parties are invited to consider doing so in an open and transparent process and to give due consideration to the provision set out in article 4, paragraph 3, of the present Convention.*
5. *Reports may indicate factors and difficulties affecting the degree of fulfilment of obligations under the present Convention.*

Progress and Concerns

All Governments are obliged to submit regular reports to the CRPD Committee on how the rights are being implemented. India's Report on the CRPD was to be submitted to the CRPD Committee in May 2010. **It is the last month of 2011 now, more than a year past the deadline, and India has still not submitted the report.**

In response to a Right to Information (RTI) query, the Government sent a draft report dated 29th April, 2011, to the National Centre for Promotion of Employment for Disabled People (NCPEDP). The draft country report has been prepared by the Centre for Disability Studies, NALSAR Law University, for the Government of India.

The Convention in Article 4(3) and 33(3) provides for close consultation with and active involvement of persons with disabilities, including children with disabilities, through their representative organisations in decision making processes and monitoring of the CRPD. However, **there has been no report of any such consultation with persons with disabilities or DPOs or Self Help Groups or organisations representing the rights of children or persons with disabilities, at the Central or the State/UT levels.**

This clearly reflects the lack of seriousness with which the Government is looking into the process and submission of its country report of the CRPD to the Committee.

Recommendations

- 1) Urgent consultations with persons with disabilities and their representative organisations for inputs for the preparation of a comprehensive country report of the CRPD.
- 2) The process of consultation with persons with disabilities to be transparent. The draft report should be available to all in different languages and in accessible formats to invite inputs and suggestions.
- 3) Government to make a time line for the process and announce a date by which the country report will be submitted. The Government should submit India's country report to the CRPD Committee at the earliest.

Article 49: Accessible Format

The text of Article 49 in the CRPD is given below.

The text of the present Convention shall be made available in accessible formats.

Survey Findings

1. The findings with respect to the efforts made by the government to make UNCRPD available in accessible formats are given below.

Rating	Percentage of Respondents
Extremely dissatisfied	53%
Dissatisfied	28%
Satisfied	10%
Extremely satisfied	0%
Do not know much about the issue	9%

About 81% of the respondents were dissatisfied with the efforts of the Government in making available the text of CRPD in accessible formats. It is clear that the Government has done little in this direction. Nearly 9% respondents did not know about the issue. About 10% were satisfied. They could be respondents who have had access to the CRPD in English through the Internet or in a language that they understand due to the efforts of an NGO.

Progress and Concerns

The Government has not taken any initiative to make available the CRPD in accessible formats for persons with disabilities. There has been no effort on the part of the Government to make the text available in Braille, CDs or in Sign Language.

India has two official languages, Hindi and English. While the text of the CRPD is available in English, **it is not available in Hindi on the website of Ministry of Social Justice and Empowerment** which is the nodal Ministry of issues concerning persons with disabilities (as on 12th December, 2011). While India has many languages, it has officially recognised 22 languages and the text of CRPD is unavailable in any of these. No effort has been done by the Government in this regard.

However, in various parts of the country, NGOs have tried to translate the text of CRPD in their local language. Some of these (Hindi, Bengali, Tamil, Malayalam, Kannada, Telugu and Gujarati) are available on the website of

UNCRPD India,²⁴⁶ an initiative of National Centre for Promotion of Employment for Disabled People (NCPEDP).

At an international level, it is important to note that while the CRPD has been translated in various languages and is available on the UN Enable website, it's translations in Indian Languages (Hindi, Tamil, Telugu, Gujarati, etc.) are not available there. Even neighbouring countries like Nepal and Bangladesh have the CRPD translations in Nepali and Bangla respectively on their websites.²⁴⁷ This clearly shows lack of initiative and interest of the Government in the affairs of the CRPD.

Recommendations

- 1) Text of CRPD to be made available in accessible formats.
- 2) Urgent translation of the text of CRPD in Hindi and other official languages (complete text and easy to read text).
- 3) Text of CRPD to be disseminated in accessible formats and in different languages through various mediums, free of cost.
- 4) The text of CRPD is available in simple language and for children. These can be used to make more appropriate versions for the Indian context.

²⁴⁶ Accessed at <http://uncrpdindia.org/> on 7th December 2011.

²⁴⁷ UN Enable website, accessed at <http://www.un.org/disabilities/default.asp?id=150> on 7th December, 2011.

Annexure 1

THE CRPD SURVEY RESPONDENTS OF THE QUESTIONNAIRE

1. A. Dhana Sekar, Ektha, Tamil Nadu
2. A. Ravichandran, Vazhnthu Kattuvom Project, Tamil Nadu
3. A.S. Narayanan National Association of the Deaf, India, New Delhi
4. Alok Sikka, Action for Ability Development and Inclusion (AADI) and Association of Disabled for Development (ADD), New Delhi
5. Amitabh Mehrotra, SPARC India, Uttar Pradesh
6. Anil Joshi, Maharashtra
7. Anjali Sardana, National Thalassaemia Welfare Society, Uttar Pradesh
8. Ankit Jindal, Karnataka
9. Arman Ali, Shishu Sarothi, Assam
10. Asha Mehra, Swavalamban, New Delhi
11. Ashok Kumar Yadav, Northern Railway Physically Handicap Welfare Association, Delhi
12. Avelino de Sa, Disability Rights Association of Goa, Goa
13. Battihun Mary, Meghalaya
14. Bertha G. Dkhar, Bethany Society, Shillong, Meghalaya
15. Bhargavi V. Davar, Bapu Trust for Research on Mind and Discourse, Maharashtra
16. Dilip Kumar Jangir, Rajasthan Association of the Deaf, Rajasthan
17. Dipendra Manocha, DAISY Forum of India, New Delhi
18. Dipti Bhatia, Vidya Sagar, Tamil Nadu
19. Divya Arora, Maharashtra
20. G. Ramanathan, Karnataka Angavikalara Rajya Okkuta (KARO) and SAMA Foundation, Karnataka
21. Dr. Garimella Subramanian, Tamil Nadu
22. Geeta Sharma, National Association of the Deaf, India, New Delhi
23. George Abraham, Score Foundation, New Delhi
24. H. P. Kotian, Access India, Maharashtra
25. Major Gen. Ian Cardozo, Rehabilitation Council of India, War Wounded Foundation, New Delhi
26. Javed Ahmad Tak, Humanity Welfare Organization Helpline NGO, Jammu and Kashmir
27. Dr. Jayanth Kumar Y.B., AIFO India, Karnataka
28. Kanchan Pamnani, Maharashtra
29. Ketan Kothari, Maharashtra
30. Prof. Dr. Ketna L. Mehta, Neena Foundation, Maharashtra
31. Konsam Sadananda Singh, Students Welfare Association for the Blind, Manipur
32. Kritu Mehra, Swavalamban, New Delhi
33. L.Subramani, Retina India, Karnataka
34. Dr. Lavanya Seshasayee, The Bapu Trust for Research on Mind and Discourse – Pune, Karnataka
35. Livingston A., Vasantham Federation for Differently Abled Society, Tamil Nadu

36. M. Srinivasulu, Network of Persons with Disabilities Organisations, Andhra Pradesh
37. M.Manikandan, Vazhnthu Kattuvom Project, Tamil Nadu
38. Mahesh Chandrasekar, CBR Forum, Karnataka
39. Meenakshi B., Vidya Sagar, Tamil Nadu
40. Dr. Meenu Bhambhani, Karnataka
41. Mohan Chaudhary, Bihar Viklang Kalyan Parishad, Bihar
42. Mohd. Iqbal, People Action Group for Inclusion and Rights, Jammu and Kashmir
43. Mukesh Garodia, Haemophilia Federation (India), Assam
44. Mukesh Gupta, Northern Railway Physically Handicapped Employees Welfare Association, New Delhi
45. Nandini Ghosh, IDSK, West Bengal
46. Neeta Parag Panchal, Disability Advocacy Group (DAG), Gujarat
47. Nirmita Narasimhan, Centre for Internet and Society, Karnataka
48. Dr. P. K. Gopal, IDEA India, Tamil Nadu
49. Parag Rasiklal Panchal, Handicap International, Gujarat
50. Poonam Natarajan, New Delhi
51. Pramod Kumar, Swavalamban, New Delhi
52. Prateeksha Sharma, Hansadhvani Foundation, National Capital Region
53. Praveen Kumar G., Voluntary Service Overseas (VSO), New Delhi
54. Premroop Alva, Hemophilia Federation India, Karnataka
55. Priya Varadan, New Delhi
56. R. C. Sharma, J & K Handicapped Welfare Association, Jammu and Kashmir
57. R. Kannan, Tamil Nadu
58. Dr. R. Narayanan, The Pondicherry Physically Handicapped Welfare Association, Puducherry
59. Rahul Cherian, Inclusive Planet, Tamil Nadu
60. Raja Mahendra Pratap, Gujarat
61. Rajesh H. Asudani, Blind Graduates Forum of India, Maharashtra
62. Rajiv Rajan, Ektha, Tamil Nadu
63. Rajni Bala, Know Well Info Domain (KID), Himachal Pradesh
64. Ravi Shekhar, Patna Deaf Friendship Club and National Association of the Deaf, Bihar
65. Reshma Valliappan, Red Door, Maharashtra
66. Rezina Khatun, Sanchar, West Bengal
67. S. Hari Hara Kumar, Deaf Enabled Foundation, Andhra Pradesh
68. Dr. Sam Taraporevala, Xavier's Resource Centre for the Visually Challenged, Maharashtra
69. Dr. Shanti Auluck, Muskaan/Parents Association for the Welfare of Children with Mental Handicap, New Delhi
70. Shivani Gupta, AccessAbility, New Delhi
71. Smitha S. S., Multiple Sclerosis Society of India, Chennai, Tamil Nadu
72. Soma Shekar, Hemophilia Society, Karnataka
73. Suchandra Dutta, Pratibandhi Yuva Federation, West Bengal
74. Suhas Karnik, Maharashtra
75. Dr. Sunil Kumar Singh, Adarash Viklang Sewa Sansthan Rosera, Bihar
76. Dr. Suresh Hanagavadi, Hemophilia Federation (India) and Karnataka Hemophilia Society, Karnataka
77. T. Raghava, All India Deaf Bank Employees Association, Tamil Nadu

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78. T.A.P. Varadakutti, Tamil Nadu Association for the Welfare of Differently Abled, Tamil Nadu
79. T.K.M. Sandeep, Deaf Enabled Foundation, Andhra Pradesh
80. T.M.N. Deepak, Tamil Nadu Handicapped Federation Charitable Trust, Tamil Nadu
81. Tanu Verma, National Thalassemia Welfare Society, New Delhi
82. Dr. V. J. Cordeiro, Karnataka
83. Vaishnavi Jayakumar, Tamil Nadu
84. Vijay Krishnamani, New Delhi
85. Y. Suresh Kumar, National Forum (an umbrella organisation representing the country's leprosy affected, (Karnataka State Branch), Karnataka
86. Zamir Dhale, Sense International-India, Gujarat
87. Zorin Singha, National Association of the Deaf, Uttar Pradesh

Annexure 2

Progress Report on Implementation of UNCRPD in India²⁴⁸

The aim of the Survey is to evaluate the progress made by the government in implementing the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in the last three-and-a-half years since the ratification and its impact on the lives of persons with disabilities.

We request you to share your opinion/satisfaction on the measures taken by the government to implement UNCRPD. The Survey comprises of three sections – Personal Information, Part A and Part B. Part A is objective type and is compulsory. Part B is open ended. Though it is an optional section, we would still encourage you to please take your time to answer it. It would help in substantiating the rating you have given and in highlighting the issues concerning persons with disabilities. If you want to attach any documents/newspaper reports, please send them to us by mail/courier/post.

This questionnaire is being sent to only a few select persons with disabilities from all over India. Your response and involvement is therefore, very crucial for us. This is an exhaustive questionnaire and will take some of your precious time. Your cooperation will go a long way in highlighting the current scenario of persons with disabilities in India. We also request you to keep in mind other persons with disabilities in the country when you are filling your responses, in addition to your own experiences.

Kindly send the filled-in questionnaire by Monday, 16th May 2011 to rama_c@deoc.in and sakshibroota@yahoo.com. *In case you fill the questionnaire by hand, please courier it to 77, 5th Main, Binny Layout Stage 2, Vijayanagar, Bengaluru - 560040. Please call us at 9880583277 or E-mail us at rama_c@deoc.in for any queries.*

²⁴⁸ Copyright © National Centre for Promotion of Employment for Disabled People (NCPEDP), New Delhi, 2011. Using this Questionnaire, in whole or part, requires the prior permission of NCPEDP.

NCPEDP Questionnaire – Progress Report on Implementation of UNCRPD in India

PERSONAL INFORMATION:

Full Name	
Age	
Gender	
Nature of disability	
Address	
State/Union Territory	
Pin Code	
E-mail ID	
Phone and mobile number/s	
Name of the Organisation (if representing any organisation)	
Occupation	

Part A (Compulsory)

Please give your Rating for each Article of UNCRPD given below with respect to the efforts made by the government in implementing it.

Rating Scale of 1 to 4

1 - Extremely dissatisfied (No steps taken by the government to implement the provisions of the Article and there are several violations)

2 – Dissatisfied (May be some small steps taken to implement the provisions of the Article, but little or no impact at the ground level)

3 – Satisfied (Steps are being taken in the right direction to implement the Article and some concrete impact seen at the ground level)

4 - Extremely satisfied (Full compliance with the letter and spirit of UNCRPD, including appropriate legislation, effective implementation and monitoring and impact felt and seen at the grassroots)

The '**Rating Question**' is given in Column 2. Please refer to the Column 3, '**Guiding Questions**²⁴⁹', which would help you in the rating. Please write your Rating (for the question in Column 2) in Column 4, (in the scale 1 to 4), as explained above.

Please note all questions should be answered. In case you do not know about a specific topic, you can write '**Do not know much about the issue**'.

²⁴⁹ Some ideas for the guiding questions have been taken from the Guidance Document 'Effective Use of International Human Rights Monitoring Mechanisms to Protect the Rights of Persons with Disabilities' developed by International Disability Alliance (IDA), May 2010

NCPEDP Questionnaire – Progress Report on Implementation of UNCRPD in India

<p>(1) Article</p>	<p>(2) Questions for Rating</p>	<p>(3) Guiding Questions (consider them when Rating)</p>	<p>(4) Give your Rating (in Scale 1 to 4) 1-Extremely Dissatisfied 2-Dissatisfied 3-Satisfied 4-Extremely Satisfied OR say "Do not know much about the issue"</p>
<p>Articles 1-5, 8, 9 and 33: Purpose, Definition, General principles, General obligations and Equality and non-discrimination of people with disabilities, National implementation and monitoring</p>	<p>1. Rate your satisfaction level with respect to the efforts made by the government to achieve the purpose and the objectives of UNCRPD.</p>	<p><i>Has the government taken steps to:</i></p> <ul style="list-style-type: none"> - set up a focal point (designated authority) to implement UNCRPD? - develop an action plan/framework/time frame for the implementation? - framed policies/schemes for implementing various provisions? -allocate adequate budget for UNCRPD? -undertake review of existing disability legislation and other mainstream legislations to identify inconsistencies with the UNCRPD? -disseminate UNCRPD to relevant ministries, state government and other stakeholders, including private sector? -translate UNCRPD in all official Indian languages and in accessible formats (Braille, audio, sign language, easy-to-read version)? -ensure a system of answerability and penalties against those discriminating against persons with disabilities? -broaden the definition of disability, covering all persons with impairments who face barriers which affect their participation in society? 	

Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
	2. Rate the impact on the lives of persons with disabilities with India's ratification of UNCRPD.	<p><i>Has there been positive changes due to UNCRPD in terms of:</i></p> <ul style="list-style-type: none"> - increased opportunities for people with disabilities? - increased accessibility to services, facilities, information, etc.? -increased awareness of rights of people with disabilities amongst various stakeholders (including private sector)? -increased awareness among people with disabilities and families? - improved social security and quality of life? - positive judgments in the courts of India, based on UNCRPD? 	
	3. Rate the involvement of persons with disabilities in the implementation and monitoring of UNCRPD.	<p><i>Has government taken measures to:</i></p> <ul style="list-style-type: none"> -mandate active involvement of persons with disabilities and representative Disabled Peoples' Organisations (DPOs) while formulating legislations, policies and schemes? -constitute committees of persons with disabilities at various levels? -organise consultations to seek inputs for writing the government report of UNCRPD? 	

NCPEDP Questionnaire – Progress Report on Implementation of UNCRPD in India

Article	Questions for Rating	<i>Guiding Questions (consider them when Rating)</i>	Give your Rating
Article 6 - Women with disabilities	6.1. Rate your satisfaction level with respect to the efforts made by the government for ensuring equality of rights and opportunities of women with disabilities when compared with women without disabilities.	<i>Has the government taken measures to:</i> <ul style="list-style-type: none"> - formulate legislation/policy to uphold the rights of women with disabilities? - ensure general laws/policies/schemes for promoting women rights include women with disabilities? - organise consultation with women with disabilities in policy making? - set up redress system for women with disabilities to file complaints? 	
Article 7 - Children with disabilities	7.1. Rate your satisfaction level with respect to the efforts made by the government for ensuring equality of rights and opportunities of children with disabilities.	<i>Has the government taken steps to:</i> <ul style="list-style-type: none"> - ensure that general laws/policies/schemes promoting the rights of children address the situation of children with disabilities? - initiate specific schemes and policies to promote equal rights of children with disabilities? - educate children with disabilities on their rights? - ensure that the views of children with disabilities are taken into account while making policies and schemes that affect them? 	

Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
Article 8 - Awareness Raising	8.1. Rate your satisfaction level with respect to the efforts made by the government to create awareness amongst persons with disabilities, their families and the society at large about disability rights, as per UNCRPD.	<p><i>Has the government taken steps to ensure:</i></p> <ul style="list-style-type: none"> - <i>UNCRPD is available in a language that you/family/community understand?</i> - <i>media portrays persons with disabilities in a positive manner?</i> - <i>use of mass media for creating awareness on UNCRPD?</i> 	
	8.2. Rate your satisfaction level with respect to the efforts made by the government to create awareness amongst government officials (central and local).	<p><i>Has the government taken steps to:</i></p> <ul style="list-style-type: none"> - <i>share information about UNCRPD through official notification to various ministries/departments at central and local levels?</i> - <i>create awareness through workshops and trainings?</i> 	

NCPEDP Questionnaire – Progress Report on Implementation of UNCRPD in India

Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
<p>Article 9 – Accessibility</p>	<p>9.1. Rate your satisfaction level with respect to the efforts made to promote accessibility of built environment.</p>	<p><i>Has the government taken measures to:</i></p> <ul style="list-style-type: none"> - <i>include disability in the urban and rural development plans, building laws/policies, etc.?</i> - <i>formulate and mandate minimum accessibility standards?</i> - <i>establish monitoring mechanisms, including setting up time frame, to ensure accessibility standards are followed?</i> - <i>mandate private entities that offer facilities and services to the public to take into account accessibility</i> - <i>include accessibility in the curriculum of courses in architecture, engineering, etc.?</i> 	
	<p>9.2. Rate your satisfaction level with respect to the efforts made to promote accessibility of transport.</p>	<p><i>Has the government taken measures to:</i></p> <ul style="list-style-type: none"> - <i>include disability in the transport laws/policies/plans?</i> - <i>formulate minimum accessibility standards for all means of transport, including railway station, bus terminus, airports, etc.?</i> - <i>set time frame and establish monitoring mechanisms to ensure accessibility standards are followed?</i> - <i>mandate private manufactures of vehicles to follow accessibility standards?</i> - <i>train the service providers to ensure appropriate services and support to people with disabilities?</i> - <i>establish redress mechanism for any complaints?</i> 	

Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
	9.3. Rate your satisfaction level with respect to the efforts made to promote accessibility of services (health, banking, etc.)	<p><i>Has the government taken measures to:</i></p> <ul style="list-style-type: none"> - <i>include disability in the laws/policies/schemes of various general services?</i> - <i>set time frame and establish monitoring mechanisms to ensure accessibility standards are followed?</i> - <i>mandate private entities to ensure non discrimination?</i> - <i>train the service providers to ensure appropriate services and support to people with disabilities?</i> - <i>establish redress mechanism for any complaints?</i> 	
	9.4. Rate your satisfaction level with respect to the efforts made to promote accessibility of information.	<p><i>Has the government taken measures to:</i></p> <ul style="list-style-type: none"> - <i>formulate laws/policy to ensure right to accessible information for persons with disabilities?</i> - <i>promote and develop sign language interpreter training?</i> - <i>ensure access to reader/scribe/ interpreter /transcriber services?</i> - <i>ensure appropriate signages (including in Braille/ voice enabled mechanisms in buildings and other facilities)?</i> - <i>provide public information in accessible formats, including in easy-to-understand language?</i> - <i>promote and recognise augmentative communication?</i> - <i>ensure easy access to communication aids/appliances and technologies?</i> 	

NCPEDP Questionnaire – Progress Report on Implementation of UNCRPD in India

Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
	9.5. Rate your satisfaction level with respect to the efforts made to promote accessibility of consumer goods.	<p><i>Has the government taken steps to:</i></p> <ul style="list-style-type: none"> - formulate legislation/policy to ensure access for persons with disabilities to consumer goods (clothing, electronics, automobiles, etc.)? - define the accessibility standards and include them in the general standards of consumer goods? - mandate private entities to follow accessibility standards? - put in place implementation and monitoring mechanism? 	
	9.6. Rate your satisfaction level with respect to the efforts made to promote accessibility of Information Communication Technology (ICT).	<p><i>Has the government taken steps to:</i></p> <ul style="list-style-type: none"> - formulate legislation/policy to ensure access for persons with disabilities to information and communications technologies and systems, including the Internet? - set a time frame and monitoring mechanisms to ensure accessibility of websites/software? - mandate private entities that provide online services to public to ensure accessibility? 	
	9.7. Rate your satisfaction level with respect to the efforts made to promote availability of assistive devices.	<p><i>Has the government taken steps to promote the design, development, production and distribution of accessible devices/technologies so that these are available at minimum cost?</i></p>	

Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
Article 10 - Right to Life	10.1. Rate your satisfaction level with respect to the efforts made by the government to promote right to life of persons with disabilities.	<p><i>Has the government taken steps to:</i></p> <ul style="list-style-type: none"> -formulate laws/policies/systems to protect the lives of persons with disabilities from various medical and other malpractices which may lead to their death? -create awareness about the right to life among medical fraternity and the community? -ensure access to support and rehabilitation services? 	
Article 11 - Situations of risk and humanitarian emergencies	11.1. Rate your satisfaction level with respect to the efforts made by the government to provide protection and safety to persons with disabilities in situations of risk and humanitarian emergencies.	<p><i>Has the government taken measures to ensure:</i></p> <ul style="list-style-type: none"> - formulation of laws/policies for protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters? - camps/shelters /places for safe refuge are accessible to persons with disabilities? - general rehabilitation measures include disability aspects? 	
Article 12 - Equal recognition before the law	12.1. Rate your satisfaction level with respect to the efforts made by the government to ensure that persons with disabilities are able to take decisions for themselves with necessary support and safeguards being made available, so as to ensure their full legal capacity as per UNCRPD.	<p><i>Has the government taken measures to:</i></p> <ul style="list-style-type: none"> - remove legal or procedural restrictions/barriers that prevent persons with disabilities to sign a contract, obtain a mortgage or other financial and legal transactions? - ensure persons with disabilities have the right under the law to accept or to refuse medical treatment or scientific experimentation/medical trials? - ensure the legal capacity of persons with disability and to provide for support to exercise that capacity? - prevent forced institutionalisation? 	

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Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
<p>Article 13 - Access to Justice</p>	<p>13.1. Rate your satisfaction level with respect to the efforts made by the government to ensure access to justice for persons with disabilities in India.</p>	<p><i>Has the government taken measures to:</i></p> <ul style="list-style-type: none"> - <i>ensure equal access to justice (i.e. for all legal proceedings; as complainants, defendants, witnesses, or third parties and at all stages of the proceedings) in terms of:</i> <ul style="list-style-type: none"> - <i>Court rooms being accessible to persons with physical disabilities?</i> - <i>Reasonable accommodations for persons with disabilities (example, sign language interpretation, augmentative communication and other forms of assistance for persons with disabilities)?</i> - <i>Access to information (court orders, etc.) in accessible formats and easy-to-read formats?</i> - <i>ensure persons with disabilities have equal opportunity to be a judge, member of a jury, or witness?</i> - <i>remove legal barriers that categorise the testimony of persons with disabilities as null or limited?</i> - <i>ensure appropriate training for those working in the field of administration of justice, including police and prison staff?</i> 	
<p>Article 14 – Liberty and security of person</p>	<p>14.1. Rate your satisfaction level with respect to the efforts made by the government to ensure the right to liberty and security of persons with disabilities in India.</p>	<p><i>Has the government taken steps to ensure:</i></p> <ul style="list-style-type: none"> - <i>the right of persons with disability to not be locked in a cell or a room (except when convicted for a crime), or have her/his movement restricted in any other extreme way?</i> - <i>accessibility of prisons in the country?</i> 	

Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment and Article 16 - Freedom from exploitation, violence and abuse	15.1. Rate your satisfaction level with respect to the efforts made by the government to prevent torture, exploitation, violence and abuse of persons with disabilities in India as per UNCRPD.	<p><i>Has government taken measures to:</i></p> <ul style="list-style-type: none"> - formulate laws/policies and administrative measures to prevent torture, exploitation, violence (including domestic violence, inhuman/degrading treatment) and abuse, including for persons who live in institutions? - create awareness to prevent violence/abuse? - establish redress mechanism for filing complaints? - ensure support to victims of violence? - ensure shelters and support services are accessible? 	
Article 17 – Protecting the integrity of the person	17.1. Rate your satisfaction level with respect to the efforts made by the government to protect the integrity of persons with disabilities in India.	<p><i>Has the government taken measures to:</i></p> <ul style="list-style-type: none"> - formulate legislation/policy, implementation and monitoring mechanisms to protect from medical and other interventions done against the will of the person (for example, sterilizing a person with disability against her/his will or without her/his knowledge, over-medicating residents in care homes or forcing a person with disability into a marriage, etc.)? 	
Article 18 - Liberty of movement and nationality	18.1. Rate your satisfaction level with respect to the efforts made by the government to ensure liberty of movement and nationality.	<p><i>Has the government taken steps to:</i></p> <ul style="list-style-type: none"> - formulate a legislation/policy to protect the freedom of persons with disabilities to go to another country or to come back to their country? - ensure people with disabilities are not discriminated in case they want to obtain/change their nationality? - ensure airport security measures or passport requirements or immigration rules do not discriminate against persons with disabilities? 	

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Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
<p>Article 19 - Living independently and being included in the community</p>	<p>19.1. Rate your satisfaction level with respect to the efforts made by the government to promote independent living for persons with disabilities and be included in the community.</p>	<p><i>Has the government taken steps to:</i></p> <ul style="list-style-type: none"> - <i>formulate legislation/policy to protect the right of persons with disability to choose where they live and who they live with, i.e. no person should be unlawfully forced into a particular living arrangement (for example be forced to live in a care home against their will)?</i> - <i>provide support services, personal assistance for persons with disabilities to realise their choice of how they wish to live in the community (live on their own, establish a household and family of their own or live in a shared flat)?</i> - <i>ensure mainstream community services and facilities accessible to persons with disabilities (for example, health, market, banking, etc.)?</i> - <i>establish community services for people to move out of institutions?</i> 	
<p>Article 20 – Personal mobility</p>	<p>20.1. Rate your satisfaction level with respect to the efforts made by the government to ensure that persons with disabilities have access to mobility and other assistive aids and technologies at affordable cost.</p>	<p><i>Has the government taken measures to:</i></p> <ul style="list-style-type: none"> - <i>formulate legislation/policy/schemes to ensure persons with disabilities can access and afford suitable assistive devices/technologies for mobility?</i> - <i>create systems for easy access to mobility aids?</i> - <i>ensure access to mobility training for those who require?</i> 	

Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
Article 21 – Freedom of expression and opinion, and access to information	21.1. Rate your satisfaction level with respect to the efforts made by the government to ensure that persons with disabilities have access to information.	<p><i>Has the government taken measures to:</i></p> <ul style="list-style-type: none"> - <i>formulate legislation/policy and systems to ensure that persons with disabilities have the right to information in accessible formats and in easy language?</i> - <i>ensure that public information is available in alternative formats at no additional cost and in a timely manner?</i> - <i>ensure deaf persons are able to use sign language in their interaction in public offices?</i> - <i>ensure that the websites of agencies offering services or information (for example, railways, banks) to the public are compliant with web accessibility standards?</i> - <i>ensure national copyright legislation allow the access of information for persons with disabilities requiring alternative formats?</i> - <i>recognise sign language as official language and promote its use?</i> - <i>promote accessibility of mass media (for example, captioning in TV, movies)?</i> 	

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Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
<p>Article 22 - Respect for Privacy</p>	<p>22.1. Rate your satisfaction level with respect to the efforts made by the government to ensure respect for privacy of persons with disabilities.</p>	<p><i>Has government taken measures to:</i></p> <ul style="list-style-type: none"> - formulate laws/policies to ensure persons with disabilities have the right to privacy, including those who live in large or small institutions or who rely on a high level of support? - ensure that the information that you share about yourself and your disability to professionals/ organisations remains confidential, unless you explicitly agree to share it? - remove barriers that may be imposed by law/policy/practice to prevent persons with disabilities from having personal and sexual relationship, as per their choice? - establish systems to complain in case of any breach of privacy? 	
<p>Article 23 - Respect for home and the family</p>	<p>23.1. Rate your satisfaction level with respect to the efforts made by the government to ensure that persons with disabilities have a right to home and family and have adequate respect and support for the same.</p>	<p><i>Has the government taken measures to:</i></p> <ul style="list-style-type: none"> - formulate laws/policies to ensure the right to persons with disabilities as others to live in their families, start a family and in all family related matters including marriage, having children, adoption, custody of children and divorce? - formulate legislation to prevent any measure of forced sterilization of persons with disabilities, especially women and girls? - ensure community support, including support to undertake their child-rearing responsibilities? 	

Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
Article 24 - Education	24.1. Rate your satisfaction level with respect to the efforts made by the government to ensure that persons with disabilities have access to education on an equal basis at the primary and secondary levels.	<p><i>Has the government taken steps to:</i></p> <ul style="list-style-type: none"> - <i>formulate legislation/policies and administrative measures to ensure that persons with disabilities are not excluded from the general education system (including private educational institutions)?</i> - <i>ensure reasonable accommodation/adjustments are provided?</i> - <i>initiate programmes in schools for facilitating the learning of Braille, sign language, augmentative and alternative modes of communication and mobility skills?</i> - <i>provide individualised support and tailor curriculum/provide flexibility based on individual need?</i> - <i>ensure education is delivered in the most appropriate modes and means of communication for the individual, and in environments which maximize academic and social development?</i> - <i>employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille?</i> - <i>train professionals and staff who work at all levels of education?</i> 	
	24.2. Rate the government's steps to ensure that persons with disabilities have access to education on an equal basis for higher education, vocational training, adult education, etc.	<i>Refer to the points above with respect to vocational/higher /adult education.</i>	

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Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
Article 25 – Health	25.1. Rate your satisfaction level with respect to the efforts made by the government to ensure that persons with disabilities have access to adequate health services.	<p><i>Has the government taken steps to:</i></p> <ul style="list-style-type: none"> - formulate legislation/policy and system to ensure non discrimination of persons with disabilities in the general health system? - guarantee those health services needed for the early identification and intervention? - ensure general health services respectful of the rights of persons with disabilities, including all accessibility related issues (sign language, information in alternative formats such as Braille and plain language, accessible facilities)? - ensure access to affordable or free of cost health services? - ensure access to public health campaigns? - ensure training to medical professionals on the rights of persons with disabilities? - ensure equal access to health and life insurance? - prevent discriminatory denial of health care or health services or food and fluids on the basis of disability? 	
Article 26 - Habilitation and rehabilitation	26.1. Rate your satisfaction level with respect to the efforts made by the government to ensure that persons with disabilities have access to habilitation and rehabilitation services close to their communities.	<p><i>Has the government taken steps to:</i></p> <ul style="list-style-type: none"> - ensure wide range of habilitation and rehabilitation services available in their own community, including rural areas? - have programmes to begin habilitation and rehabilitation at the earliest possible stage? - provide initial and continuing training for professionals and staff providing services? - promote the availability, knowledge and use of assistive devices and technologies for habilitation and rehabilitation? 	

Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
Article 27 - Work and employment	27.1. Rate your satisfaction level with respect to the efforts made by the government to ensure that persons with disabilities have access to employment opportunities in the public sector.	<p><i>Has government taken steps to:</i></p> <ul style="list-style-type: none"> - ensure legislation/policy and administrative measures to prohibit discrimination on the basis of disability, including denial of reasonable accommodation/adjustments, with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions? - ensure people with disabilities are not prevented from joining a job based on their choice and skills? - ensure persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others? - initiate programmes to general technical and vocational guidance, placement services and vocational and continuing training? 	
	27.2. Rate your satisfaction level with respect to the efforts made by the government to ensure that persons with disabilities have access to employment opportunities in the private sector.	<p><i>Has the government taken steps to:</i></p> <ul style="list-style-type: none"> - formulate legislation/policy and systems to prohibit discrimination on the basis of disability in the private sector, including denial of reasonable accommodation/adjustments? - communicate to private sector about the provisions in the UNCRPD? - set up redress mechanism to file complaints by people with disabilities? - promote employment opportunities by providing effective incentives? 	

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Article	Questions for Rating	<i>Guiding Questions (consider them when Rating)</i>	Give your Rating
	27.3. Rate your satisfaction level with respect to the efforts made by the government to ensure that persons with disabilities have access to self employment opportunities and entrepreneurships.	<i>Has the government taken steps to: - initiate effective programmes to promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business?</i>	
	27.4. Rate your satisfaction level with respect to the efforts made by government to provide support to people with high support needs to secure and retain employment.	<i>Has the government taken steps to: - formulate laws/policies/programmes for promoting employment for people with high support needs? - ensure access to support like job coaches, etc.? - ensure access to individualised support including on-the-job training? - initiate incentives and support to employers to encourage their employment?</i>	

Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
Article 28 – Adequate standard of living and social protection	28.1. Rate your satisfaction level with respect to the efforts made by the government to ensure that persons with disabilities have access to adequate standard of living and social protection.	<p><i>Has the government taken steps to:</i></p> <ul style="list-style-type: none"> <i>- ensure appropriate legislation/policy, schemes and administrative measures to ensure the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions?</i> <i>- provide adequate allowances to people with disabilities to cover disability-related extra expenses?</i> <i>- formulate policies and programmes to ensure equal access by persons with disabilities to clean water services?</i> <i>- formulate policies/schemes to ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes?</i> <i>- ensure access by persons with disabilities to public housing programmes?</i> <i>- ensure equal access by persons with disabilities to retirement benefits and programmes?</i> 	

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Article	Questions for Rating	<i>Guiding Questions (consider them when Rating)</i>	Give your Rating
<p>Article 29 - Participation in political and public life</p>	<p>29.1. Rate your satisfaction level with respect to the efforts made by the government to ensure that persons with disabilities have access to equal participation in political and public life.</p>	<p><i>Has the government taken steps to:</i></p> <ul style="list-style-type: none"> - <i>ensure legislation/policies and administrative measures to ensure equal participation of persons with disabilities in political and public life?</i> - <i>repeal any general electoral law/s that exclude some persons with disabilities from the right to vote or from the right to be elected?</i> - <i>ensure that voting procedures, facilities and materials are appropriate, accessible and easy-to-understand?</i> - <i>facilitate vote by secret ballot in elections without intimidation; stand for elections and perform all public functions at all levels of government?</i> - <i>ensure participation of persons with disabilities in non-governmental organisations and associations?</i> - <i>ensure representation and participation of persons with disabilities at international, national, regional and local levels seminars, meetings, etc.?</i> 	

Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
Article 30 – Participation in cultural life, recreation, leisure and sport	30.1. Rate your satisfaction level with respect to the efforts made by the government to ensure that persons with disabilities have access to participation in cultural life, recreation, leisure and sports.	<p><i>Has the government taken steps to:</i></p> <ul style="list-style-type: none"> - <i>formulate legislation/policy and systems to ensure that persons with disabilities are able to take part on an equal basis in cultural life, including access to cultural materials in accessible formats (including sign language); access to television programmes, films, theatre and other cultural activities; places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and access to monuments and sites?</i> - <i>provide opportunities to develop and utilise their creative, artistic and intellectual potential?</i> - <i>encourage and promote the participation of persons with disabilities in mainstream sporting activities?</i> - <i>ensure persons with disabilities have an opportunity to organise, develop and participate in disability-specific sporting and recreational activities?</i> - <i>ensure children with disabilities have equal access to participation in play, recreation and leisure and sporting activities, including those activities in the school system?</i> - <i>repeal intellectual property laws that may be a barrier to persons with disabilities seeking access to cultural material?</i> 	

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Article	Questions for Rating	Guiding Questions (consider them when Rating)	Give your Rating
<p>Article 31 - Statistics and data collection</p>	<p>31.1. Rate your satisfaction level with respect to the efforts made by the government to collect, maintain and disseminate data on persons with disabilities.</p>	<p><i>Has the government taken steps to:</i></p> <ul style="list-style-type: none"> - collect appropriate information, including statistical and research data, to formulate and implement policies to give effect to UNCRPD? - collect, maintain and disseminate disability data for its various development schemes and programmes? - ensure that the process of collecting and maintaining data comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities? - disseminate the statistics and ensure their accessibility to persons with disabilities and others? 	
<p>Article 32 - International cooperation</p>	<p>32.1. Rate your satisfaction level with respect to the efforts made by the government to promote international cooperation to complement national efforts to achieve the objectives of UNCRPD.</p>	<p><i>Has the government taken measures to:</i></p> <ul style="list-style-type: none"> - ensure that international development programmes (such as poverty reduction, education, livelihoods, work towards achieving millennium development goals, etc.) are inclusive of and accessible to persons with disabilities? - facilitate and support capacity building, including through the exchange and sharing of information/ experiences and best practices with other countries that have ratified UNCRPD? - facilitate cooperation in research and access to scientific and technical knowledge? 	
<p>Article 49 – Accessible Format</p>	<p>49.1. Rate your satisfaction level with respect to the efforts made by the government to make UNCRPD available in accessible formats.</p>	<p><i>Has government taken steps to:</i></p> <ul style="list-style-type: none"> -translate UNCRPD in local languages? -convert UNCRPD in accessible formats (Braille, audio, sign language, easy-to-read versions etc.)? -make UNCRPD easily available? 	

PART B (optional)

In this part of the questionnaire, we encourage you to share with us your experience (positive or negative) vis-à-vis any of the provisions of UNCRPD and the impact of government's efforts on the lives of persons with disabilities or issues of violation of rights. You can mention website links, newspaper articles, personal experiences, letters written to the government, experiences of friends and family, annual reports of the ministries, any other data that will substantiate the ratings you have given in Part A of the questionnaire. This will help us to analyse the data with examples. You can write about more than one Article/issue. If you quote from somewhere, please remember to give the source of information. If your experience is quoted in the final report, we will acknowledge your name in the document that we prepare. However, if your name needs to be kept confidential, please let us know. You may use extra sheets and attachments. Example of positive experience could be the use of UNCRPD to win a case of the woman with intellectual impairment to have a baby. Negative experience could include harassment, abuse, discrimination or lack of facilities and systems leading to denial of rights.

The following points can help you think of the examples of efforts made by the government or violation of rights in the area of:

- Promoting non-discrimination and ensuring the provisions of UNCRPD*
- adequate involvement of people with disabilities while formulating laws/policies that concern them*
- rights of women with disabilities*
- rights of children with disabilities*
- awareness raising on UNCRPD*
- promoting accessibility as per UNCRPD*
- right to life of persons with disabilities as per UNCRPD*
- protecting and safeguarding persons with disabilities in situations of risk and humanitarian emergencies as per UNCRPD*
- legal capacity of persons with disabilities*
- access to justice by persons with disabilities*
- right to liberty and security of persons with disabilities*
- preventing torture or cruel, inhuman or degrading treatment, punishment, exploitation, violence or abuse of persons with disabilities*
- integrity of persons with disabilities*
- ensuring that persons with disabilities are granted nationality or have been provided birth certificate*

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- *ensuring that persons with disabilities are able to live independently without barrier and with support services*
- *access to mobility and other assistive aids and technologies at affordable cost*
- *access to information*
- *respect for privacy of persons with disabilities*
- *right to home and family, and adequate respect and support for the same*
- *right to education of children and persons with disabilities*
- *adequate health services*
- *habilitation and rehabilitation services*
- *employment and livelihood opportunities*
- *access to adequate standard of living and social protection*
- *access to equal participation in political and public life*
- *participation in cultural life, recreation, leisure and sports*
- *collect, maintain and disseminate data on persons with disabilities*
- *promoting international cooperation to complement national efforts to achieve the objectives*

Write your positive or negative experience here (you can also use additional sheets)

Article No.: _____

Experience:

THANK YOU SO MUCH FOR YOUR TIME AND COOPERATION!!

DEOC (On behalf of NCPEDP)