



Inclusion of PwDs in the UNDP Thematic Areas – A Scoping Study



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1. Preamble

The concept of inclusion emphasizes universal design for policy-oriented physical accessibility issues, such as ease-of-use of physical structures and elimination of barriers to ease of movement in the world, but the largest part of its purpose is on being culturally transformational. Inclusion typically promotes disability studies as an intellectual movement and stresses the need for disabled people — the inclusion-rights community usually uses the reclaimed word "cripple" or "crip" instead — to immerse themselves, sometimes forcibly, into mainstream culture through various modes of artistic expression. Inclusion advocates argue that melding what they term "disability-art" or "dis/art" into mainstream art makes integration of different body types unavoidable, direct, and thus positive. They argue it helps able-bodied people deal with their fears of being or becoming disabled, which, unbeknownst to the person, is usually what underlies both the feelings of "inspiration" and feelings of pity s/he may have when watching a disabled person moving in his or her unusual way(s), or in participating in activities that obviously draw attention to the person's condition(s). Inclusion advocates often specifically encourage disabled people who choose to subscribe to this set of ideas to take it upon themselves to involve themselves in activities that give them the widest public audience possible, such as becoming professional dancers, actors, visual artists, front-line political activists, filmmakers, orators, and similar professions. Mainstreaming is typically limited to putting a person with a disability next to typical people in the usually quite vague and unspecific hope that each will adapt to and learn about the other. Inclusion, while acknowledging the value of mainstreaming as a tool, argues that this is not enough: the whole of society, its physical accessibility, and its social attitudes, they say, should exist with universal design in mind, thus ending physical marginalization of all kinds by ending the idea that a body that is different is incapable of self-management, physical attractiveness, etc. This all-encompassing practice, its advocates argue, ensure that people of differing abilities belong to, are engaged in, and are actively connected to the goals and objectives of the whole wider society¹.

Historically, people with disabilities have been among the most economically impoverished, politically marginalized, and globally least visible members of their societies. Yet this group represents approximately 10 % of the world's population, or more than 650 million people, of who 470 million are of working age. This includes people with physical, sensory, intellectual and psycho-social disabilities. According to UN statistics, 82 % of disabled people in developing

¹ Wikipedia

countries live below the poverty line, and are among the most vulnerable and marginalized in these countries; an estimated 20 per cent of all people living on less than US\$ 1 per day worldwide are people with disabilities. Their opportunities to emerge from poverty are limited in many cases by the lack of enabling legislation to promote their access to skills development (including life skills, technical skills and entrepreneurship skills) and employment opportunities. The weak implementation and enforcement measures, of legislation add to the predicament of PwDs in seeking gainful livelihood. Women with disabilities face greater difficulties than their male counterparts or than non-disabled women in earning a living² and people with disabilities living with HIV/AIDS (PLWHA) are frequently overlooked in policy and programme measures³.

1.1 Situation of Persons with Disabilities in India

The charity mode of understanding disability continued until the sixth 5 year plan which was still influenced by the 16th century, Elizabethan poor law of Britain. Noticeable changes took place with the government thinking with the advent of international year of disabled people where substantial allocation of budget was seen. Since then the civil society movement in India became strong with several service delivery organizations came into existence. The programmes of the government both at the centre and state are being implemented through the NGOs. The enactment of RCI Act 1993, Persons with Disabilities Act 1995 and National Trust Act 1999 by the parliament was a landmark move in the history of disability of the country. With this legislative initiative several department and ministries were bound to include disability component in their programming. This also encouraged the government to include first time ever a census on disability to be integrated in the overall National Decadal Census 2001. Though there has been serious definitional problem including lack of training of the enumerators it brings a figure of 2.19% of the total population as PwDs.

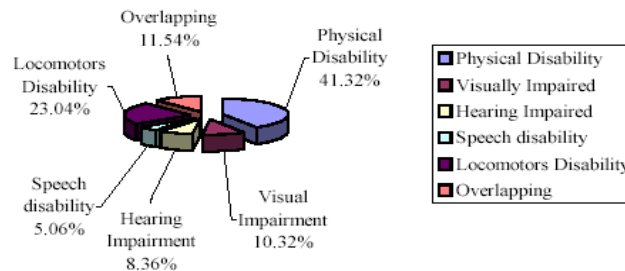
Though there has been substantial movement from the legislative side, implementation of the act in its earnest has been grossly lagging behind in terms of both spirit and functionality. The gap in education, access to health and rehabilitation medicine, employment, barrier free environment, sports and recreation as well as attitude remains fairly wide. Respectability and recognition to rights based approach is still socially desirable answers widely heard but fails to

² O'Reilly, A. (2007): The right to decent work of persons with disabilities (ILO, Geneva).

³ World Bank (2004): HIV/AIDS & disability: Capturing hidden voices. The World Bank/Yale University Global Survey on HIV/AIDS and Disability

translate into actual practice. Nevertheless the government of India and a few state governments have adopted specific policy on disability.

Figure 1: Disability-specific Data



Source: SARVEKSHANA, 36th & 47th rounds, National Sample Survey Organization, Department Of Statistics, Ministry of Planning & Program Implementation, Government of India.

Age wise distribution of Person with Disabilities in India as per UN estimate

Age Group (in yrs)	Group	Total (in crores)			Rural (in crores)			Urban (in crores)		
		Total	Male	Female	Total	Male	Female	Total	Male	Female
0-4	ECCD	0.79	0.41	0.38	0.57	0.29	0.28	0.22	0.12	0.10
5-19	Educational	2.27	1.17	1.10	1.64	0.84	0.80	0.63	0.33	0.30
20-59	Employable	2.66	1.38	1.29	1.92	0.99	0.93	0.74	0.39	0.35
>= 60	Pensionable	0.45	0.23	0.22	0.32	0.17	0.16	0.12	0.07	0.06
Total Population		6.17	3.19	2.98	4.45	2.29	2.17	1.72	0.90	0.81

The above figure itself is sufficient to bring home the point that there is an immense service gap when compared with the services available to the general population. Unfortunately, there is a loss of imagination by the implementing authorities when it comes to programming for PwDs in India. Experience has also shown that mainstream organizations such as government bodies including NGOs have been less sensitive to both quality as well as scaling up of the issue. There are inadequacies in both quantum and quality of the programmes for PwDs that range to all sectors, be it Early Detection or Old Age Pension. This is largely due to not complying with the rights based approach at the policy and programming level. Even where schemes have been framed there are gaps in both designing implementation & monitoring strategies which needs to be addressed through continuous and concerted manner.

2. Thematic Areas

2.1 Environment & Energy

It has become common knowledge that the poor are likely to be hit hardest by climate change, and that capacity to respond to climate change is lowest in developing countries and among the poorest people in those countries. It seems clear that vulnerability to climate change is closely related to poverty, as the poor are least able to respond to climatic stimuli. Furthermore, certain regions of the world are more severely affected by the effects of climate change than others. Generally speaking, vulnerability and adaptation to climate change are urgent issues among many developing countries.

Within the context of the Climate Change Knowledge Network (CCKN), a project on the impacts of economic changes and climate change on India's agricultural sector is being pursued jointly by the International Institute for Sustainable Development (IISD), the Centre for International Climate and Environmental Research (CICERO) and the Tata Energy Research Institute (TERI). The project is innovative in that it uses the concept of "double exposure" (O'Brien and Leichenko 2000). This refers to the fact that climate change and globalization are occurring simultaneously, and that regions, sectors, ecosystems and social groups are often confronted by the impacts of both processes.

The 60 million Persons with Disabilities (PwDs) in India do not find a place while framing the Climate Change policies and programmes. This has led to their: Invisibility in response systems; lack of understanding of consequences of climate change on them due to high level of illiteracy amongst PwDs; Exclusion from climate change response efforts; Communication difficulties as document formats are not accessible for eg., pdf files are not readable by the blind and most documents on the web today are in pdf format. No Braille documents are available, no spoken documents also can be found. No appropriate sign language for the hearing impaired. In this situation, Persons with Disabilities (PwDs) need to understand their own risks in climate change and lead the process to reduce it. At the same time it is of extreme importance that the policy makers and all agencies dealing with the issue of climate change take the cognizance of the fact that PwDs should fall in the high priority index amongst the vulnerable groups.

Definitions and Issues

While discussing climate change, the following seven areas are of prime concern where inclusion needs to be considered;

1. Sensitivity: degree to which a system is affected by, or responsive to, climate stimuli
2. Vulnerability: degree to which a system is susceptible to injury, damage or harm
3. Impact potential: degree to which a system is susceptible to climate stimuli
4. Resilience: degree to which a system rebounds, recoups or recovers from a stimulus
5. Responsiveness: degree to which a system reacts to stimulus
6. Adaptive capacity: the potential or capability of a system to adapt to (to alter to better suit) climatic stimuli
7. Adaptability: the ability, competency or capacity of a system to adapt to (to alter to better suit) climatic stimuli

The policy implication generally takes into account the above mentioned factors while framing the national environment policy related to climate change. It is imperative that the PwDs who are highly vulnerable to climate change be involved and their issues appropriately understood and addressed.

Climate change threatens the effectiveness of development efforts by disproportionately affecting PwDs and other vulnerable groups in low- and middle-income countries. In the face of these imminent challenges, PwDs and their families require adaptation and robust systems that promote sustainable access to basic necessities, secure livelihoods, health care, and social and civic participation.

The WHO Global Burden of Disease (GBD) study provided useful results in measuring global health status and attributable risk. Very few studies have, however, examined the relationship between climate change and disease burden, although the impact may be substantial. According to calculations taken from the 2000 global-burden-of-disease study (WHO, 2004), 5,517,000 Disability Adjusted Life Years (DALYs) were attributable to climate change worldwide. The geographic distribution of DALYs lost because of climate change is uneven across the world, with almost 50 percent of the DALYs lost in regions with high child and adult mortality in Southeast Asia, followed by the losses in regions in Africa (23 percent) and the Eastern

Mediterranean (14 percent) (WHO, 2002a). Given the size of its population, Africa has the largest number of DALYs lost per 100,000 inhabitants as a result of climate change (Table 1).

TABLE 1 Morbidity Burdens (DALYs) Attributable to Climate Change in the WHO Subregions (a) in 2000

		Africa	Africa	America	America
	World	D	E	A	B
DALYs (X,000)	5,517	1,267	626	3	71
DALYs per 100,000 inhabitants	90	358	207	1	16

	America	Eastern Mediterranean	Eastern Mediterranean	Europe	Europe
	D	B	D	A	B
DALYs (X,000)	23	20	748	3	10
DALYs per 100,000 inhabitants	32	14	213	1	5

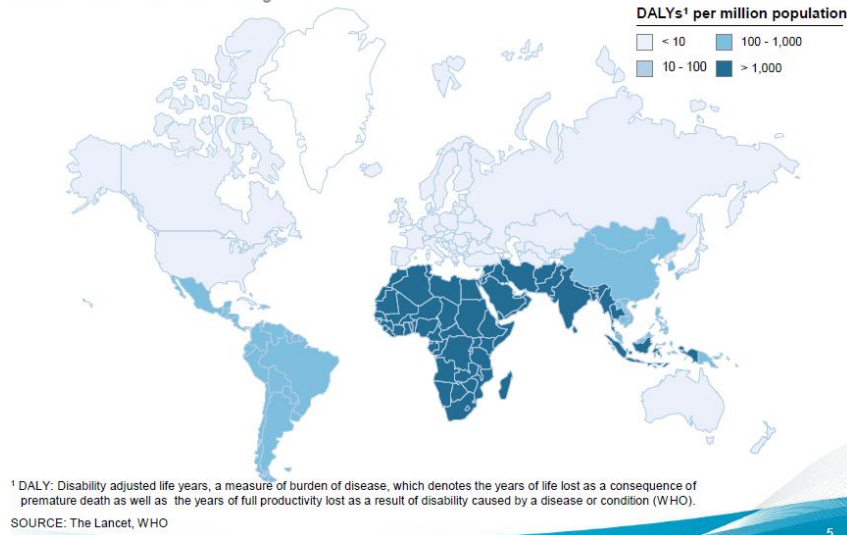
	Europe	Southeast Asia	Southeast Asia	Western Pacific	Western Pacific
	C	B	D	A	B
DALYs (X,000)	4	34	2,538	1	169
DALYs per 100,000 inhabitants	2	11	201	1	11

Definitions of WHO subregions: A = regions having very low child and very low adult mortality, B = regions having low child and low adult mortality, C = regions having low child and high adult mortality, D = regions having high child and high adult mortality, and E = regions having high child and very high adult mortality. Data retrieved from Attributable DALYs by Risk Factor and WHO Subregion (WHO, 2002a).

It should be acknowledged that because of the lack of research in developing countries on this topic, actual DALYs may be much higher. According to the limited results from WHO, children under five years of age suffer the most from the consequences of climate change, with 88 percent of lost DALYs attributable to climate change occurring in this age group in both developed and developing countries (WHO, 2002b).

Climate change challenges human health globally – but the poorest are the most vulnerable

Estimated effects of climate change in 2000



It is well known that disabled and older people are more vulnerable in emergencies. For example, 60% of the deaths caused by Orissa Super cyclone as well as more recently the Kosi flood of Bihar were in people aged 60 or older including large number of PwDs. By 2030, 350 million people worldwide will be affected by natural disasters. More awareness is needed of the particular needs of disabled people in emergencies.



Orissa Super Cyclone

Finally, the problems of food and water scarcity, plus natural disasters, plus rise in sea level, will generate more displaced people. Already, there are 26 million climate-displaced people in the world, and each year, another 1m are displaced due to climate related disasters. These figures are projected to triple by 2030, with low lying lands such as part of Uttar Pradesh, Bihar, Orissa and West Bengal which are particularly vulnerable.



Kosy Flood in Bihar

Migration is more complex for disabled people, who will face access and transport barriers, and are not likely to be a priority when it comes to resettlement.

To summarize, the message from these projections seems to be that because of global warming, more people might become disabled; more disabled people are likely to become sick or die; and that disabled people will be more affected by factors such as famine, weather disaster and consequent migration. The obvious conclusion is that climate change is a disability rights issue.

In the light of the above, the following 4 areas were given top priority in the international conference held in 2008 in Bhubaneswar. They are;

- There has to be advocacy and training of disabled on climate change and understand rights in climate disaster situations
- Production of accessible formats in material and use it to create awareness among PwDs internationally accessible and an awareness campaign with simple messaging on climate disasters and disability that is easily understood & recognizable
- Ensure that disability is included in the United Nations Framework Convention on Climate Change (UNFCCC) work plans specifically COP. It must also be ensured that there is full recognition and implementation of UNCRPD to facilitate better links between climate change initiatives and PwDs.
- Above all awareness creation in communities affected by climate change as well as the disaster rescue, relief and rehabilitation functionaries at all levels that includes the government.

2.2 Crises Prevention & Recovery

The Draft Convention of the Rights of Persons with Disabilities (PwDs) passed by the United Nations Ad Hoc Committee on Disability on 25th August 2006 under Article 11 proposes that “State parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights necessary measures to ensure protection and safety of Persons with Disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters”. The Convention has been signed by more than 100 nations.

The term “disaster” means a progressive or sudden, widespread or localized, natural or human-caused occurrence which

- (a) Causes or threatens to cause –
 - (i) Death, injury or disease;
 - (ii) Damage to property, infrastructure or the environment; or
 - (iii) Disruption of a community; and
- (b) Is of a magnitude that exceeds the ability of those affected by the disaster to cope with its effects using only their own resources;

Disaster Management

The term “**disaster management**” means a continuous and integrated multi-sectoral, multi-disciplinary process of planning, and implementation of measures, aimed at –

- (a) Preventing or reducing the risk of disasters;
- (b) Mitigating the severity or consequences of disasters;
- (c) Emergency preparedness;
- (d) A rapid and effective response to disasters; and
- (e) Post-disaster recovery and rehabilitation;

Disaster Management therefore refers to programmes and measures designed to **prevent, mitigate, prepare for, respond to and recover** from the effects of all disasters.

Consequences of Disaster on People with Disability

Additional challenges for persons with disabilities often begin during flight. In the chaos of displacement, some are left behind because they need assistance to move and no one stops to help them or because they are unable to call out for help due to speech impairments. Difficulty in seeing, hearing or understanding may prevent some persons with disabilities from being aware of early

warning systems and can also lead to them being disoriented and thus separated from their family during flight. Separation from or loss of a caregiver can have severe consequences for a person with disabilities, particularly if they are dependent on the caregiver for vital activities such as eating, moving or toileting. When families are displaced, they often need to make hasty decisions about what to take with them. Assistive devices such as wheelchairs are often left behind, making even simple tasks such as reaching latrines extremely difficult for the person with disabilities during displacement.

Disasters have an impact on disability, by disproportionately affecting persons with existing disabilities and by creating a new generation of persons with disabilities who will be in need of rehabilitation services. In settings where resources are limited, the impact of disasters on these groups of people can be long-term and far-reaching.

Consequences of a disaster

For survivors with existing disabilities, the following issues may be of particular concern.

- 1) In comparison to their non-disabled peer, PwDs can be more at risk during disasters.
- 2) Many PwDs lose their assistive devices during disasters, including artificial limbs, crutches, hearing aids and spectacles.
- 3) PwDs can have greater difficulty in accessing basic needs, including food, water, shelter, latrines and health care services
- 4) Rehabilitation infrastructure is destroyed and rehabilitation personnel, including the caregivers of PwDs, may be killed or injured or diverted to other tasks

For survivors with injuries and/ or newly acquired disabilities, the following issues may be of particular concern

- 1) Untreated or inadequately treated fractures and infected wounds may lead to severe and long lasting disabilities
- 2) Referral of these survivors to appropriate health facilities often becomes difficult
- 3) There is a scarcity of rehabilitation personnel and infrastructure poised to handle a new generation of Persons with Disabilities
- 4) Many survivors with newly acquired disabilities will struggle with the loss of their livelihood, an additional consideration for them and their families

Financial vulnerability

The response community may perceive this population as needing less financial assistance though in reality, the frail and the Persons with Disability actually can be more vulnerable to

property damage due to lack of insurance, a smaller financial cushion, and poor credit-worthiness due to low or no income and lack of employment. A Person with Disability may utilize financial aid sources less than the other groups simply because they do not meet the qualifications to obtain such assistance. For example, many Persons with Disability due to complex and varied definitions cannot qualify for assistance for, Small Business Association (SBA) disaster loans to rebuild property etc. Even when the aid received is commensurate with the amount of damage, it is more problematic for the Persons with Disability to acquire additional money for uncovered losses. NGOs and civil society organizations may be important for addressing this gap. This group has fewer opportunities and less ability to generate income in disaster situation, have to be increasingly reliant on Social Security benefits, and is more likely to live near or at abject poverty level than are the non-PwDs.

In the aftermath of a disaster, the Persons with Disabilities who are victims of disaster may be subjected to frequent and stressful residential changes as they are moved among different families or shelters. Other potential sources of stress include language and cultural barriers, lower reading ability, and speaking difficulties that may cause confusion and misunderstanding between the Persons with Disability and those trying to communicate with them. Therefore, it is commonly assumed that Persons with Disability suffer disproportionately from different stressful events that need to be appreciated.

Some of the states such as Bihar, Chhattisgarh and Rajasthan have specifically drafted State Disability Policy has dedicated chapter on Disability & Disaster. This mandates the States to have special provisions concerning rescue, relief and rehabilitation of PwDs due to disaster. However, the National Policy on Disability do not speak about any specific provisions for PwDs during disaster although disaster of various kinds are almost an annual phenomena in the country.

Strategies include: Responses to be taken after a disaster

Following a disaster, disability-related responses to support people with existing disabilities and to prevent new disabilities can be classified in two phases:

The acute phase - Immediately following a disaster, priority responses include:

- 1) Identifying persons with existing disabilities in temporary shelters and camps

- 2) Responding to the specific health care needs of persons with existing disabilities, such as insulin for diabetics, soft mattresses for people with spinal cord injuries and spectacles for people with low vision.
- 3) Identifying people with injuries and providing appropriate trauma care to save lives and minimize future functional impairment and disability
- 4) Implementing other curative and therapeutic interventions that can prevent disability such as prevention of pressure sores and possible deformities
- 5) Transferring people with severe injuries and / or newly acquired disabilities to referral centres for medical rehabilitation. In settings where such centers don not exists, efforts should be made to ensure that such persons are treated by specialists in existing facilities.
- 6) Establishing a multi-disciplinary task force to prepare a long-term rehabilitation program, taking into consideration the resources available and socio-economic conditions of the country.

The reconstruction phase - In the longer-term, priority responses include:

- 1) Identifying persons with existing and newly acquired disabilities, and assessing their immediate and long-term needs
- 2) Conducting mapping of resources and other community assets for meeting basic needs, including general health care and medical rehabilitation services
- 3) Developing the infrastructure necessary to provide medical rehabilitation services, especially therapy and assistive devices. Institute Based Rehabilitation (IBR) or medical rehabilitation is focused on restoring abilities, and should begin soon after emergency trauma care has been provided and continue until the person returns to his / her community. The functional recovery of persons with injuries often involves complicated rehabilitative measures, including coordinated input from a team of rehabilitation professionals (physiatrists, physiotherapists, occupational therapists, prosthetists and othotists and others) and the treatment of ongoing medical problems. In developing countries, such teams do not often exist, so special efforts are needed to train local health personnel and family members to perform some of the tasks of the various rehabilitation professionals.
- 4) Initiating Community Based Rehabilitation (CBR) Programmes, ensuring that persons with disabilities have equal access to services and are treated as equal members of society. As with their non-disabled peer, the basic problems for persons with disabilities

in post disaster situations are access to health care, food, shelter, education and opportunities to earn a livelihood, and the barriers to these for persons with disabilities are great. A comprehensive, multi-sectoral CBR programme is essential to meet these needs and to help persons with disabilities to make the best possible use of their abilities. CBR should be considered as citizens of their societies with the same rights, entitlements and responsibilities as others. Both persons with existing and those with newly acquired disabilities should be involved in rebuilding their communities. An ideal CBR programme would reduce the effects of poverty, promote human rights and ensure dignity for all persons with disabilities and their family members.

- 5) Attending to the social needs of persons with disabilities by ensuring their integration with their families and communities and facilitating opportunities for them to earn their livelihood.
- 6) Following the “Design for All” concept during rebuilding of infrastructure. When rebuilding a community’s infrastructure, efforts are needed to ensure that physical spaces are designed and built to be accessible to and safe for all, especially persons with disabilities. The Design for All concepts should be routinely adapted during the reconstruction phase.

2.3 HIV and Development

In 2006, a comprehensive study was instituted on Social Exclusion by UNICEF, Mumbai. This study has 2 major parts. One part was dedicated to the tribal and the second part was on HIV/AIDS and PwDs. The second part of the study was carried out by Ms. Anagha Ghosh of Shodhana Consultancy, Pune⁴. 5 years have passed since then, unfortunately with no change in the National HIV/AIDS Policy of the country. To substantiate the importance and implications of HIV/AIDS and PwDs, it is sufficient to summarize the essence of the study which not only critically evaluates the subject through literature review but also primary data collection by way of case studies in some of the most endemic districts of Maharashtra, where she made personal visits and spent time with affected PwDs.

In the same year, a nation-wide study was instituted by DFID which was commenced by Mr. Kevan Moll⁵ which was shared between the two researchers before finalizing of the report. The DFID report states that - *an estimated number of 320,000 people with disabilities living with HIV in India, most programmes reach only a fraction of that figure, between 0-2 percent. With 6% of the population not included in HIV programmes, is this too large a section of society to ignore and will this impact upon efforts to slow the spread of HIV?*

Both the reports concluded with similar results and substantiated the fact that Persons with Disabilities were at equal risk if not more when compared to the general population.

Excerpts from the study

Disability and HIV, both are surrounded by a lot of stigma, misconceptions and prejudices. Though HIV has been the disease of this century and much research is undertaken on various aspects of this epidemic, not much attention has been provided to already disabled people and HIV; due to various reasons. Sexual and reproductive health issues are closely linked with HIV/AIDS. There are also some myths surrounding the sexuality of PwDs. It is generally thought that PwDs do not have sexual desires and are not sexually active. All such myths result in intentional or unintentional exclusion of PwDs from sexual health information, services and rights that are

⁴ <http://www.shodhana.org/shodhana/reports/HIVandPersonswithDisabilities-AstudyinMaharashtra,UNICEF.pdf>

⁵ Too few to worry about? Too many to ignore? The Exclusion of PwDs from HIV Programmes in India

so very crucial to HIV/ AIDS. It was therefore felt essential to study the issue of sexuality of PwDs and its linkage to HIV/ AIDS with special focus on PwDs in the state of Maharashtra and assess their exclusion from HIV/ AIDS programming.

The objectives of HIV policy fail to have any specific mention of PwDs. As a result, the disabled population is “forgotten’ & “excluded” till date from all services and interventions. This clearly indicates urgent need of the specific mention of this marginalized group bringing about a focus so that the special needs are addressed in appropriate ways.

The disability policy has an overwhelming focus on rehabilitation. There is no specific mention of inclusion of PwDs in existing general health care services and HIV/AIDS programs in specific. As a result, the disabled population finds the access to health care services in general very problematic. HIV/ AIDS being a disease referred with taboo, the access to services to HIV/ AIDS remains out of reach of disabled population.

The HIV / AIDS programming by National AIDS Control Organization (NACO) and its state partners once again miss out on any specific plan for disabled population as of the current framework of interventions. Since, PwDs find no specific mention in the objectives; as a result, this invisible population remains excluded from existing programmatic interventions.

The second part of the study focused on Review of literature. Though HIV has been the disease of this century and so much is written about the epidemic, It is surprising to note that the studies regarding PwDs & HIV are far and few. The first ever global survey on PwDs and HIV is as recent as 2004 by World Bank and Yale University, USA. Other few studies are mostly in African countries and none to mention in India. Almost all the studies conclude that there is a definite need of inclusion of PwDs in HIV programming.

The third part of the study was evidenced based research. The evidence based study was aimed at exploring the existing situation of PwDs with regards to the access to information, services, and rights related to sexual & reproductive health as well as HIV/ AIDS and to put forth the gaps

in knowledge and database that need to be looked into for further policy making and programming.

The study included major stakeholders including adolescents & young adults with disability, Parents groups, National and state level NGOs working in the field of HIV/ AIDS as well as Disability, Chief functionaries at Govt., professionals in various service centers of Govt. of Maharashtra such as PPTCT and ART centers, Private Practitioners in the HIV /AIDS field.

The methodology for the study included Focus group discussions with groups & NGOs, Interviews with individuals with disability, Related case studies and Existing database, if any, available on the topic.

The study revealed that situation of disabled people with regards to HIV / AIDS leaves far from desired. Some of the major findings include the following;

- The awareness level among the disabled population is limited to the words – HIV/ AIDS rather than the understanding of risks. The vulnerability of PwDs, especially disabled girls and women is quite high due to violence, exploitation and abuse.
- Attitudes of health care professionals, especially in terms of confidentiality need major orientation.
- The content of current training programs hardly has any considerations the special needs of various categories of PwDs. Some disabled friendly IEC material is available, especially for visually impaired but the reach to the needy leaves far from desired.
- There is hardly any information among the disabled population on VCTC, ART, and PPTCT.
- Current condom promotion activities exclude disabled people. Information on STI or its relevance to HIV is very poor among disabled population. In the context of rampant sexual abuse, the information and understanding of sexual and reproductive health are of crucial importance. However as the findings suggest it is very low among the disabled population, which is definitely not good news.

- PwDs are part of the society at large and it reflects in their views regarding HIV as majority of them also consider HIV status as a stigma and need a lot of education regarding relevant issues.
- Contrary to the belief, disabled people are found to be sexually active, as individuals, as homosexuals, as commercial sex workers and as customers of Commercial Sex Workers, indicating the need to further explore these issues with regards to high risk behavior leading to HIV. In fact, the study underlines an urgent need for deeper understanding into the exploitation of girls and women with disabilities. The AIDS epidemic can never end if this population is not included in the efforts of prevention & care.
- The invisibility of disabled population among the HIV sector and movement does not indicate their absence but their exclusion for variety of issues related to marginalization & exclusion.
- Almost all the HIV NGOs had never thought of PwDs as a possible group in need of interventions and hence had never thought of including them into existing programs. However, once the discussion was open, almost all HIV/AIDS organizations mentioned that the PwDs are vulnerable to STI and HIV/ AIDS as much as the normal population. Girls and women with disability especially mentally handicapped and mentally ill were considered more vulnerable because of their dependency and multiple disadvantages. It was heartening to see open & positive attitude among the HIV NGOs to include the disabled population provided they are guided properly.
- Almost all disability organizations also thought that PwDs are vulnerable to STI and HIV/ AIDS. In addition, the residential schools representatives shared their experiences regarding incidences of homosexuality as well as inappropriate social behavior due to lack of proper knowledge, curiosity and desire to explore new experiences. The disability NGOs in general suggested that the range of sexual and reproductive health issues need to be reached to young PwDs and this was substantiated by the PwDs and their parents' groups. Issues related to abuse and exploitation needs to reach this group. To understand that one is abused one needs to know what abuse is and it is shocking to note that many of the disabled young adults are not aware of such issues.

- The private practitioners as well as the health care professional in Govt. indicated a requirement of major attitudinal change towards the PwDs in general.
- While observing a lack of availability in terms of numbers of PwDs living with HIV, their inclusion into HIV programming needs to be considered as the human right to health care, information and related services as well as issue of mainstreaming.

To address the current situation some of the major recommendations are as follows;

- Building data base
- Appropriate service delivery
- Research
- Policy Advocacy
- Capacity building and
- A multi sectoral and convergent approach.
- Promote / Identify disability organizations to take up the issue of HIV/AIDS and Disability.

It is hoped that as always the marginalized of the marginalized group does not remain excluded any longer and urgent actions are taken for their inclusion for their inclusion in HIV/ AIDS programming.

2.4 Democratic Governance

*Good governance is an indeterminate term used in development literature to describe how public institutions conduct public affairs and manage public resources in order to guarantee the realization of human rights. Governance describes "the process of decision-making and the process by which decisions are implemented (or not implemented)". The term governance can apply to corporate, international, national, local governance or to the interactions between other sectors of society.*⁶

India is the house to the second largest disabled population in the world, perhaps next to only China. The Indian Parliament enacted the Persons with Disabilities Act 1995 that ensures providing equal opportunities, full protection and a right space approach in government programming. The acceptance and response to the Act by the federal structure of the governance was extremely slow with a large number of state assemblies ratifying the Act 5 to 7 years later than that of the enactment year. Even today there are several state governments who have fail to prepare and adopt the rules which is the independent prerogative of the state governments. With the advent of the Act, it mandated several development programmes particularly education, training and livelihood programmes to allocate minimum 3% of the budget for the benefit of the PwDs. Unfortunately most of the programmes remains highly underutilized due to lack of proper insight and poor implementation strategies at the conceptual as well as functional level.

A CAG review⁷ was instituted to examine the efficiency, economy and effectiveness of implementation of various programmes for the welfare of the disabled with reference to the PWD Act, 1995. Accordingly, audit examined factors that impinge critically on efficient and cost effective implementation of the various schemes like role of apex level institutions in rehabilitation of the disabled, coordination among various implementing agencies, institutional support to voluntary organizations, utilization of resources and adequacy and effectiveness of monitoring. The review covered the functioning of the Ministry of Social Justice and Empowerment, National/Apex-level institutions and NGOs working in the area of rehabilitation of the disabled, State and District Social Welfare Departments during the period 1998-99 to 2002-03.

⁶ http://en.wikipedia.org/wiki/Good_governance

⁷ Reports, Notes/CAG Report on PwDs upto 2003.htm

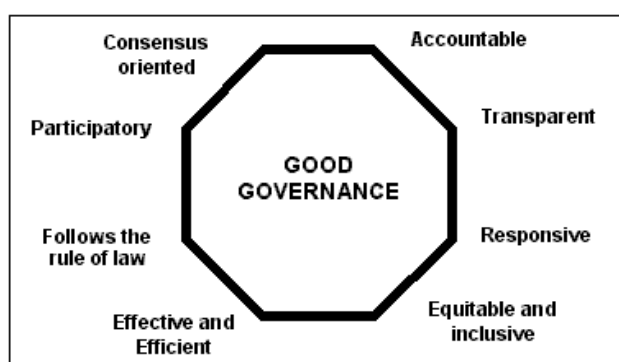
The broad CAG finding was that the nodal ministry i.e. Ministry of Social Justice & Empowerment and all other ministries' programmes lack monitoring and convergence. This resulted in extreme poor performance under each of the schemes and by and large fail to benefit the PwDs. Clearly there was no vision for inclusion. Some of the basic programme gaps and the findings of CAG wherever relevant is being given underneath;

Sector-wise Programme Gap

Sectors	Current Scheme/ Programme gap
Education	<p>Currently the department provides with inadequate educational scholarship. There is no intervention on appropriate pedagogy which is an integral part of education for PwDs. Extremely inadequate provision for higher education. Availability of Braille books are only upto primary level.</p> <p><i>CAG Finding: The Department of Secondary and Higher Secondary Education, Ministry of Human Resource Development is responsible for extending integrated education for PwD. However, audit inquiry revealed that the Ministry had no information regarding disabled children in the normal schools and availability of trained teachers in such schools, and was in the process of collecting it. The Ministry of Social Justice and Empowerment stated in December 2003 that the draft NSSO report for the 58th round indicated that around 45 per cent of the children with disabilities were enrolled in regular schools. However, the reply of the Ministry does not indicate availability of precise information with the Ministry of Human Resource Development regarding number of disabled children enrolled in the normal schools and availability of trained teachers in such schools</i></p>
Health Care	<p>The department currently looks into Polio corrective surgery and related assistive device. The health requirement of all other categories is absent.</p> <p><i>CAG Findings: The Ministry of Health and Family Welfare is responsible for - (a) prevention of disabilities through programmes like leprosy eradication, blindness control, immunisation etc., (b) training of PHC workers. However, the Ministry of Health and Family Welfare has no ready information on number of trained PHC workers.</i></p>
Employment and Economic Empowerment	<p>There is a huge gap in realizing and enhancing the livelihood opportunities of PwDs. Currently there is no initiative made by the government on this aspect.</p> <p><i>CAG Findings:</i></p> <ul style="list-style-type: none"> <i>The non-availability of upto date information (as of March 2003) either with CCPD or with the Ministry of Social Justice and Empowerment indicates that the implementation of reservation provisions for PWD was not being effectively monitored.</i> <i>Data supplied by the Ministry of Rural Development revealed that the PWD provided employment by the Ministry under its poverty alleviation scheme 'Swarnjayanti Gram Swarajgar Yojana' (SGSY) during 1999-2003 constituted less than one per cent as against the stipulated reservation of three per cent.</i>
Skills Development	<p>Currently the department of SJE funds the vocational training activities of NGOs. A close look at most of these activities undertaken by NGOs, do not translate to any meaningful livelihood. All most all of them are undertaken as a part of education curriculum.</p>
Social Security & Safety Net	<p>Some of the state governments have their pension schemes and unemployment benefit for PwDs. However, the criteria set for such pension were extremely harsh and impractical further CAG observed that in spite of having such schemes the implementation in terms of reach out to the beneficiaries was almost nil.</p>
Barrier Free Access	<p>Currently Commissioner Disability undertakes statutory review of only architectural barrier and advices appropriately for making it barrier free wherever necessary. However the CAG observes that the government building in most of the states posses non-accessibility of main entrances, absence of appropriate toilets, non-accessibility of waiting spaces & floors and absence of slopes in case of lifts, etc.</p>
Transport	<p>While some of the state governments provide concessions and/or free ship for PwDs in the state transport, effort towards making the state transport accessible was lacking.</p>
Disaster and PwDs	<p>Though PwDs are most severely affected during disaster there are no special schemes being run by either central or any of the state governments.</p>
Prevention	<p>Currently there are no such special schemes being run by the government. Extremely</p>

	inadequate training in the ICDS sector where it talks about only early identification with no intervention programme. <i>CAG Finding: The Department of Women and Child Development is responsible for- (a) supplementing nutrition through ICDS, and (b) conducting training courses for Anganwadi workers for early detection and timely prevention. However, the Department informed audit that it was not implementing the PWD Act.</i>
Research & Development Statistics	CAG observes that most of the central government and almost all the state governments did not have either a centralized database management system for PwDs nor had taken any research initiative towards assistive device in spite of the mandate given by the Act.
Programme development and implementation	Only 4 state governments have initiated on comprehensive state disability policy that will ultimately provide for programme development. However, both at the central and state government level there is serious lack of appropriate implementing structure.
Programme Monitoring & Compliance	Limited monitoring and compliance is currently mandated with Commissioner Disability. There is no system of quality and quantity check as per the need and requirement.
Community Based Rehabilitation (CBR)	CBR could be an effective approach under the Panchayati Raj Institution. Currently, disability has not been made as a serious subject under the PRI structure.

Since governance is the process of decision-making and the process by which decisions are implemented, an analysis of governance focuses on the formal and informal actors involved in decision-making and implementing the decisions made. The above analysis depicts that there are several programme gaps which hamper the basic human rights of PwDs in India.



Characteristics of good governance

Going by the above 8 major characteristics of Good Governance⁸ it assures that the programmes for PwDs is implemented at its best. However there are ample scope of improvement and extensive work need to be initiated at various levels of the government that includes all the sectors mentioned in the Sector-wise programme gap matrix. Only then it can protect the basic human rights of PwDs in India contributing towards the achievement of Millennium Development Goals.

⁸ <http://www.unescap.org/pdd/prs/ProjectActivities/Ongoing/gg/governance.asp>

3. UNDP and Disability Sector in India

UNDP (particularly Poverty Reduction Unit) has demonstrated a forthright view on inclusion. The unit has played crucial role in the State of Rajasthan on the inclusion issue through the Rajasthan Mission on Skill and Livelihoods (RMoL) on account of which the skill development of PwDs have now been included as an integral agenda of the government. In addition it is extremely commendable that the unit has supported formulation of a Comprehensive State Disability Policy that has been accepted by the government and very soon likely to be sent for cabinet approval. The unit in collaboration with Planning Commission has also instituted a comprehensive best practice study on enhancement of livelihood of PwDs in 10 states of India which will serve as a prelude for the 12th five year plan.

This scoping study is to highlight in brief the inclusion potential for UNDP's other 4 thematic areas VIZ Environment & Energy, Crises Prevention & Recovery, HIV & Development and Democratic Governance. The analysis clearly demonstrates the immense potential of inclusion of PwDs into each of these thematic areas. It further expects that all other thematic leaders take the progressive step of making inclusion an agenda in their scheme of thinking for the coming years and demonstrate their belief in human rights and rights based programming approach if they are already not doing so.