

# URBAN GOVERNANCE AND INCLUSION OF RIGHTS OF PERSONS WITH DISABILITY: NEED FOR COVERGENCE

2012



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# Abbreviation

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<b>PWD</b>	<b>Persons with disability</b>
<b>DDRC</b>	<i>District Disability Rehabilitation Centre</i>
<b>UNDP</b>	<i>United Nations Development Programme</i>
<b>UNICEF</b>	<i>United Nations</i>
<b>NSSO</b>	<i>National Sample Survey Organisation</i>
<b>CSOs</b>	<i>Civil Society Organisations</i>
<b>FGD</b>	<i>Focus Group Discussions</i>
<b>SC</b>	<i>Scheduled Caste</i>
<b>ST</b>	<i>Scheduled Tribe</i>
<b>ANMs</b>	<i>Auxiliary Nursing and Midwifery</i>
<b>PHC</b>	<i>Primary Health Center</i>
<b>RCI</b>	<i>Rehabilitation Council of India</i>
<b>CBR</b>	<i>Central Rehabilitation Register</i>
<b>RTE</b>	<i>Right to Education</i>
<b>UNCRPD</b>	<i>United Nations Convention on the Rights of Persons with Disabilities</i>
<b>CWSN</b>	<i>Children with Special Needs</i>
<b>DLHS</b>	<i>District Level Health Survey</i>
<b>CWSN</b>	<i>Childrens with Special Need</i>
<b>RSK</b>	<i>Rajya Shiksha Kendra</i>
<b>SSA</b>	<i>Sarva Shiksha Abhiyan</i>
<b>MSJE</b>	<i>Ministry of Social Justice and Empowerment</i>

## Forward

There is an observable trend of disability in India as a greater number of persons are getting enumerated under the disability definition. The Census of India, 2011 recorded 2.2% of total population under disability category. There are 2.24% persons with disability in rural areas and 2.17% in urban areas in India. There are 2.45 % persons with disability in the Scheduled Caste social group and 2.05 % in Scheduled Tribes. It is also revealed that the Scheduled Caste women are at a higher risk as 2.20 % SC women were disabled compared to the 2.01 % total women with disability in India. It clearly reflects that the disadvantaged population and those with greater societal neglect and oppression have higher risk of being disabled. The development planning and allocation of resources for addressing the community needs have larger implications for addressing the current issues of disability as well as to proactively prevent cases of disability.

The study was designed to understand the extent of inclusion of persons with disability in Governance process. It also attempted to assess disability related issues in existing framework of developmental planning. The study also looked at the trends of resource allocation, flow of funds and process bottlenecks in district budgeting and expenditures with respect to disability. The study framework is developed on the premise that the quality of governance has close relationship with the degree and extent of disability. The local governance institutions have critical role in addressing the issues of disability by reaching out each individual and providing specific support to make them more productive and live a life of dignity as a citizen of India.

The study is based on primary and secondary data. The study findings clearly highlight that the current decentralized planning is not disability sensitive. The Panchayat and urban and rural local body elected representatives are unaware of various positive provisions and lack skills in integrating needs of the disabled in decentralized planning exercise of the Government of MP. Lack of inter departmental co-ordination or effective convergence has greater implications for delivering benefits or preventing disability. Therefore, decentralized planning, convergence of resources and co-ordination of departments is significantly crucial.

We are thankful for the Christian Blind Mission (CBM), Bangalore for commissioning the study to Samarthan. Their financial support and regular guidance was of immense value for undertaking such a relevant study. We would like to express our gratitude for the communities, persons with disabilities and their family members for sharing their perspectives, emotions and solutions from their point of view. We are also thankful to the Government officials of MP and Civil Society Organizations for generating and sharing data for the study. Last but not the least, the team of Samarthan deserves a word of appreciation for putting hard work from inception of the study till its completion.

I hope that the report will be relevant for the policy makers and the practitioners to improve planning and implementation of programmes designed to address specific needs of the persons with disabilities.

Yogesh Kumar  
Executive Director

# **Urban Governance and Inclusion of Rights of Persons' with Disabilities: Need for Convergence**

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## **1. Introduction**

The last 10 years has seen a slow yet significant shift in the governance approach towards persons with disabilities in India. From being approached as merely a part of the large umbrella of the 'marginalised sections' in all the major policy documents to the recognition that the needs and the aspirations of persons with disabilities are very different from other marginalized social and economic groups. Much of this credit goes to the emergence of the disability rights movement in the 1990s which in many ways was inspired by other social movements and also the international disability rights movement. The legislation of the Persons with Disabilities Act 1995 is many ways considered a significant effort on the part of the government to go beyond the traditional view that the persons with disabilities as not just a diseased group that needs medical rehabilitation to approaching them as a group that has special needs from the government to function to the fullest of their capabilities. The specific focus of the Persons with disabilities Act since the Ninth Five year Plan has reconfirmed the shift in welfare based approach to rights based approach towards persons with disabilities. Tenth and the Eleventh Planning Commission reports and the approach paper of the twelfth Planning commission provide hope to the belief that greater emphasis on disability rights in our policy making and implementation would be given in India. These have all been very positive changes considered the complete ignorance to the persons with disabilities in India until 1990s.

While the changing approaches in governance towards persons with disabilities should be acknowledged, the reality suggests that persons with disabilities continue to be one of the most marginalized sections of the Indian society and are even today estranged from the social, economic, political fabric of the society. In particular, their lack of access to mainstream and quality health and education services, employment opportunities and the failure of the state to provide a barrier free physical environment persist as the problem areas that disable the persons with disabilities even further. However this would only seem like a general observation in the absence of any systematic research initiatives to understand the issue of disability in India, the needs of the persons with disabilities, the meaning of 'disability rights' and the effectiveness of our governance and policy approaches to persons with disabilities.

### **1.1 Rationale and Scope of the study**

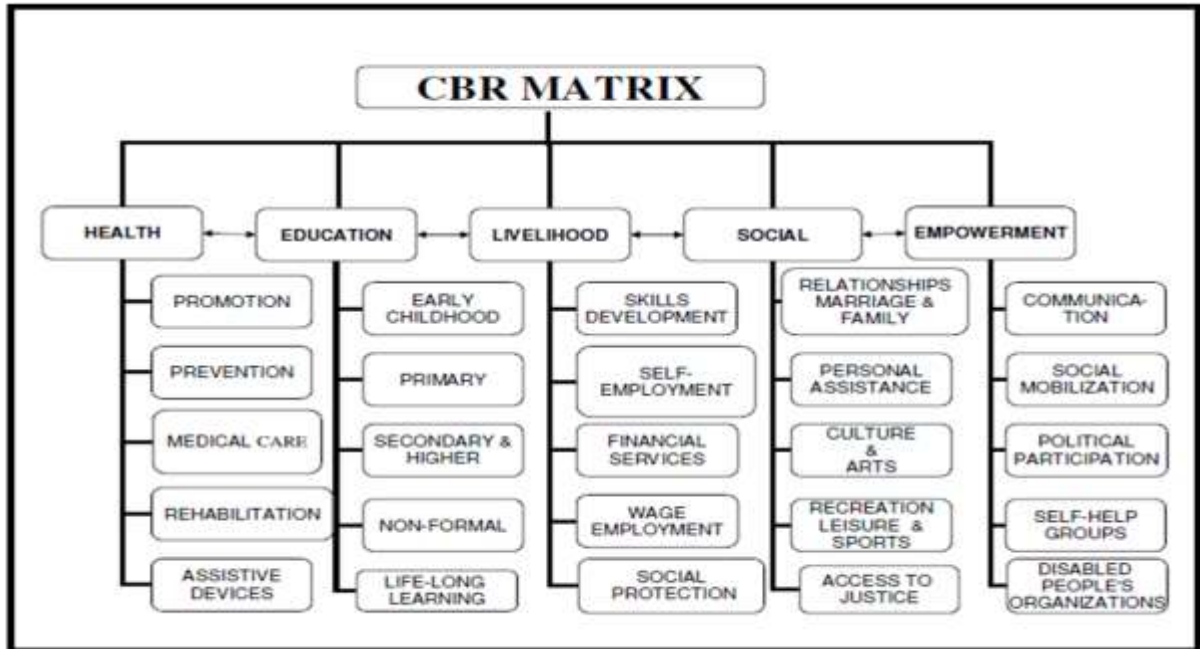
The poor state of disability studies in India has resulted in very poor knowledge creation about the status and effectiveness of the state policies for the disabled. For instance between 2002 and 2012 only 13 studies were funded by the Government on disability out of which only very limited issues were explored.<sup>1</sup> Even though the planning documents like the 10<sup>th</sup> and 11<sup>th</sup> Five Year Plans have emphasised the importance of a holistic approach to ensuring disability rights, the profile of the research studies conducted in this period have largely failed to contribute to our understanding of such a holistic approach to addressing persons with disabilities. Very little

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<sup>1</sup> Further details regarding the studies are available at: <http://socialjustice.nic.in/listofresearch11plan.php>  
Available at: <http://socialjustice.nic.in/listofresearch10plan.php> [last accessed on 12-12-2012]

efforts have been made to explore the possibilities of the Community based rehabilitation model in tackling the issues faced by persons with disabilities.

Across the globe, Community Based Rehabilitation is being recognised a strategy to improve the quality of life of the persons with disabilities by improving service delivery, ensuring equitable opportunities and by protecting their rights. For this model to take shape, equal participation is required from the persons with disabilities, their families, community and also the key providers of health, education, vocational and social services. It is believed that such a model can ensure the social and economic integration of the persons with disabilities (Dalal, 1998). In India, while there is greater recognition of the potential of the model from the non-governmental organisations, the government has not yet experimented with the model. The concept of CBR seems suitable in the Indian context for two key reasons. The first is the special place and relevance attributed to community based ideas/activities in our society. Moreover, there is a greater realisation among both the citizens and the government that there is urgent need to tackle challenges posed by urbanisation, population explosion, corruption in governance and lack of public participation. Inclusive governance and participation of various groups of citizens in policy making and implementation is now recognised as necessary conditions for growth. Persons with disabilities being one of the most vulnerable communities that could contribute significantly to the society if provided ample opportunities and rehabilitation services and included in the mainstream governance activities, a community based model for their inclusion and rehabilitation is crucial for the nation's growth. Secondly, there is close link between disability and poverty in India. Combating poverty should therefore be a critical objective of any disability related policy and community development programs have been found to be relatively successful in reducing poverty in many cases. Thus it is only logical to believe that community based rehabilitation holds greater significance in the lives of persons with disabilities who are poor and vulnerable.



Source: World Health Organisation Website<sup>2</sup>

<sup>2</sup> World Health Organisation, 2012, Community Rehabilitation Matrix, Available at: [http://www.who.int/disabilities/cbr/cbr\\_matrix\\_11.10.pdf](http://www.who.int/disabilities/cbr/cbr_matrix_11.10.pdf) [last accessed on 03-01-2013]

The above is the framework for community based rehabilitation of persons with disabilities as recommended by the WHO. The model aims at providing a holistic improvement in the quality of life of persons with disabilities by making interventions related to health, education, livelihood, social and community empowerment. In the case of developing countries like India where persons with disabilities are even today denied access to basic services, a discussion on the social and empowerment components would be too immature in terms of time and content. It is argued here that though the persons with disabilities in general have been sidelined from the mainstream governance processes, it is the persons with disabilities living in poverty that are the victims of poor disability policy design and implementation. Persons with disabilities belonging to relatively better social-economic backgrounds have an option of turning to the private sector for services and also are less affected by the public infrastructure like transport as they have an access to the 'alternate services'. It is in this context that the present study aims to understand and evaluate the reach and quality of three basic services health, education and livelihood available to persons with disabilities to understand how these sectoral policies have addressed the issues of prevention/early detection of disabilities, rehabilitation, barrier free access to physical environment and equal opportunities.

Besides focusing on the experiences of the persons with disabilities living in poor conditions, the scope of the study is limited to the urban setting. With rapid urban growth, rural-urban migration, a resultant growth in urban poor population and the unique challenges faced the government in tackling urban issues have made the separate analysis of any kind of social, demographic or economic issues in rural and urban context in India. The magnitude of disability, the governance frameworks available to address the issue of exclusion of disability, the experiences of the persons with disabilities and the attitude of persons with disabilities towards the environment around them could be very different. Consequently the present study bases its arguments, analysis and findings regarding persons with disabilities in the urban context. The status of urban governance and urban planning themselves are in their rudimentary stages and therefore it is well-recognised that to identify and place the role and status of persons with disabilities in these processes would be very highly challenging.

## **1.2 Research Questions**

Since the importance of inclusive planning and participatory governance has been positioned as the way forward to ensure citizen centric governance in India, the extent to which persons with disabilities rights have been protected and promoted in India is largely dependent on the status of persons with disabilities in our planning and governance framework. Based on this understanding, the present study aims to understand the urban governance and planning framework from disability rights perspective.

The key research questions addressed in this study are as follows:-

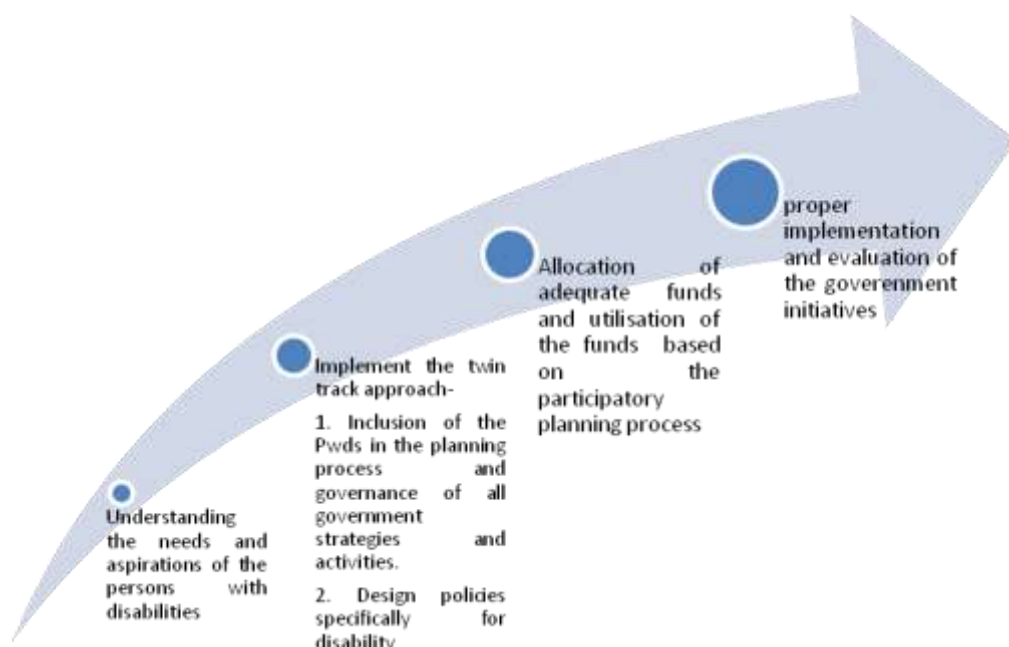
- Extent of policy discussions on the rights and specific needs of the disabled
- Streamlining the rights of persons with disabilities in urban development, urban planning, projects and schemes



- Does the budget allocated and the expenditure incurred by various sectoral departments in the urban areas designed to meet the specific needs of the persons with disabilities?
- Do the persons with disabilities in our cities feel that their rights and specific needs are addressed and catered to in the urban governance processes?

### 1.3 Conceptual Framework

There is growing consensus of disability advocates, experts and researchers that the most pressing issue faced globally by persons with disabilities is not their specific disability, but rather their lack of equitable access to resources such as education, employment, health care and the social and legal support systems, resulting in persons with disabilities having disproportionately high rates of poverty<sup>3</sup>. There is a shift in approach from merely focusing on the disabling conditions within the persons with disabilities to the disabling conditions around the persons with disabilities that limit the possibilities of them attaining their capabilities to their fullest abilities. From a medical rehabilitation approach to disability inclusive development approach, our understanding of disability has come a long way. The two most widely used approaches to disability are- disability inclusive and disability specific. The former includes persons with disabilities as a key stakeholder in all the development planning and implementation processes and the latter designs specific policies with the specific goal to enhance the quality of life of the persons with disabilities. These two approaches are not mutually exclusive and it is believed that both they should be integrated so that persons with disabilities can be brought back to mainstream society and also empowered to attain their maximum capabilities. The United Kingdom’s Department for International Development (DFID) proposed the “Twin Track” approach for disability inclusion that emphasises on supporting both inclusion of persons with disabilities in all development work and the fostering of targeted programmes as needed for specific disabled populations in order to ensure inclusion.<sup>4</sup>



<sup>3</sup> United Nations, 2012, Disability and the Millenium Deveopment Goals, Available at: [http://www.un.org/disabilities/documents/review\\_of\\_disability\\_and\\_the\\_mdgs.pdf](http://www.un.org/disabilities/documents/review_of_disability_and_the_mdgs.pdf) [last accessed on 03-01-2013]

<sup>4</sup> [http://www.dfid.gov.uk/r4d/PDF/Outputs/Disability/PolicyProject\\_IsabelOrtizReportFinal1.pdf](http://www.dfid.gov.uk/r4d/PDF/Outputs/Disability/PolicyProject_IsabelOrtizReportFinal1.pdf)

One of the most important indicators of the state of disability is the actual experiences of the persons with disabilities in accessing their rights and entitlements. There are many issues faced by the citizens while accessing various services. It is important to understand these issues so that a better understanding of the needs and aspirations of the persons with disabilities can form the basis for the creation of the plans and policies for the support of the disabled. For the disabled persons to achieve maximum capability levels, two things are important- involving persons with disabilities in evolving strategies of the government and involving organizations of persons with disabilities and their representatives in the decision making processes and involving the persons with disabilities in the strategies and activities of all government programs and schemes(12<sup>th</sup> Plan Approach paper). The Centre, state and the local bodies all have very important role, however post 74<sup>th</sup> CAA the role of Urban Local Bodies in the welfare of the citizens has assumed utmost importance. However the status of urban governance in general has been below expectations and that the municipal corporations are largely dependent on the central and state governments. Another important indicator of the state of disability rights is the budgeting of funds for the rights and entitlements of the persons with disabilities. The trend in allocation of funds for the welfare of the disabled and the utilization of these funds indicates attitude of the planners towards disability. How committed are the planners to the cause of disability rights is could be largely evident from the sectoral budget allocations at the district level, the trend in the expenditure of the allocated funds. It is also important to look at how the funds available for the development of wards are utilised and whether disability is considered an important component while planning for the activities

## **2. Methodology**

**The specific objectives of the study are:**

1. To understand the inclusion of persons with disabilities in the existing urban developmental planning.
2. To see the trends of resource allocation, flow and process bottlenecks for persons with disabilities in district budget and spending.
3. Access of resources and services to persons with disabilities at the local level and issues involved.

### **2.2 Sampling plan**

Bhopal is purposely selected to enhance the advocacy outputs. Similarly wards within the city are selected on the basis of their geographical location, as the distance a definite influence on the accessibility of the service. Selection of Bhopal as an area of research is motivated from the fact that Bhopal is capital city, therefore the place where all state level policies are formed. Being capital of Madhya Pradesh, Bhopal is the centre where key policy decisions are made. Thus the proximity and access to officials and schematic benefit is more in Bhopal. It is also likely that awareness, expectations, and demand among the respondents for the services are also higher due to higher awareness in the city. The effect of Bhopal Gas tragedy may also provide a useful and interesting dimension to the study.

Sampling plan specifically-

- Five wards of the Bhopal city were chosen for the purpose of data collection.
- The wards belonged to old Bhopal, New Bhopal and Peripheral region of city to understand the geographical spread of disability in Bhopal.
- Random sample methodology was used for collection of primary data

- Interviews of field level functionaries were held from the sampled geographical area
- A sample of 100 randomly selected persons with disabilities are from the five selected slums
- The grassroots level functionaries of the same area are interviewed for further data collection.

**Table:1 Sample from Bhopal**

S. No.	Settlement Name	Ward No.	Geographical	Type
1	Anna Nagar	57	New Bhopal	Slum
2	Gautam Nagar		New and Central Bhopal	Slum
3	Bag Mugalia Nai Basti	53	Peripheral Bhopal	Slum
4	Arif Nagar	14	Old Bhopal ( Gas affected)	Slum
5	Shyam Nagar	28	New and Central Bhopal	Slum

## 2.3 Survey tools

The following tools are used to collect data from both the supply and demand side stakeholders:

### i. Household tracking sheet/inventory (annexure-A)

A Household Tracking Sheet has been developed and used in the collection of primary data at the level of the users. The sheet generated data of 100 households per slum selected on a random basis. Also the same tracking sheet was used to collect data from the villages. Ten randomly selected villages from the mentioned block villages were exhaustively surveyed to identify any disability. The Tracking Sheet recorded information related to the socio- economic profile of the household, existence of disability and severity of disability-if found in the household and reasons. It also recorded the any of the State services availed by the persons with disabilities.

### ii. Interview schedule for the persons with disabilities

It will record the status of access, service delivery and various other rehabilitation and prevention issues. Three different types of interview schedules were administered to persons with disabilities during the study depending on their age. As the persons with disabilities in different age group will have need for different service for intervention and rehabilitation, i.e. a child in 0 to 6 years of age need prevention and early detection while a 25 year old adult would be interested in employment related issues. Similarly inclusive education would be pertinent for 15 year child and pension schemes for disabled old. Therefore, three different interview schedules are prepared to cater to children below six years of age, children in school going age and adults above 18 years (employable) age so as to capture different perspectives and experiences.

The study attempted to take equal number of respondents from each age group, however depending on the availability of persons with disabilities in different age group, the number may vary.

#### **iv. Time and Cost Tracking sheets (annexure D)**

To ascertain the time and cost incurred in using the targeted services for persons with disabilities such as getting a disability certificate or assistive aids etc.

#### **v. Semi Structured Interviews with all levels of the service providers (annexure E)**

Semi- structured interviews covering the same range of issues as discussed with the users of services, have been conducted with a range of grassroots functionaries and officials at the supervising, managing and decision making level. This covered the vertical line of functionaries for several issues that are pertinent to the study. The details of positions/personnel interviewed is given in the annex F

#### **vi. Semi- structured interviews with elected representatives (annexure F)**

Semi - structured interviews were conducted with elected representatives to ascertain their perspective as well as role. This included two ward members from Bhopal.

### **3. Understanding Disability in the Indian Context**

There is recognition of the fact that disability is a complex and multidimensional phenomenon and persons with disabilities form a specific group with needs different from persons without disability. Persons with disabilities as a group are not homogenous in nature. Their needs and experiences vary with type of disability, age, gender, socio-economic status etc.

However the Social Justice Department which is responsible for the persons with disabilities is guided by a medical definition and classification of the persons with disabilities whereby one's disability either falls into the category of loco-motor, visual, hearing, speech or mental (GOI, 2005)<sup>5</sup>. These broad categorisations cannot demonstrate the extent or exact type of impairment, which could assist in assessment of medical, and in some cases educational, need, and have no bearing on the social aspects of disablement. Perhaps reflecting cultural perceptions of what 'disability' means in India. DFID (2000: 2)<sup>6</sup> appears to neatly combine both the medical and social models in its definition of disability as: "...long term impairment leading to social and economic disadvantages, denial of rights, and limited opportunities to play an equal part in the life of the community."

In India, the broad definitions of different categories of disabilities have been adopted in the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 as well as under the Rehabilitation Council of India Act, 1992. "Person with Disability" means a person suffering from not less than forty percent of any disability certified by a medical authority. As per the Act "Disability" means - (i) Blindness; (ii) Low vision; (iii) Leprosy-cured; (iv) Hearing impairment; (v) Loco motor disability; (vi) Mental retardation; (vii) Mental illness. However, the Census of India 2001 document notes the difficulty involved in counting disabled persons and that the definition of disability as per the persons with disabilities Act makes identification and classification difficult and complicated is a Persons with Disabilities Act definition makes counting disability extremely difficult. It says: "Defining and measuring disability is a complex issue and it is not easy to communicate these concepts during the census process, in which only a limited amount of questioning time is possible to be spent with a

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<sup>5</sup> GOI (2005) Ministry of Social Justice and Empowerment Annual Report 2004-05, New Delhi: Government of India

<sup>6</sup> [http://www.create-rpc.org/pdf\\_documents/PTA15.pdf](http://www.create-rpc.org/pdf_documents/PTA15.pdf)

household for obtaining detailed information on every individual."<sup>7</sup> Census therefore used its own version of definitions in 2001 which defined types of disabilities:-

(i) Seeing, (ii) speech, (iii) hearing, (iv) movement, and (v) mental.

Organisation that collects data on disability in India is the National Sample Survey Organisation and Census. For the latest study conducted by NSSO in 2002 on disability, NSSO defined disability as a "person with restrictions or lack of abilities to perform an activity in the manner or within the range considered normal for a human being was treated as having disability. It excluded illness/injury of recent origin (morbidity) resulting into temporary loss of ability to see, hear, speak or move. Despite being able to capture the social aspect of disability apart from the physical manifestations in its definition, the inadequacies in the questionnaire restricted the organisation's ability to capture data accurately.

Census is also an important organisation that records disability. Most recently, the defining of disability has been enlarged in Census 2011. In comparison to the 5 Codes in Census 2001, 8 Codes have been provided in the present Census.

### 3.1 Counting Disability in India

The first ever official attempt to count disability was made in 1981 Census of India. However there were many concerns of the method of enumeration which allegedly resulted in the under-enumeration of disability. Following this, disability was not included in the 1991 Census of India. Notwithstanding the growing pressure from disability rights movement, persons with disabilities enumeration were again included in the 2001 Census of India enumeration<sup>8</sup>. Disability was included in the Indian Census for the first time in 2001, following a sustained campaign by the Indian disability movement. The Census found that 2.2 per cent of the population were disabled.

Census 2001 has revealed that over 21 million people in India as suffering from one or the other kind of disability. This is equivalent to 2.1% of the population. Among the total disabled in the country, 12.6 million were males and 9.3 million were females (Census of India, 2001). The number of disabled is more in rural than urban areas and more in males as compared to females (between 57-58 percent for males and 42-43 percent females.) Among the five types of disabilities on which data has been collected, disability In seeing at 48.5% emerges as the top category. Others in sequence are: In movement (27.9%), Mental (10.3%), In speech (7.5%), and In hearing (5.8%). Across the country, the highest number of disabled has been reported from the state of Uttar Pradesh (3.6 million). Significant numbers of disabled have also been reported from the state like Bihar (1.9 million), West Bengal (1.8million), Tamil Nadu and Maharashtra (1.6 million each).

**Table 2: Number of disabled population and type of disability**

	<b>Population</b>	<b>Percentage (%)</b>
Total population	1,028,610,328	100.0
Total disabled population	21,906,769	2.1
Disability rate ( per Lakh population)	2,130	--

<sup>7</sup>[http://mospi.nic.in/Mospi\\_New/upload/disability\\_india\\_statistical\\_data\\_11mar2011/Chapter%203%20Definition%20Disability.pdf](http://mospi.nic.in/Mospi_New/upload/disability_india_statistical_data_11mar2011/Chapter%203%20Definition%20Disability.pdf)

<sup>8</sup> Ministry of Statistics, (2011), Dimension of Disability, [http://mospi.nic.in/Mospi\\_New/upload/disability\\_india\\_statistical\\_data\\_11mar2011/Chapter%204-Dimension\\_Disability.pdf](http://mospi.nic.in/Mospi_New/upload/disability_india_statistical_data_11mar2011/Chapter%204-Dimension_Disability.pdf)

Type of Disability		
(a) In seeing	10,634,881	1.0
(b) In speech	1,640,868	0.2
(c) In hearing	1,261,722	0.1
(d) In movement	6,105,477	0.6
(e) Mental	2,263,821	0.2

*Source : Census of India 2001.*

The percentage of disabled people among the total population of any country would depend on the definition of 'disability' in that particular country as well as the enumeration methodology and its accuracy. In India, the definition of disability used in the Census is very different from that in the Persons with Disabilities Act, 1995.

Based on the Persons with Disabilities Act definition the Census 2001 reports that only 2.3 per cent of the Indian population have one or more disabilities. However this seems highly under-reported especially when we make a comparison of the number of persons with disabilities in India with other nations. For instance, developed nations like Australia and New Zealand have as much as 20% of their population affected by one or more types of disability and the reported disability rates in our neighbouring countries are 5.6% in Bangladesh, 6.3% in China and 7% in Sri Lanka.<sup>9</sup>

### **3.2 Disability Rights and Policies in India**

Understanding disability from human rights perspective focuses on the fact that persons with disabilities have rights and should not be confined to 'objects of charity'.<sup>10</sup> Such an approach emphasises on the role of the government to ensure that the persons with disabilities enjoy their rights and freedoms and are provided equal opportunities to participate completely in the society.

However, evidences suggest that persons with disabilities have been discriminated against either directly or indirectly in various ways. There has been neglect on the part of the government to ensure that the rights of the persons with disabilities are not violated. There are many more instances where apathy and lack of understanding from the government as well as the community deny the persons with disabilities their rights. In this context it is important to understand whether the policies designed specifically for the persons with disabilities and the development policies related to key sectors like health, education and vocational services, have approach disability and how inclusive and comprehensive are these policies of the rights of the persons with disabilities.

There are a number of policies in India that ensures rights and equal opportunities to the persons with disabilities. Some of them are specifically designed to address disability and other is disability inclusive development policies.

<sup>9</sup> Planning Commission of India 2007, Social Justice: Scheduled Castes, Scheduled Tribes, Other Backward Classes, Minorities and other Vulnerable groups

[http://planningcommission.nic.in/plans/planrel/fiveyr/11th/11\\_v1/11v1\\_ch6.pdf](http://planningcommission.nic.in/plans/planrel/fiveyr/11th/11_v1/11v1_ch6.pdf)

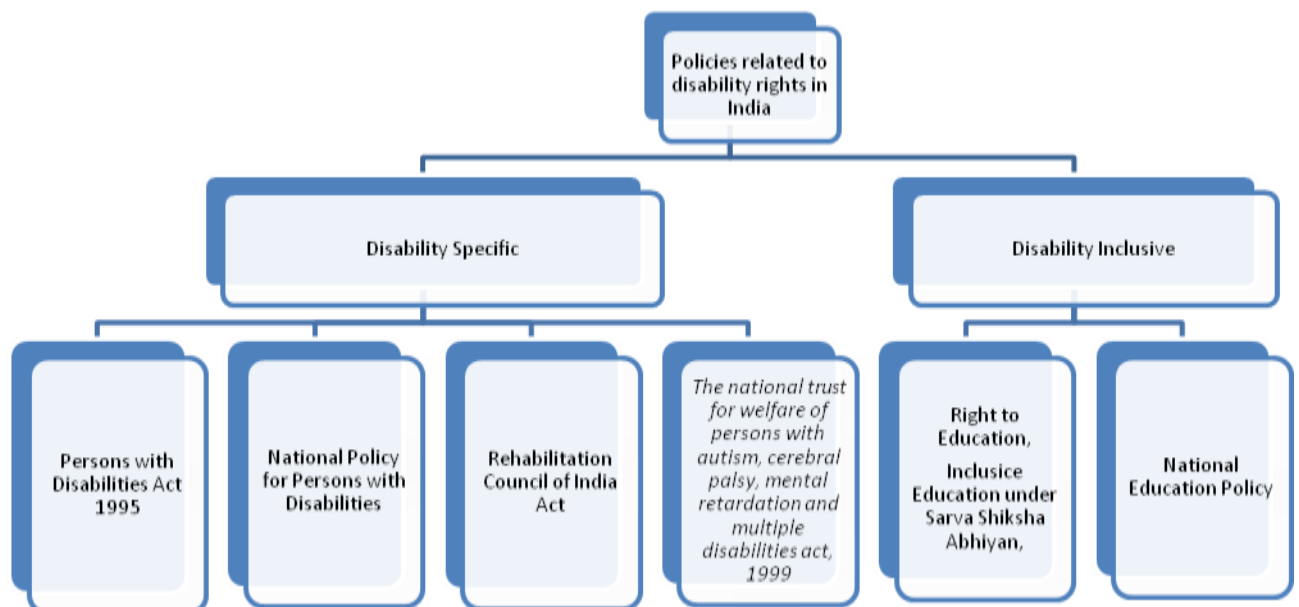
<sup>10</sup> <http://www.disabled-world.com/editorials/drpi-human-rights.php>

## i The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act - 1995

In India, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 defines disability as one or more of the following: blindness, low vision, leprosy cured, hearing impairment, locomotor disability, mental retardation and mental illness. It says that to be considered disabled, a person must suffer from not less than 40 per cent of any disability, as certified by a medical authority. The Persons with Disabilities Act has both binding entitlements and more general commitments. The key provisions are:

### Education:

The following are binding on Government (i.e. not subject to economic factors): Governments shall ensure that every person with disability has access to free education “in an appropriate environment” until the age of eighteen. The key responsibilities of the Government under the Act with regard to education were to conduct or support research for the development of assistive devices and special learning materials for children with disabilities in order to promote equal opportunity in education.



The Act also recognised the importance of teacher training to produce “the requisite manpower” for teaching of children with disabilities both in special schools and integrated settings.. The Act also mandated the government to create a comprehensive education scheme for children with disabilities which includes characteristics like transport or financial incentives, barrier free access to schools, supply of assistive devices and special learning materials

### Employment:

Section 33 of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 provides for a reservation of 3% in the vacancies in identified posts

(1% each for persons with blindness or low vision, hearing impairment and locomotor disability or cerebral palsy) in the Government establishments including the Public Sector Undertakings. Section 41 of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 provides for incentives to employers to ensure that at least five percent of their work force was composed of persons with disabilities.

The act says that- The Government shall: identify posts for Person with disability in public establishments and update the list every three years and reserve not less than 3 percent of identified posts for Person with disability, with 1 percentage point reserved for people with blindness/low vision, hearing impairment, locomotor disability or cerebral palsy respectively. "Within the limits of their economic capacity and development," Governments shall provide incentives to both public and private sectors for employment of persons with disabilities with a target of at least 5 percent of their workforce to be persons with disabilities.

Governments and local authorities shall formulate schemes for promotion of employment of persons with disabilities which may provide for training of persons with disabilities, relaxation of age limits in employment, measures related to OHS, provisions for financing such schemes etc. Reservation of not less than 3 percent in all poverty alleviation schemes

### **Prevention and early detection of disabilities:**

All commitments in this area are given with the provision "within the limits of their economic capacity and development". With proviso, Governments should undertake surveys on causes of disability and promote "various methods" for preventing disabilities. It should also screen children at least once a year for identifying at-risk cases. Alongside it should provide facilities for training PHC staff. Conduct or sponsor awareness campaigns on hygiene, health, and sanitation, and on causes and prevention of disabilities and "take measures" for pre-, peri- and post-natal care of mother and child.

### **Affirmative Action:**

Governments shall frame schemes for provision of aids and appliances to persons with disabilities, preferential allotment of land for housing, business, recreation centres, special schools, research centres, and factories run by enterprising persons with disabilities.

*Non-discrimination in access:* All commitments in this area are given with the proviso "within the limits of their economic capacity and development". With proviso, Governments should: Adapt all forms of transport to make them accessible to persons with disabilities and provide for a variety of assistive devices in the built environment, including auditory signals, ramps in public buildings and health facilities, Braille signage etc.

Considering that the Act was the first ever attempt to specifically address the issue of disability through a composite legislation, it is important to acknowledge the progressive nature of the Act. The Act was drafted and passed in 1995 which is 12 years before the United Nations Conventions for the Rights of Persons with Disability came into existence in 2007.

### **ii National policy for the persons with Disability, 2006**

Based on the rights based understanding of disability and its commitments under the UNCRPD, national policy for the persons with disabilities addresses multi-sectoral and multi-dimensional aspects of disability from a rights perspective. The ministry of Social Justice designed the policy in 2006 and is considered to be one of the most progressive policies in India on disability. Some of the key features of the policy are as follows:-



- It focuses on prevention, early detection, and rehabilitation of the persons with disability. It promotes training of paramedical staff like ASHA, ANM, Anganwadi workers etc in early detection and prevention. Further, it talks about strengthening of immunisation program to control disability through immunisation or improved nutrition
- It provides for physical, economic, and educational rehabilitation and points towards specific measures to do the same.
- It pays special attention to inclusive education and educational rights of the disabled children and identifies the Ministry of Human Resource as the nodal agency to ensure the implementation of inclusive education programs.
- Employment being critical to dignified living, the policy reinforces the reservation in employment; also it states the encouragement of development of suitable skills in the disabled persons for employment in the private sector. Rehabilitation and vocational training centres will play an expanded role in doing the same.
- The policy lays special emphasis on the women and children with disabilities
- The policy talks about a barrier free environment for ensuring access of the disabled to the services
- There is special mention of the social security measures to the persons with disabilities and states that state government will be encouraged to bring out a comprehensive social security policy for the disabled.

### **iii Persons with disability act 2011-working draft- Draft legislation to replace the Persons with Disabilities Act, 1995**

With the increasing demand from disability rights advocate, the Persons with Disabilities Act 1995 is being considered to be replaced by a more rights based legislation. The rationale behind this demand is that the Persons with Disabilities Act 1995 focuses more on the medical rehabilitation of the persons with disabilities and less on the social and economic life of the persons with disabilities. Resultant, the 'Ministry of Social Justice and Empowerment', by notification F.No. 16-38/2006-DD.III, dated 30th April 2010, constituted a Committee. The committee was chaired by Dr Sudha Kaul with members representing persons with disabilities, NGO's and experts from the disability sector, to draft a new legislation to replace the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995.

The proposed legislation guarantee equality and non-discrimination to all persons with disabilities and recognizes legal capacity of all persons with disabilities along with making provision for support where required to exercise such legal capacity. The proposed bill recognizes the multiple and aggravated discrimination faced by women with disabilities and inducts a gendered understanding in both the rights and the programmatic interventions.

It emphasises the special vulnerabilities of children with disabilities and ensure that they are treated on an equal basis with other children. It mandates to establish National and State Disability Rights Authorities which facilitate the formulation of disability policy and law with active participation of persons with disabilities. The proposed bill also mandates that all establishments shall reserve not less than seven percent of all posts and in promotions for persons with disabilities.

#### **iv Rehabilitation Council of India Act -1992**

The Act provides for the constitution of Rehabilitation Council of India (RCI) for regulating the training of rehabilitation professionals and the maintenance of Central Rehabilitation Register to enrol rehabilitation professionals who possess recognised rehabilitation qualifications. It seeks to ensure that disabled people are treated by qualified personnel, and acts as an accreditation and quality control facility. The Act provides an elaborate account of the formation, membership and functions of the Council. One of the most important features of the Act is the recognition of qualifications granted by University or other institution for rehabilitation professionals.

The key functions of the Rehabilitation Council as per the Act include laying down minimum standards of education required for granting recognized rehabilitation qualification, registration of professionals in the Central Rehabilitation Register, prescribing standards of professional conduct and a code of ethics and removal of names from the Central Rehabilitation Register.

#### **V. The national trust for welfare of persons with autism, cerebral palsy, mental retardation and multiple disabilities act, 1999**

The National Trust Act, 1999 (Act no.44 of 1999) has been enacted by the Union Ministry of Law, Justice and Company Affairs on 30th December, 1999 for providing facilities and welfare of the persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. For enforcement of this Act, necessary Rules were published by the Union Ministry of Social Justice and Empowerment on 27th July, 2000 in the Gazette of India notifying The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Rules, 2000.<sup>11</sup>

#### **vi. National Education Policy:**

An important point to note at the national level is that policy has progressed significantly in some areas since the persons with disabilities Act. In particular, in the area of education, policy towards inclusion of persons with disabilities into mainstream education has become increasingly clear in recent years, and the policy statement of the MHRD in 2005 represents a more robust and concrete commitment to realizing the right to education of persons with disabilities.

#### **vii. Right to Education Act(2010)**

The Right of children to Free and Compulsory Education Act came into force from April 1, 2010. This was a historic day for the people of India as from this day the right to education will be accorded the same legal status as the right to life as provided by Article 21A of the Indian Constitution. Every child in the age group of 6-14 years will be provided 8 years of elementary education in an age appropriate classroom in the vicinity of his/her neighbourhood.

Any cost that prevents a child from accessing school will be borne by the State which shall have the responsibility of enrolling the child as well as ensuring attendance and completion of 8 years of schooling. No child shall be denied admission for want of documents; no child shall be turned away if the admission cycle in the school is over and no child shall be asked to take an admission test. Children with disabilities will also be educated in the mainstream schools. The National Commission for Protection of Child Rights (NCPCR) has been mandated to monitor the

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<sup>11</sup> Government of India, 1999, 'The national trust for welfare of persons with autism, cerebral palsy, mental retardation and multiple disabilities Act, Available at [http://www.autism-india.org/National\\_Trust\\_Act.pdf](http://www.autism-india.org/National_Trust_Act.pdf) [last accessed on 12-11-2012]

implementation of the Act. A special Division within NCPCR will undertake this huge and important task in the coming months and years.

Right to Education has been a part of the directive principles of the State Policy under Article 45 of the Constitution, which is part of Chapter 4 of the Constitution. Rights in Chapter 4 are not enforceable. However, this right has been made enforceable by putting it in Chapter 3 of the Constitution as Article 21. This entitles children to have the right to education, as a fundamental right.

### **Viii Inclusive education for the disabled children**

The Scheme of Inclusive Education for Disabled at Secondary Stage (IEDSS) has been launched from the year 2009-10. This Scheme replaces the earlier scheme of Integrated Education for Disabled Children (IEDC) and would provide assistance for the inclusive education of the disabled children in classes IX-XII. To enable all students with disabilities, after completing eight years of elementary schooling, to pursue further four years of secondary schooling in an inclusive and enabling environment

The scheme covers all children studying at secondary stage in Government, local body and Government-aided schools, with one or more disabilities as defined under the Persons with Disabilities Act (1995) and the National Trust Act (1999)

The School Education Department of the State Governments/Union Territory (UT) Administrations is the implementing agency. They may involve NGOs having experience in the field of education of the disabled in the implementation of the scheme. Central assistance for all items covered in the scheme is on 100 percent basis. The State Governments are only required to make provisions for a scholarship of Rs. 600 per disabled child per annum.

### **ix 11<sup>th</sup> Five Year Plan and positive provisions for disability**

The 11 five year plan confirmed that the percentage of Persons with disability in NSSO and Census is very low. Therefore, it negated census and NSSO figures on disability and accepted far more prevalence of disability than enumerated in census. Further it strengthened the shift from a "Welfare Approach" to a "Rights based approach".

Therefore in the 11<sup>th</sup> Plan – the approach is more pragmatic and serious efforts are made to empower the disabled and focusing special attention on monitoring mechanisms. 11<sup>th</sup> Plan is based on the persons with disabilities Act, National Policy for persons with disabilities 2006 and UNCRPD. The 4 pronged approaches are as follows:

- Delineate clear cut responsibilities amongst concerned Ministries/ Departments
- Concerned Ministry/ Department to formulate detailed rules and guidelines within 6 months of approval of plan
- Ensure each Ministry/ Department reserves not less than 3% of the annual outlay for persons with disabilities
- Set-up monitoring mechanisms at various levels and develop review systems

The 11<sup>th</sup> Plan recommended that the Office of the 'Commissioner Disabilities' to be strengthened, so that they can perform more effectively and ensure different Ministries/ Departments perform their function. It advocated setting up of 'National Institute of Universal Design' – promoting barrier-free environment and expansion of DDRC to 300 districts.

It further advocated the rights of the disabled, by raising income ceiling for assistance under ADIP to Rs. 10,000/- and enhancement to Rs 25,000 aids and appliances per person. The plan emphasised on the grey areas such as disability certification and inclusive education.

## x. Decentralised District Planning

Zilla Yojna Samiti Adhinyam 1995 envisages a district planning committee headed by minister in charge of district as chairman and elected members as member. District planning committee plays a key role in decentralised planning. It is suppose to provide leadership in collective vision building of the district wherein local priorities and expectations are determining factor. It accommodates development priorities of the district. Plans are prepared at the ward levels with participation of the community, therefore includes local needs and local expectation. These plans then integrate and culminate to make district plan. The decentralised district planning process is unique and unprecedented for accommodating local priorities and participation of community. It has potentials to integrate the aspirations and priorities of persons with disabilities as well other marginalised. It not only integrates the demand for development vertically but also potentially handles the need for horizontal convergence of departmental deliveries for a meaningful output.

### 3.4 Analysing the Strengths and Bottlenecks of Disability Policies

The policies have been a result of several civil society disability rights movements that gained momentum internationally and in India in the 1990s. The international movement for disability rights, the UN convention for the rights of persons with disabilities (UNCRPD) and the UN decade for disability have had its impact on how our policies have been shaped.

- The policies have focussed on comprehensive human rights approach
- Disability specific policies have addressed the inter-sectoral nature of the rights and entitlements of the persons with disabilities.
- Education sector is one of the frontrunners in creating disability inclusive development plans through National Educational Policy, Inclusive education component of the Sarva Shiksha Abhiyaan.
- With respect to all the disability specific policies, it has been commonly observed that the policies have not adequately recognised the potential of the Urban Local Bodies (ULBs) in delivering services to the persons with disabilities. The democratically elected bodies at the local level play very little role in the implementation model envisioned in our disability policies.
- On one hand the importance of inter-sectoral and inter-departmental coordination is emphasised, however policies provide no clear responsibilities to the relevant departments

**Table -3 Positive spaces and bottlenecks in different legal instruments**

<b>Policy and legislations</b>	<b>Positive spaces</b>	<b>Bottlenecks ( ADJUST TEXT)</b>
<b>11<sup>th</sup> Five Year Plan</b>	<ul style="list-style-type: none"> <li>• Accepts far more disability than identified in census</li> <li>• Calls for 3% allocation of budgets in relevant department for disability</li> </ul>	<ul style="list-style-type: none"> <li>• Poor implementation of the mandatory conditions. Most departments haven't allocated 3% of their budgets to disability</li> </ul>

	<ul style="list-style-type: none"> <li>• Approach and focus shifted from 'welfare to approach to Right based approach'</li> <li>• Promotes vigorous implementation of the comprehensive action plan for inclusive education</li> <li>• Extends the coverage of DDRC and income ceiling to 25000 for assistance under DDRC.</li> <li>• Amends building bylaws to promote barrier free access</li> <li>• Incentive to promote jobs in Private sector</li> <li>• Makes district planning mandatory to access the funds of 11<sup>th</sup> five year plan</li> <li>• Identify and encourages prevention and early intervention with the help of village level service providers from other departments</li> </ul>	<ul style="list-style-type: none"> <li>• District planning is sketchy and weak</li> <li>• Disability is not addressed adequately in the ward plan</li> <li>• Slow progress on rights based approach</li> <li>• Poor integration and implementation at the ground level</li> <li>• Grass root functionary are poorly trained on disability</li> <li>• Panchayats have been neglected for providing downward linkage</li> </ul>
<b>National Policy on disability</b>	<ul style="list-style-type: none"> <li>• Clearly articulates physical, economic and educational rehabilitation</li> <li>• Strongly promotes inclusive education</li> <li>• Right based approach</li> <li>• Schemes and reservation in employment</li> <li>• Affirmative action such as</li> </ul>	<ul style="list-style-type: none"> <li>• <del>Poor implementation of the act, with only the commissioner's office made in charge for the grievance and complaints with respect to implementation of the act.</del></li> <li>• Poor budgetary allocation to justify the agenda of the act.</li> <li>• Relies on census data for identifying the Person with disability - the data is inadequate</li> </ul>
<b>Person with disability Act 1995</b>	<ul style="list-style-type: none"> <li>• <del>Provision of assistive aids &amp; technologies, preferential allotments in land housing ,loans etc</del></li> <li>• Advocates non discriminatory access, equal opportunities and equal participation of disabled</li> </ul>	<ul style="list-style-type: none"> <li>• Does not an clear component for downward linkage and departmental integration</li> <li>• Non comprehensive in approach</li> <li>• No concrete backing in state acts and policies</li> <li>• Poor aggregation</li> <li>• Department budgets may have mismatch with village plan</li> <li>• Process of district planning and village planning still very sketchy</li> </ul>

<b>District planning and decentralised planning</b>	<ul style="list-style-type: none"> <li>• Potential for bottom up planning</li> <li>• Potential to include disability and other specific issues of the village in the village master plan</li> <li>• District budgets are sanctioned only on approved aggregates of village master planning</li> </ul>	

## 4. Disability in Madhya Pradesh

According to Census 2001, total population of Madhya Pradesh is 60,348,023, out of this 14,08,528 persons are living with disability. Currently Department of Social Justice and Welfare is the concerned authority for the welfare of Person with Disability in Madhya Pradesh. There are 14,08,528 disabled people in Madhya Pradesh, making up 2.3% of the state's total population (Census 2001). The NSSO reports 11,66,856 disabled people. Visual disability is the most prevalent disability according to Census 2001. The NSSO says ortho-disability is the most prevalent. Disabled children number around 100,929. About 60% in the 6-14 age-groups are male. Fifty percent of the total disabled population in Madhya Pradesh is literate, 45% in rural areas and 55% in urban areas (NSSO). However, a majority (66%) of the literate disabled have not progressed beyond primary school. The literacy rate (CENSUS 2001) for the disabled (49.7%) is much lower than the literacy rate for the general population (64.11%).

Only 37.6% of disabled people (529,648 people) are employed (main and marginal). The remaining 62.4% are not engaged in any income-generating activity. About 81% of total disabled workers belong to rural areas, and 19% to urban areas. The high percentage of employment in rural areas might be result of disguised employment in agriculture. Nearly 52% of the total disabled workforces in Madhya Pradesh belong to the visually disabled category. About 42% of total disabled workers are cultivators, followed by agricultural labourers (27.5%).

Disabled children number around 100,929. About 60% in the 6-14 age-groups are male. Madhya Pradesh has its own state disability policy, adopted in 1997. Thirty-eight out of 48 forty eight districts have a local-level committee, as mandated under the National Trust, which provides legal guardianship to disabled adults.

### 4.1 Development Planning of Urban Areas and Inclusion of Persons with Disability

Traditionally the planning process in India has largely followed a top-down process which has often failed to understand the local issues- real issues affecting real people, thereby increasing the gap between the people and the government. There was an increasing realisation among policy makers that the structures of local governance need to be empowered to improve the development indices accelerate the rate of socio- economic growth, and to ensure "Inclusive Growth". The involvement of Panchayat Raj Institutions and Urban Local Bodies in development planning, monitoring and evaluation is the major milestone to be achieved after 73<sup>rd</sup> and 74<sup>th</sup> constitutional amendment.

## 4.2 Inclusion of Persons with Disabilities in urban planning

The preparation of “Integrated District Plan” in decentralized manner is the major step in this direction. The presence of institutions of local self governance in the state provides a opportunity to translate programs and policies into better outcomes. 73rd and 74th constitutional amendments made it compulsory to constitute the District Planning Committees which has mandatory function of formulation of district plans, and monitoring at district level and also the constitution of local bodies in the rural and urban areas. Accordingly, the District Planning Committee Act 1995 was enacted in the state of Madhya Pradesh.

While these mandates have been initiated to some extent, not much was achieved, particularly in the urban areas. Role of district planning committee in charting out an inclusive development plan of Indian cities, town and villages , as envisaged in Eleventh five year plan stressed on the importance of convergence of resources and enforcement of inter-sectoral priorities. Madhya Pradesh, after Kerala are considered to be the two most progressive states in realising the spirit of decentralised planning. Despite, being considered an under-developed state in the country, the initiatives of the MP government towards creating DPCs since 2001 should be considered a positive step in terms of planning.

Operational Framework of district planning:

- State Planning Commission will provide support and direction for preparation of District Plan and allocate plan ceiling of the districts
- DPC in consultation with subject matter Specialists, Government officials,
- Civil Society Organisations and other stakeholder(s) will determine plan ceiling between rural & urban segments and formulate strategy to prepare and integrate plan proposals of local bodies
- Urban plan proposals will be prepared by local bodies with support from the Technical Support Group (TSG) constituted for each of the Ward.
- Local bodies are expected to come up with vision of development based on local needs and specific strengths.
- The plans prepared at urban wards are integrated and consolidated at each subsequent level finally to be consolidated at the district level by District Planning Sub Committee. This is further submitted to the District Planning Committee for approval and consolidation.
- All the line departments will be grouped into key sectors.
- Further working groups will be constituted for each sector for preparing proposals keeping in view the needs and possible inter and intra sector convergences. Working groups will also prepare positioning paper for the achievement of MDGs at their levels.

Understanding the importance of inter-departmental linkages and the need for creating a comprehensive plan that consolidates departmental plans based on their sectoral relevance, the state planning commission has suggested the need for convergence of the plans of selected departments to develop a consolidated sectoral plan.

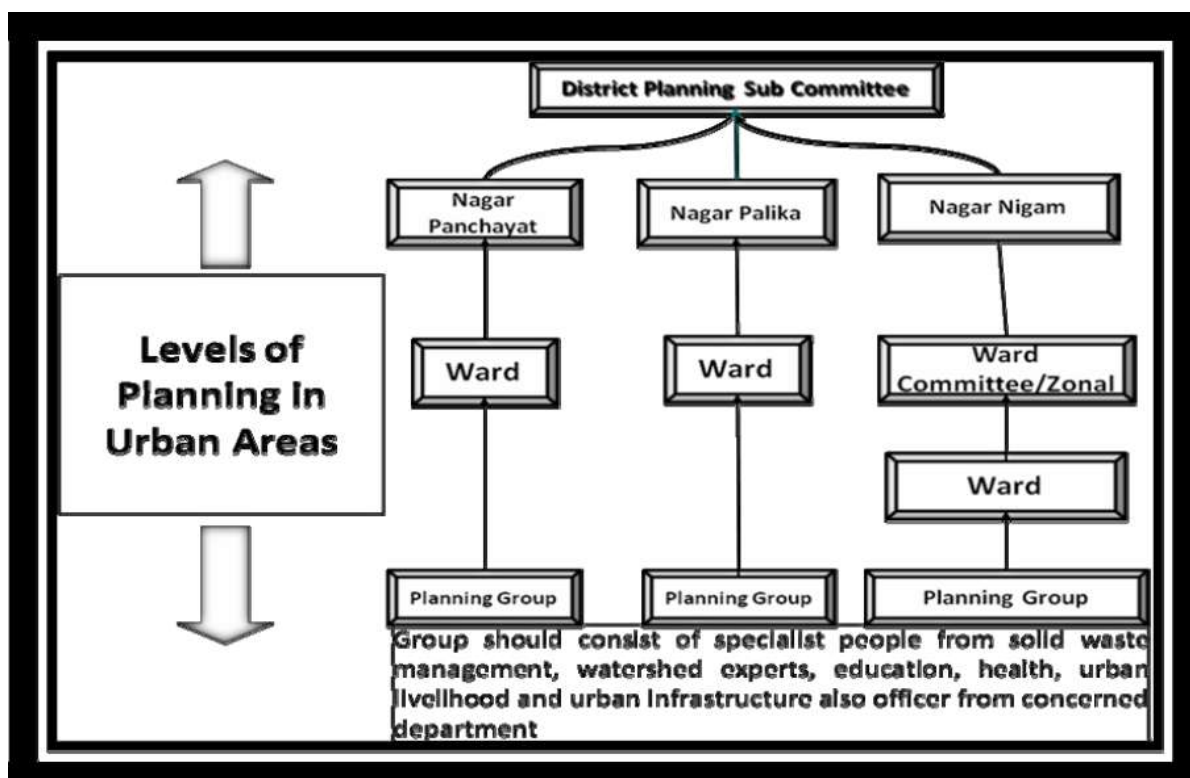
The following table lists the selected departments that would be converged to create the specific sectoral plans

**Table 4: Sector Specific Convergence among Selected Departments**

Sector	Concerned departments
Education	School Education, Higher Education, Technical Education, Non-formal Education, Vocational Education.
Health & Nutrition	Public Health and Family Welfare, Public Health Engineering, Woman and Child Development, Food & Civil Supplies
Livelihood	Agriculture, Horticulture, Forest, Panchayat, and Rural Development, Veterinary and Dairy, Village Industries, Social Justice, Water Resource, Fisheries, Handloom, Cooperation, Sericulture, Welfare of SC, ST and OBCs.
Infrastructure Management	Public Works Department, Rural Development, Rural Engineering Service, Water Resource, Energy, Planning
Energy management	Energy, Rural Development, Forest, Planning
Civil Right Protection	Land Reform, Social Justice, Women and Child Development, Revenue

Source: 12<sup>th</sup> Five Year Plan Madhya Pradesh, 2012

### Structure of Urban Decentralized Planning



Source: Twelfth Five Year Plan- Madhya Pradesh, 2012



### 4.3 Participation of the Persons with Disabilities in the Urban Planning

Experiences suggest that the policy and practice of decentralized planning in the rural areas are far better than the decentralized planning trends in urban areas. It was evident that there was no public participation (including those of persons with disability) in planning process had taken place in the intervened wards. However, the state claims are different. The Planning Commission website reports contradictory data

**Table 5: Details of the meetings/consultations conducted with specific groups in various wards as a part of decentralised urban planning in Bhopal District**

Block	Panchayat	Village	Male	Female	Total	SC	ST	Disable
ULB-Bhopal	Bairasia	Ward 02	30	40	70	43	23	3
ULB-Bhopal	Bairasia	Ward 03	80	80	160	48	34	6
ULB-Bhopal	Bairasia	Ward 04	100	50	150	41	32	6
ULB-Bhopal	Bairasia	Ward 10	30	40	70	35	4	4
ULB-Bhopal	Bairasia	Ward 13	150	0	150	25	52	2
ULB-Bhopal	Bairasia	Ward 14	200	135	335	26	48	5
ULB-Bhopal	Bairasia	Ward 15	100	100	200	51	40	2
ULB-Bhopal	Bhopal	Ward 04	22	15	37	20	12	3
ULB-Bhopal	Bhopal	Ward 12	7	4	11	5	3	1
ULB-Bhopal	Bhopal	Ward 20	30	20	50	25	10	5
ULB-Bhopal	Bhopal	Ward 21	24	22	46	20	20	5
ULB-Bhopal	Bhopal	Ward 24	10	21	31	10	10	5
ULB-Bhopal	Bhopal	Ward 35	3	1	4	2	2	0
ULB-Bhopal	Bhopal	Ward 36	4	1	5	2	2	1
ULB-Bhopal	Bhopal	Ward 37	4	2	6	2	2	1
ULB-Bhopal	Bhopal	Ward 38	3	2	5	2	2	1
ULB-Bhopal	Bhopal	Ward 39	3	1	4	2	1	1
ULB-Bhopal	Bhopal	Ward 66	41	49	90	43	40	3
ULB-Bhopal	Kolar	Ward 01	8	4	12	3	4	2
ULB-Bhopal	Kolar	Ward 09	7	5	12	4	4	3
ULB-Bhopal	Kolar	Ward 12	9	6	15	4	2	2
ULB-Bhopal	Kolar	Ward 20	10	15	25	12	6	3

**Source: Decentralised Planning Meeting details 2011-2012**

According to the website, a sector wise survey was conducted among citizens to analyse the current situation/ problems faced by them. The sector wise survey was designed in such a way that the convergence plan of all the key sectors can address the issues faced by the citizens.

This survey is used to understand the key sectoral issues faced by urban and rural citizens. This data is key in prioritizing demands, allocating funds, designing and amending schemes to ensure greater citizen satisfaction levels.<sup>12</sup>

**Table 6: Surveyed Persons with disabilities participated in ward or city level planning**

S. No.	Poor settlement Name	Ward No.	No. of disabled persons included in ward planning (Data as on Decentralised planning website)	Percentage of persons with disabilities surveyed who have participated in any kind of development planning of their ward
1	Anna Nagar	57	Data unavailable	0%
2	Gautam Nagar		Data unavailable	0%
3	Bagmugalia Nai Basti		Data unavailable	0%
4	Arif Nagar		Data unavailable	0%
5	Shyam Nagar	28	Data unavailable	0%

**Source: Author's Analysis of the data collected for this study**

Interviews with the ward councillors also reinforced that the planning for the development of their ward has largely been a top-down approach, where the ward councillor receives both the list of planned activities and the funds from the Municipal Corporation Bhopal. The real issue of development planning at the ward level is clear from the discussion with the Ward Councillor of the Bhopal Gas Affected slum named Arif Nagar.

#### **Role of Ward Councillors in ward Planning: Case of Arif Nagar**

Nisha Khan was elected the ward councillor of Arif Nagar 4 years back. The total population of the ward is approximately 25000. According to her the ward has a relatively large persons with disabilities population more so because the slum houses large number of the Bhopal gas tragedy victims. She says that around 330 people have disability certificate and 80 people are left out. There have been no formal and structured efforts to create a ward plan in her ward. According to her *"the plan for each ward comes from the higher authorities at the municipal corporation level. A list of works to be done in the ward is sent to the ward councillor, which the ward councillor ensures completion. There is enough fund available for a ward councillor to complete work in a ward as per the needs of the people, however, there are a number of issues that affect the work of the ward councillor."* Being from the opposition party she says that there is very little access to the Mayor's fund. For example in her ward, most of the area is under the ownership of the Waqf board. Due to some conflict between the board and the municipal authorities, all the ward development work in the ward has been stalled. She says that there have been many works in the ward that has been sanctioned however due to this conflict no work has been done. She says that while a formal planning system does not work in reality, the ward councillor accepts complaints/requests for public work that are verified by the councillor and sent to the zone for further consents. She says that no requests for work related to disabled welfare have reached her in the last 4 years. She reiterated the fact that though the ward councillor is an elected representative, they remain restricted by a number of issues that are most often beyond their abilities and this prevents them from working for the people. She said that she regularly attends the zone committee meetings where they discuss about the

<sup>12</sup> <http://mwh.mpforest.org/dcpnew/FrmProblemAnalysis.aspx>

issues that affect their respective wards and the ward councillors also present the requests for works in their wards which are then debated in the zone committee. She says that much of the work gets sanctioned at the zonal level however the issues between the waqf board and the municipal corporation has caused all the works to come to a standstill. However she has made complete efforts to inform people whenever camps are organized and also provide them with transportation services for the people to reach the camp and also come back home. However she thinks that such camps are not well organised as they are made to wait for a long time. While disability certificates are made then and there, since the devices are not made available at the camp people have to go another day to collect their devices. Such cumbersome process has greater effect on the disabled.

Through her experience, she says that the disabled are faced with a number of issues:-

1. The disabled people are made to visit every office multiple times and no preferential treatment is given to them while present at the office. For example she said that the disabled are made to stand outside the bank for hours to get 150 Rs pension. According to her the bureaucratic red tapism is the biggest issue in ensuring disability welfare.
2. The cost and time expenditure to access the services made available to the disabled are so high when compared to the benefits, that the disabled most often are found to stop accessing services like pension.
3. The ward councillor has no powers to design the plan of the ward as envisioned in decentralised planning. In reality all the planning work is done at the state and district level and the ward committee remains only a legal entity that does not exist in real.
4. Party politics, bureaucratic inefficiencies and the lack of decentralised planning in reality are the major issues that make the lives of disabled miserable.
5. There is a need for a ward planner who should suggest the technical aspects of planning to the ward councillor. In the present scenario, most often the works are so unplanned that multiple authorities have a say on the same work.

**Table 7: Varying Opinions on participatory ward planning from different category of stakeholders**

<b>Stakeholder</b>	<b>Opinions of the Nature of Process followed for Ward planning</b>	<b>Description of the process</b>
Persons with Disability	Top-down	Ward planning always follows a non-participatory process and they have never been included in any of the ward level planning processes
Citizens	Top-down	Planning has always been non-participatory and decided by the leaders
Ward Councillors	Top-down	Ward Plans are created at the Municipal Corporation level. A list of works is suggested by the Municipal Corporation to the Ward Councillor for the development of the ward which is to be implemented by the councillor. Funds are also allocated to the Ward Councillors for development of ward based on the needs of the people, however no work which specifically addresses the needs of the persons with disabilities have never been done.
District and State Planning Officers	Bottom-up (as per the opinion of the planners and the data available of the decentralised	According to them, the planning for urban areas has largely been participatory in nature and the plans created at the ward levels have been inclusive of the demands of the people. However, they are said that since the size of the wards are extremely large with

	planning website)	more than 25000 people living in each ward, it is very difficult to seek inputs from every household and therefore a few people were consulted at the ward office and ward committee. They suggested that in the absence of fully functioning Mohalla Samitis the inclusion of every household in planning process would become a herculean task.
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#### 4.4 Ward Planning and Inclusion of Persons with Disabilities- The Reality

It is important to analyse the extent of inclusiveness of the development planning at ward level from the perspective of the 'rights of persons with disabilities'. The table below the lists the activities of Bhopal Municipal Corporation in Arif Nargar ward. The table capture presents the activities without any specific relevance to persons with disabilities.

##### Case Study: Arif Nagar Ward 14 proposed activities 2012-2013

Sector	Proposed activities	Cost	Department	Implementing agency	Relevance
<b>Social Security</b>	Widow pension	4800	SJ dept	Nagar Nigam	No direct relevance
	Old age Pension	610500	SJ	Nagar nigam	No direct relevance
	Social Security pension	205200	SJ	Nagar nigam	<b>High relevance</b>
<b>Electrification</b>	Electricity	750000	Schedule Caste welfare	Mandal/board	No direct relevance
	Electricity	500000			No direct relevance
<b>Infrastructure development</b>	Park	200000	UADD	UADD	No direct relevance
	Play ground	800000	UADD	UADD	No direct relevance
	Park construction	1000000			No direct relevance

Source: Ward Plan accessed from Decentralised Planning website MP

The only directly relevant development work in the plan for the disabled is the disbursement of social security pensions by the Municipal Corporation. It also does not appear from the details that the costing of the park development or play ground construction keeps disability friendly structures to address physical challenges of the persons with disability.

#### 5.4 Role of the ULBs in Enhancing the Quality of Life of Urban Poor with Disabilities

The 12<sup>th</sup> Schedule therefore listed 18 key functions of the ULBs which ensured that the ULBs play the most important role in realising a city's development vision. According to the 12th

schedule, the responsibility of welfare of the marginalised sections of the society including the persons with disabilities rested upon the ULBs. However, as seen in earlier sections, the disability related policies in India are not adequately aligned to the vision of the 74<sup>th</sup> CAA and does not recognise the ULBs as a key stakeholder in planning and implementation of disability related policies.

For instance, if the planned and budgeted activities of the Municipal Corporation of Bhopal is analysed, it is revealed that much of the focus of the Municipal Corporation has been to work on infrastructural development and administrative costs. The total income (calculated as the cumulative amount of the revenue, loan and capital receipts) estimated for the year 2011-2012 was Rs.139312.9 lakhs and the estimated expenditure(calculated as cumulative of revenue payments, loan payments and capital payments) was Rs. 146452.45 lakhs.

There is no specific budget-line allocated for activities for disability welfare. The two activities conducted under the function of social welfare by the municipal corporation are community engineering and community awareness. The community engineering section concerns itself with the infrastructural aspects of community welfare like maintenance of Rain Basera, upgradation of slums and so on and the community awareness section handles activities like Welfare of handcart rickshaw drivers, panchayat of working women, CM Kanyadan Yojna. Thus no specific activity is planned by the Municipal Corporation for the welfare of the persons with disability.

The below table is provides the detailed budget estimate of the social welfare activities undertaken by the Municipal Corporation of Bhopal in 2011-2012.

<b>Table 8: BUDGET ESTIMATE FOR SOCIAL WELFARE ACTIVITIES, MUNICIPAL CORPORATION BHOPAL (2011-2012) in lakhs</b>					
<b>Community Engineering Section</b>					
	<b>Account head</b>	<b>2009-2010 Actual</b>	<b>2010-2011 Sanction</b>	<b>2010-2011 Revised</b>	<b>2011-2012 Estimate</b>
<b>Revenue Receipt</b>	Charges for Ram roti yojna	0	0	1	5
<b>Loan Receipt</b>	Valmiki Ambedkar housing scheme, VAMBHAY	33.5	10	10	10
<b>Capital Receipt</b>	Welfare scheme for minorities, slum networking, Valmiki Ambedkar housing scheme, development in SC area, national slum development program, slum rehabilitation, construction of Rain Basera	0	2070	61	2570
	Construction of shed for labourers	16.8	0	0	0
<b>Cumulative Income</b>		<b>50.3</b>	<b>2080</b>	<b>72</b>	<b>2585</b>
<b>Revenue Payments</b>	Maintenance and operation of Rain Basera, Environment improvement in slum areas, renovation in harijan colonies	5.91	40	40	60
<b>Capital payments</b>	Construction of shed for	0	16.8	0	60

	labourers				
	Construction of quarters for kamgar	0	100	100	100
	Capital work in progress	20.7	2215.46	2134.46	2775.07
<b>Cumulative Expenditure</b>		<b>26.61</b>	<b>2372.26</b>	<b>2274.46</b>	<b>2995.07</b>
<b>COMMUNITY AWARENESS SECTION</b>					
<b>Cumulative Income</b>	Safai kamgar ayog, mahapanchayat of hand cart and rickshaw drivers, panchayat of working women, CM Kanyadan Yojna	<b>51.84</b>	<b>0</b>	<b>30.79</b>	<b>5</b>
<b>Cumulative Expenditure</b>	Welfare of handcart rickshaw drivers, panchayat of working women, CM Kanyadan Yojna	<b>49.36</b>	<b>8</b>	<b>18.16</b>	<b>12.67</b>
<b>TOTAL BUDGET ESTIMATE OF SOCIAL WELFARE ACTIVITIES(2011-2012)</b>					
<b>INCOME</b>	Community engineering +Community Awareness	<b>102.14</b>	<b>2080</b>	<b>102.79</b>	<b>2590</b>
<b>EXPENDITURE</b>	Community engineering +Community Awareness	<b>75.97</b>	<b>2380.26</b>	<b>2292.62</b>	<b>3007.74</b>
<b>TOTAL BUDGET ESTIMATE OF BHOPAL MUNICIPAL CORPORATION(2011-2012)</b>					
<b>Income</b>	All function groups	<b>58753.87</b>	<b>86147.77</b>	<b>72279.37</b>	<b>139312.9</b>
<b>Expenditure</b>	All function groups	<b>57317.78</b>	<b>89952.49</b>	<b>84232.04</b>	<b>146452.45</b>

Considering the need to focus more on urban poverty alleviation, the JNNURM program mandated that the ULBs earmark 25% of its budget for activities specifically to enhance the quality of life of urban poor. However, an analysis of the budget allocated by the Bhopal Municipal Corporation for the urban poor, there is no specific activity earmarked for the persons with disabilities in living in urban slums

## **Bhopal City Development Plan**

A City Development Plan (CDP) is both a perspective and a vision for the future development of a city. It establishes a logical and consistent framework for investment decisions. As a step to achieving this goal, the CDP focuses on the development of economic and social infrastructure, strategies that deal specifically with issues affecting the urban poor, strengthening of municipal governments and their financial accounting and budgeting systems and procedures, creation of structures for bringing in accountability and transparency, and elimination of legal and other bottlenecks that have stifled the land and housing markets. Considering the importance of this document in shaping the development future of the city, an attempt is made to see the planning process adopted to create the CDP and how inclusive it has been of the needs of the disabled.

The planning process for creating the CDP in 2005 is claimed to have followed a participatory planning process. The preparation specifically for CDP under JNNURM started on July 2005. The initial step was to conduct internal meetings with various departments like Public Works Department (PWD), Health and Sanitation Department, Water Supply, Planning and Development and Garden and Park Department etc. and the 14 zones of BMC. The Suggestions and proposals from the officers and HOD's of the various departments were compiled and

presented for discussions at various levels. After this exercise at the Zonal level, BMC had conducted meetings with the Municipal Councillors and identified stakeholder's election ward wise from who data was collected to understand the satisfaction with various municipal services. A workshop was organised to present the findings of the data collected. The workshop was attended by public representatives, technocrats, citizens, government and nongovernmental organisations.

While the process of creating the CDP has largely been participatory, it should be highlighted that there were no specific efforts made by the BMC to meet and understand the development needs of the disabled. This is a major drawback as one of the key role of the CDP is to provide a vision for the infrastructure and social development of the city and it has been very well established in the first chapter that the needs and aspirations of the disabled are very specific to their disability and diverse from the needs of persons without disabilities.

#### **4.5 Inclusion on Rights of Persons with Disabilities in the Planning**

It is important to note that much of the work initiated for the urban development in Madhya Pradesh are through the centrally sponsored schemes like JNNURM, National Urban Sanitation Mission, RAY and SJSRY. Some other major projects are funded by International organisations like DfiD run MPUSP program. Some others are state funded projects like the CM drinking water scheme, CM sanitation program, CM housing for urban poor scheme and so on. There are many benefits of implementing development policies in project mode as they are found to be more output driven and time-bound. However, the key issue is that such projects are applied for and funded based on Detailed Project Reports (DPRs). They are largely created by the technical staff placed in the Municipal Corporation without much participation. However during the project creation phase the team conducts a survey of all the households in the slum and makes a special mention of disabled persons in the household. In cases where a disabled person has to be allocated houses, then houses on the ground floor are reserved for the persons with orthopaedic disability. However, there is no specific mention of inclusion of disabled in the policy guidelines for the implementation of these large schemes except for the SJSRY project.

**JNNURM and IHSDP-** The Jawaharlal Nehru National Urban Renewal Mission (JNNURM) was launched by the Prime Minister of India on 3rd December, 2005 with an objective of providing focused attention to integrated development of urban infrastructure and services in select 65 cities. The Mission proposes reforms driven, fast track, planned development of identified cities with focus on efficiency in urban infrastructure/services delivery mechanism, community participation and accountability of Urban Local Bodies (ULBs) towards citizens.

The need for Sub-Mission on Basic Services to the Urban Poor (BSUP) under JNNURM arose because the ever increasing number of slum dwellers causes tremendous pressure on urban basic services and infrastructure. The supply of land for housing has failed to keep pace with increase in urban poor population resulting in large number of households without access to basic services, poor housing, and proliferation of slums and widespread poverty. It calls upon States/Cities to undertake fiscal, financial, and institutional changes required to create shelter and basic civic amenities for the urban poor.

In addition, Ministry of Housing and Urban Poverty Alleviation has formulated a scheme namely Integrated Housing and Slum Development Programme (IHSDP) which is applicable to all cities and towns as per 2001 census except those cities which are covered under mission cities under JNNURM. This scheme aims at combining the existing schemes of VAMBAY and NSDP under the new IHSDP scheme for having an integrated approach in ameliorating the conditions of urban slum dwellers who do not possess adequate shelter and reside in dilapidated conditions. The components for assistance under the Scheme will include all slum improvement/upgradation/relocation projects including upgradation/new construction of houses and infrastructural facilities like water supply and sewerage. Allocation of funds among States will be on the basis of the States' urban slum population to total urban slum population in the country.

The Ministry is achieving higher levels of attainment in the implementation of the aforementioned Mission. Under the Scheme of Basic Services for the Urban Poor (BSUP) and Integrated Housing & Slum Development Programme (IHSDP), the Government of India has sanctioned more than 15.70 lakh housing units with supplementary basic services. More than 497 Projects have been approved under the BSUP scheme and over 1020 Projects under the IHSDP scheme have been approved. Additional Central Assistance (ACA) of Rs 12,448.31 crores released (including PMU, PIU and DPR charges). All Mission Cities have been covered under BSUP and all States and UTs except Goa and Lakshadweep have been covered under IHSDP.

**Rajiv Awas Yojna (RAY):** The Government with the objective making the country slum-free as early as possible, by providing slum-dwellers basic services and access to decent shelter and creating conditions of urban development that contain the need for the emergence of slums. The Phase 1 of Rajiv Awas Yojana is for a period of two years from the date of approval of the scheme with a budget of Rs. 5000 crore. The Scheme proposes to address the problem of slums in a holistic and definitive way adopting a multi-pronged approach focusing on bringing existing slums within the formal system and enabling them to avail of the same level of basic amenities as the rest of the town; redressing the failures of the formal system that lie behind the creation of slums. Even though the project implementation in Bhopal has not begun, it is important to note that no persons with disabilities in the slums have been approached so far to understand their specific needs with respect to the infrastructure and other specifications of the housing units.

**Swarna Jayanti Urban Employment Generation Scheme:** The key objective of the scheme is to address urban poverty issues through gainful employment to the urban unemployed or underemployed poor by encouraging them to set up self-employment ventures, supporting for their sustainability or undertake wage employment. The scheme aims to provide skill development and training programmes to enable the urban poor to access employment opportunities opened up by the market or undertake self-employment; and empowering the community to tackle the issues of urban poverty through suitable self-managed community structures like Neighbourhood Groups (NHGs), Neighbourhood Committees (NHC), Community



Development Society (CDS), etc<sup>13</sup>. The delivery of inputs under the Scheme is through the medium of urban local bodies and community.

The Urban Self Employment Program (loans and subsidy) focuses on providing assistance to individual poor beneficiaries for setting up gainful employment opportunities. Under the Urban Self Employment Programme (USEP) and Skill Training for Employment Promotion amongst Urban Poor (STEP-UP) components of the Scheme of Swarna Jayanti Shahari Rozgar Yojana (SJSRY), a special provision of 3% has been reserved for the disabled category. Under USEP (Individual loan & subsidy), out of the, total of 11,97,497 beneficiaries, 26974 belong to disabled category, which is about 2.27% of the total beneficiaries assisted. Under STEP-UP, out of the total, 23,61,891 beneficiaries were provided skill training as on 07-03-2012, 24,715 belong to disabled category, which is about 1.05%.

With regard to Budget allocation for the disabled, it may be mentioned that there is no separate earmarking of budget for the disabled categories under Swarna Jayanti Shahari Rozgar Yojana (SJSRY). The allocation under the Scheme of Swarna Jayanti Shahari Rozgar Yojana (SJSRY) is a pool of funds meant for utilization under its various components viz. Urban Self-Employment Programme (USEP), Urban Women Self-help Programme (UWSP), Skill Training for Employment Promotion amongst Urban Poor (STEP-UP), Urban Wage Employment Programme (UWEP) and Urban Community Development Network (UCDN), IEC activities, Administrative and Other Expenses (A&OE) etc.

**Table 9: Summary of the budgetary allocations and spending on urban development in MP**

Program	2007-2008		2008-2009		2009-2010		2010-2011		2011-2012		2012-2013
	Outlay	Expenditure	Outlay	Expenditure	Outlay	Expenditure	Outlay	Expenditure	Outlay	Expenditure	Outlay
<b>SJSRY</b>	642.79	1206.8	1228.32	1574.31	1469.46	1689.46	1635	1885	1676	unavailable	2245
<b>SJSRY: Admin Dist</b>	231.95	200	200	200	220	0	250	0	275	unavailable	300
<b>SJSRY admin HQ</b>	0	27.92	35	33.05	45.61	41.8	54.6	51.66	66.31	unavailable	65.06
<b>JNNURM</b>	18967.9	10491.8	20384	20268.8	18878	28877.5	30863.2	28841.2	34990.2	unavailable	59535
<b>IHSDP</b>	9540.3	3644.46	3141	1232.17	2594	1407.85	3682.51	3682.59	4051.29	unavailable	4300
<b>MPUSP</b>	1500	767.53	5500	2300	5500	3311.19	7005.41	7005.41	8000	unavailable	11000
<b>Urban Sanitatio</b>	0	0	1000	299.87	854.7	642.38	1214.14	1098.86	1500	unavailable	Na

<sup>13</sup> <http://mhupa.gov.in/pdf/guidelines-scheme/urbanemp-povallev/Swarna%20Jayanti/ReGuidelinesSJSRY.pdf>

n Mission										e	
MP Urban Infrastructure fund	0	0	0	0	100	0	100	100	100	unavailable	Na
Drinking water facilities	0	0	0	0	4000	0	3500	7500	20000	unavailable	Na
ILCS	0	0	0	0	0	0	89.09	89.09	89.09	unavailable	
Nagar Vikas Jojna	0	0	0	0	0	0	500	1069	375	unavailable	100
Rajiv Awas Yojna	0	0	0	0	0	0	0	576.5	10	unavailable	3000
C.M. Drinking Water Scheme	0	0	0	0	0	0	0	0	0	0	13225
CM sanitation Programme	0	0	0	0	0	0	0	0	0	0	3355
CM infrastructure project	0	0	0	0	0	0	0	0	0	0	12500
CM housing scheme for urban poor	0	0	0	0	0	0	0	0	0	0	10

Source: Annual Report 2012-2013 and 11<sup>th</sup> plan outlay and expenditure report

The above table illustrates that there are no specific schemes initiated by the urban development department implemented through the Municipal Corporation that specifically benefit the persons with disabilities. A large focus of the urban development schemes have been towards infrastructure development.

## 5. Access to Rights, Entitlements and Services: Enablers and Constraints

Madhya Pradesh has made some progressive steps towards protecting and promoting disability rights beginning with legislating a state disability policy in 1997 to conducting regular campaigns to reach out the welfare of the disabled<sup>14</sup>. Various departments of the government

<sup>14</sup> PACS, 2011. Disability Audit in Madhya Pradesh. Available at <http://www.empowerpoor.org/backgrounder.asp?report=538> (last accessed on 18 Jan, 2013)

have many activities specifically aimed to providing welfare and services to the persons with disabilities.

## 5.1 Role of the Social Justice Department

The Social Justice Department is the key nodal agency that is responsible for protecting the rights and ensuring the access the entitlements guaranteed to the persons with disabilities in India. The Office of the Commissioner for Persons with Disabilities at the state level acts as the quasi judicial body which acts as an intermediary between the persons with disabilities and the key departments that have specific responsibilities towards the persons with disabilities.

The following table lists the specific persons with disabilities related activities coordinated by various departments in the state.

**Table 10: Disability welfare related responsibilities of key government departments**

Sl.No	Name of the department	Disability specific responsibility
1	Commerce Ministry, Labour department	Preference to disabled persons while allocating plots/sheds
2	Sahakarita department	3% benefits of the housing schemes
3	General Administration Department	6% of the posts reserved in Class 2, 3 and 4 level workers level.
4	Housing and Environment Department	Reservation of 4% of the commercial or residential land
5	Public Health and Family welfare	Conduct prevention related activities like Pulse polio campaign, National Blind treatment camps, appointment of medical board who sanctions disability certificate and meeting once in a week
6	Department for Women and Child Development	Prevention of disability, registration of pregnant women, care, immunization of children, delivery nutritious food, awareness
7	Department of School Education	Free education for disabled children upto the age of 18, special education and care of disabled children, implementation of inclusive education activities under SSA
8	Department of Social Justice	Appointment of the OCPD, state level Samanvay samiti, karyakarini samiti, Access the nirashrit fund, social security pension, scholarship and artificial aid and appliances distribution
9	Department of Urban Administration Development	Reservation of 2% of shops to blind,
10	Public Works Department	Building ramps in public places/buildings

**Source: Annual Report of the Office of the Commissioner for Persons with Disabilities, 2012**

Besides this, the social justice department of the state of Madhya Pradesh have initiated many services and entitlements to persons with disabilities. The department is entrusted with the role of the nodal agency that monitors and ensures that all the above listed departments fulfil their responsibilities towards ensuring disability rights. Apart from being the nodal agency, the social justice department also provides the following services and entitlements to the persons with disabilities to ensure the fulfilment of the objectives of the Persons with Disabilities Act (1995) and the National Policy for persons with disabilities

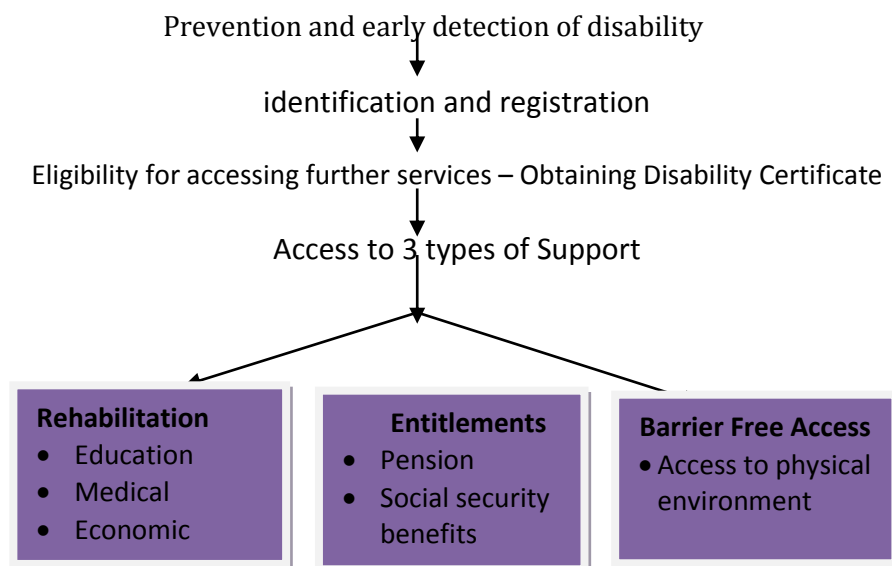
- (i) Conduct medical camps and Issue Disability Certificates
- (ii) Provide Artificial limbs/aids/appliances
- (iii) Preventive/Corrective surgery
- (iv) Scholarships for Persons with Disabilities
- (v) Financial Assistance of Rs. 500/- per month to MR/MD Persons with Disabilities
- (vi) Social Security Pension
- (vii) Assistance for Loan for self employment
- (viii) Professional Trainings
- (ix) Marriage promotion for Persons with Disabilities
- (x) Reservation of 6% of all Government posts for Persons with Disabilities
- (xi) Provision of Legal Guardianship
- (xii) Health Insurance for MR & MD

In order to ensure proper implementation of the various disability related schemes and initiatives of various departments it carries out different campaigns to cater to the needs of persons with disabilities. It conducts surveys from time to time, aimed at identifying and registering persons with disability, and then uses this data base to link them to various services and entitlements provided by various departments.

In the past the government had conducted Utthan Abhiyan, Indira Sahara Abhiyan etc.. The most recent initiative of the Madhya Pradesh Government to reach out to the persons with disabilities is the Special Project for Assistance, Rehabilitation and Strengthening of Handicapped (SPARSH) campaign. The campaigns undertook door to door survey for identification of the persons with disabilities with the help of NGO's and other district level agencies. Further the collected data is computerised and is available for on the department's website. This data is then used by the Social Justice department to link the beneficiaries to various schemes and service run by various departments.

The SPARSH project is unique and a progressive step by the government of Madhya Pradesh to the extent that it combines the campaign mode of identification and registration of persons with disabilities, then using ICT tool to make the data collected available in the public domain for enhancing the quality of services by responsive and transparent governance.

Disability is a complex phenomenon in which the social, economic and health needs of one person with disability could be very different from the needs of another person with disability. It was recognised in Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 that to ensure full participation and equality of persons with disabilities there is a need for "multi-sectoral and collaborative approach by various departments and local bodies". It was in this context that the social justice department was appointed as the nodal department to monitor the disability centric activities of various key departments. The Sparsh campaign therefore became the key strategy through which the social justice department coordinates supports and monitors the activities related to disability welfare.



## 5.2 Prevention and Early detection of disability

While disability can be worsened by the environmental and social factors, disability primarily is a health condition and it is precisely due to this reason that discussion on disability often begins with a discussion on health and medical care. Health sector plays a crucial role in the life of a person with disabilities. It is argued that the health and medical care sector plays five important roles in various stages of the life of a disabled. According to Section 25 of the persons with disabilities Act<sup>15</sup>, all commitments in this area are given with the provision “within the limits of their economic capacity and development”. It requires the state to

- Undertake surveys on causes of disability and promote “various methods” for preventing disabilities.
- It should also screen children at least once a year for identifying at-risk cases.
- Alongside it should provide facilities for training PHC staff.
- Conduct or sponsor awareness campaigns on hygiene, health and sanitation, and on causes and prevention of disabilities
- “Take measures” for pre-, peri- and post-natal care of mother and child.

The two key departments responsible for the prevention and early detection of disability are the Department of Public Health and Family Welfare and the Department of Woman and Child Development. The health department anchors a number of nationally sponsored programmes that are intended to eradicate various causes of disability.

It carries out-

- 1.Implementation of Pulse Polio Campaign
- 2.Conduct camps under National Program for Control of Blindness
- 3.And barrier free access to health centres for Persons with Disabilities
- 4.Issuance of disability certificate at the District hospital

**Table 11: List of National programmes aimed at Preventing or Rehabilitation of Persons with Disability**

Program	Objective
<b>National Immunization Programme</b>	Aimed at saving the lives of children from the life threatening diseases including polio, TB, Hepatitis B, whooping cough, measles and tetanus
<b>National Leprosy Eradication Programme</b>	Special survey, health education and treatment camps are being organised under the programme
<b>National Blindness Control Programme</b>	Controlling blindness
<b>Integrated Disease Surveillance Project</b>	The Project aims to have surveillance over communicable and non-communicable diseases and take control measures. The Project incorporates setting up of State and District Level Surveillance Committees/Rapid Response Teams
<b>National Iodine Deficiency Disorders Control Programme:</b>	Conducting survey and has been promoting awareness for the consumption of iodised salt
<b>National Programme For Prevention And Control Of Deafness</b>	Training by ENT specialists to medical officers and grass root level workers for prevention, early identification and management of hearing impaired and deafness cases. Assistance is provided for strengthening the ENT department of the District Hospitals. Camps are organised for detecting hearing impaired cases and hearing aids are provided

<sup>15</sup> [http://www.ccdiseases.nic.in/page.php?s=reg&p=pwd\\_act\\_c4&t=yb](http://www.ccdiseases.nic.in/page.php?s=reg&p=pwd_act_c4&t=yb)

Both the health and WCD department work towards improving nutrition, reduce MMR and IMR through constant support and care of pregnant women, lactating mothers and children between the age group of 0-6 years.

### Anganwadi workers

The Anganwadi worker is entrusted with the duty of conducting the community survey and enlistment of the beneficiaries. Vital statistics particularly of new births and deaths (especially child and maternal deaths) is recorded by her. Handicapped, exploited and destitute children should are also listed

Assisting health staff in immunization and health check-up, referral services for severely under-nourished/ mal-nourished, sick and at-risk children and cases of communicable diseases and children with impairments is undertaken by the Anganwadi workers.

### ANMs

The ANMs are also a very important stakeholder who could play an active role in the prevention and early detection of disability. They are responsible for administration of micro-nutrient like Vitamin A or iodine deficiency. They are responsible for referring abnormal pregnancy and case with medical and gynaecological problems to hospital.

Despite the criticality of the Anganwadi workers and ANMs as preventers or early interventionists with regard to disability, the findings of the study revealed a different picture. The below table shows that around 3.2% of the persons with disabilities are children in the age group of 0-6 years. While the number seems small, it is important to note that the disability caused in this age could have been to a large extent avoided or reduced by proper intervention of the AWW or ANMs.

**Table 15: Age-wise distribution of Persons with Disabilities in Bhopal**

	total registered	0-6 years	6 - 14 years	14-18 years	18-40 years	40-60 years	60-80 years	80 and more
<b>BHOPAL</b>	20046	652	2665	1663	8722	3771	2343	230

Source: Sparsh Abhiyan website

While the data is too less to make any conclusive remarks, there are families in slums with children who have disabilities due to causes that could have been avoided or by the AWW and ANM. Yet out of the 100 interviewed persons with disabilities, 58% of the persons have been disabled from birth. Thus there is a serious case for intensifying the work of the local service providers like ANM/AWW/ASHA to prevent disabilities.

### Interview with Anganwadi worker of Baghmugalia Slums

There is no specific training or orientation provided to the anganwadi workers to deal with the needs of the disabled children. There are 5 disabled children in the ward, however no targeted action is taken by the anganwadi to either prevent or treat these children. For example one of the disabled children is a polio affected child which could have been prevented through timely intervention from the part of the anganwadi. The worker complained that people do not cooperate with the activities of the anganwadi and since a majority of the people in the slum are

labourers, both the parents leave for work so early that they do not find time to collect the nutritious food pack for the child. She says that one of the children is disabled because of malnutrition. Despite constant efforts from the anganwadi, the parents do not provide ample attention to the disabled children. The anganwadi worker said the duty of the anganwadi is to inform the disabled persons about the operation facilities, the camps organised under the sparsh abhiyan, the provision of getting disability certificate which will qualify them to access many benefits, however she says that the people feel that the costs of accessing these services are much high when compared to the benefits these schemes provide them.

**Table 16: Statistics of Types of disability among registered persons with disabilities**

Total no. of registered persons with disabilities in Bhopal	Visual	HI	MR	MI	Neurosis	MD	Locomotions	Hand/Foot/Disability	polio	Cerebral Palsy	Leprasy	Hear t valve
<b>20046</b>	1816	1556	1862	1343	232	537	6984	5721	263	75	28	136

Source: Ministry of Social Justice and Empowerment website

### Disability Certificate: Being Eligible for Entitlements

A disabled person is entitled to specific rights and entitlements. However the access to these rights, entitlements, and services are ensured only if the person with disability is diagnosed medically and is issued a disability certificate. Thus a person needs to fulfil the condition of possessing a disability certificate to access various services guaranteed under various state and central legislations. While this seems like a straightforward process at the outset, data and the experiences of the persons with disabilities while interacting with the governance framework to attain the disability certificate revealed a different picture.

**Table 17: Details of the procedure to issue disability certificate**

<b>Monitoring Agency</b>	Social Justice Department
<b>Implementing Agency</b>	Department of public Health and Family Welfare
<b>Issuing Agency</b>	Medical Board at District Civil Hospital
<b>Eligibility Criteria</b>	<ul style="list-style-type: none"> <li>possess medical reports explaining type of his/her disability.</li> <li>minimum degree of disability should be 40% in order to be eligible</li> </ul>
<b>Disability certificate distributed in Bhopal District</b>	16138

Source: Bhopal District Department of Social Justice, 2012

### Interview with Medical Board member at 1250 hospital

The district Hospital also known 1250 hospital is responsible for the issuance of disability certificate in Bhopal. The interview with the orthopaedic specialist member of the Medical Board, one of the biggest issues in the whole process is that only one hospital is responsible for the issuance of the certificate. Being located in central Bhopal, people living in peripheral areas would find it difficult to access the hospital. Outlining the process followed for the issuance of disability certificate he said that "For example, the orthopaedic disabled patients are allowed to submit the forms and get diagnosed on Mondays and Thursdays and similarly specific days are allotted to other types of disabilities. It is almost practically impossible to have all the medical board members present while diagnosing the disabled patients as it will affect the day

to day activities of the hospital. As a result, system has been put in place where only the special diagnoses the patients and recommends whether the person should be given the certificate or not. This is then countersigned by the other board members and also the superintendent which is then given for the preparation of the disability certificate.” Around 15 to 30 persons with disability visit the hospital to get the certificate out of which 80% of the patients get their certificates the same day. Only in the case of multiple disabilities and also in the cases where the patients have not brought with them the required documents, then they are required to come back. When asked about how the intensity of disability would be determined through a preliminary check up as observed during the data collection process, the specialist claimed that since he has been a member of the medical board for many years he is experienced with the symptoms and signs and therefore he has good knowledge about determining the intensity of the disability. Another issue raised by him regarding the issuance of disability certificate faced by the medical board is the lack of awareness among the persons with disabilities about the process and the documents they are required to submit while appearing for the medical examination. He suggests that none of the persons with disabilities bring the necessary test results and medical reports which makes it impossible for the medical board to make a decision in one sitting and they are forced to ask the person to visit the Medical board one more time. He says that the intention of the Medical Board is always to be of support to the persons with disabilities however the lack of awareness amongst them makes the experience unpleasant for the persons with disabilities.

In order to understand the real issues with respect to obtaining the disability certificate, persons with disabilities were identified from the 5 sample slums.

**Table 18: Findings from the survey of slums**

<b>No. of persons with disabilities with 46% disability certificate</b>	
<b>Major reasons for not obtaining disability certificate in rest of the cases</b>	<ul style="list-style-type: none"> <li>• Difficulty in reaching ‘1250 hospital’ from far off places</li> <li>• Lack of knowledge about the procedure to obtain disability certificate</li> <li>• Did not take initiative as they were not aware of the purpose of the certificate</li> <li>• Medical board did not certify despite being highly disabled</li> </ul>

## 5.4 Educational Rehabilitation

Schemes dealing with Children With Special Needs (CWSN) can be categorized into educational and supplementary schemes. The former includes the Integrated Education of Disabled Children (I.E.D.C.) and the latter includes the Scholarship as well as the Assistance to Disabled Persons for Purchase/ fittings of aids and appliances (A.D.I.P.). The IEDC scheme provides educational opportunities for disabled children in common schools, to facilitate their retention in the school system and also to place in common schools, such children already placed in special schools after they acquire the communication and daily living skills at the functional level. The scheme provides for the following:

- Actual expense on books and stationery up to Rs 400 per annum.
- Actual expenses on uniforms up to Rs 200 per annum; transport allowance up to Rs 50 per month. If a disabled child resides in the school hostel within the school premises, no transportation charges would be admissible.
- Reader allowance of Rs 50 per month in case of blind children up to Class V.
- Escort allowance for severely disabled children with lower extremity disability at the rate of Rs 75 per month.
- Actual cost of equipment subject to a maximum of Rs 2,000 per month for five years.



Besides these, it also provides for teachers' salaries, facilities to students in terms of board and lodging allowance, readers allowance, transport allowance, escort allowance, cost of equipment, cost of uniform, cost of removal of architectural barriers, and provision of resource room, etc. The ADIP scheme is one such scheme.

A commendable effort to provide accessible and quality education to children with disabilities is the provisions for inclusive education under the Sarva Shiksha Ahbiyan.). Constitutional (86th amendment) Act, making free and compulsory elementary education a Fundamental Right, for all the children in the age group of 6-14 years. This Amendment has given a new thrust to the education of Children with Special Needs (CWSN).

The major thrust of SSA is on inclusion or mainstreaming CWSN into the fabric of normal elementary schooling. There might also be still some WSN with severe profound disabilities, who would require an educational programme and intensive specialized. Thus, SSA has adopted a more expansive and a broad-based understanding of the concept of inclusion, wherein a multi-option model of educating CWSN is being implemented support completely beyond the purview and scope of a formal school in the current situation.

SSA provides up to Rs.3000/- per child for the inclusion of disabled children, as per specific proposal, per year. District plan for children with special needs is formulated within the Rs.3000/- per child norm. The interventions under SSA for inclusive education are identification, functional and formal assessment, appropriate educational placement, preparation of Individualized Educational Plan, provision of aids and appliances, teacher training, resource support, removal of architectural barriers, research, monitoring and evaluation and a special focus on girls with special needs. SSA aims to ensure that every child with special needs, irrespective of the kind, category and degree of disability, is provided education in an appropriate environment. SSA adopts adopt 'zero rejection' policy so that no child is left out of the education system

Madhya Pradesh is the first State that has taken an initiative to use the ICT for the tracking of the assistance being provided to the CWSN to ensure personalized follow-up.

This application facilitates the registration of all identified CWSN and online tracking of their medical evaluation and assistance and necessary follow up to the child.

**Table 19: Block wise data on No. of Identified CWSN in Bhopal District in 2012**

Block	Children (between 6-14 years )with disabilities	HI	VI	OH	MR	MD	Other
<b>Berasia</b>	512	78	70	193	172	0	0
<b>Phanda Gramin</b>	282	24	34	91	138	0	0
<b>Phanda Urban</b>	1651	236	94	950	460	0	0
<b>Total</b>	<b>2445</b>	<b>338</b>	<b>198</b>	<b>1234</b>	<b>770</b>	<b>0</b>	<b>0</b>

Source: Zilla Shiksha Kendra Bhopal, 2012

This is clear from the statistics below:

**Table 20: Poor Implementation of IE in Bhopal District and specifically in Bhopal Urban**

No. of CWSN identified and registered in Bhopal district	2445
No. of CWSN in Bhopal Urban	1651
No. of mobile resource consultants currently working in Bhopal district	3
No. of MRCs currently working in Bhopal ULB block	0
No. of children given home based education in Bhopal district	27
No. of children given home based education in Bhopal urban	0

**Source: Zilla Shiksha Kendra, Bhopal**

The above table clearly indicates that 67.5% of the CWSN in Bhopal district belong to its urban areas. However, the services of inclusive education ( IE) scheme are least implemented in urban areas. There is a large dependency on the Mobile resource consultants (MRC )to deliver, and in the absence of any MRC in urban areas, the implementation of IE is in deplorable condition.

**Table 21: Details of children enrolled in schools in Bhopal district**

	HI	VH	OH	MMR	MD	CP	OT	VI
Boys	40	30	106	64	11	2	1	4
<b>Total CWSN</b>	Girls	25	22	63	47	7	4	1
	<b>Total</b>	<b>65</b>	<b>52</b>	<b>169</b>	<b>111</b>	<b>18</b>	<b>2</b>	<b>5</b>
<b>Enrolled in school</b>	Boys	40	30	106	64	11	2	1
	Girls	25	22	63	47	7	4	1
	<b>Total</b>	<b>65</b>	<b>52</b>	<b>169</b>	<b>111</b>	<b>18</b>	<b>2</b>	<b>5</b>

**Source: Sparsh Abhiyan website**

Two additional forms of resource support, complimentary to each other, being provided to CWSN are through assistive devices and barrier free access. Both of these aim at enhancement of the functional capacity/ mobility of CWSN to promote their easy access to the schools.

### **Challenges in education of CWSN**

One of the major challenge is the availability of specialised human resource. As highlighted above, there are no mobile resource consultants in Bhopal. In the absence of the MRC in the city, there is a high possibility that many of the CWSN remains unidentified and therefore denied the opportunity of education.

The interactions with the MRC revealed that vacancies remaining unfilled due to the poor salaries given to the MRC in Madhya Pradesh when compared to other states. The remuneration for the MRCs is Rs. 8000 in Madhya Pradesh.

Much of the funds available to the Bhopal district for the implementation of IE remain unspent and the only continuous expense is the salaries of the staff under the program and the funds disbursed to the NGOs. Many of the funds have been unused.

**Inadequate Co-ordination between NGOs and SSA department-** While enquiring about the number of aids and appliances distributed to the CWSN in Bhopal district, it was found that the responsibility of procuring the aids from ALIMCO and distributing among children lies with NGOs. However, it was found that there is no updated information on many of the activities implemented by NGOs at the SSA district office.

**Table 22: Expenditure for Inclusive Education from March 2011 to 2012**

Activity	Expenditure
TLM	Rs. 12000 (MRC salary)
	Rs. 20,000 (activities)
MRC salary	Rs 45,000
Volunteer expenses	Rs. 22500
DIET	Rs. 1,20,000
Braille Training	Rs. 20,000
7 day volunteer training	Rs. 4200
7 day MRC training	Rs.14000
NGO Deegdarshika	Rs. 32000
Total expenditure	Rs. 2,89,700

**Source: SSA District Office, Bhopal**

## 5.5 Medical Rehabilitation

Medical rehabilitation could be delivered in two ways: providing assistive devices for the person to attain functional independence and corrective surgeries for reduction or removal of the difficulties caused due to disability. The Social Justice Department coordinates the delivery of these two services through NGOs and the health department.

**Table 23 : Medical Assistance and Rehabilitation provided by Social Justice department, Bhopal**

No. of aids/devices supplied	1995
Corrective surgeries in 2012	23
Total no. of registered persons with disabilities in Bhopal	20,046

**Source: Social Justice Department, Bhopal**

## 5.6 Livelihood Opportunities for Persons with Disabilities

There is a lack of recognition of the fact that persons with disabilities if given equal opportunities could be a very productive human. Yet, the education and employment rates for persons with disabilities are far lower than the non-disabled persons. The opportunities for persons with disabilities, to earn are less. Even though the employment opportunities have increased in the last two decades, the Persons with disabilities face serious barriers in getting jobs. Unequal access to education and training programmes is a major challenge. They also face social and psychological barriers - ignorance, myths, prejudice, stereotyping, and

misconceptions about their capacities, acceptance by fellow workers, and low self-esteem, fear and over-protective families<sup>16</sup>.

### Employment related guarantees for persons with disabilities

The Persons with Disabilities Act mentions in the chapter on employment that appropriate Governments shall :

- Identify posts, in the establishments, which can be reserved for the persons with disability;
- At periodical intervals not exceeding three years, review the list of posts identified and update the list taking into consideration the developments in technology;
- 3% vacancies in Public sector reserved for persons with disabilities
- In Madhya Pradesh, there is 6% reservation in 100 point roster for Class II, Class III and class IV category for direct recruitment for persons with disabilities

In order to understand the reasons for this very poor work participation rate among persons with disabilities despite many policy provisions, persons with disabilities in the employable age were interviewed to understand their access to livelihood opportunities, their demand for such services and the extent to which the government is effective in ensuring that persons with disabilities are provided adequate support to access employment opportunities.

**Table 25: Reasons for the low work participation rate among persons with disabilities**

Percentage of sampled persons with disabilities who are employed in the public sector	0%
Percentage of sampled persons with disabilities who have received any livelihood related support from the government	0%
Attitude of the sampled persons with disabilities about themselves as unfit or less capable for employment	68%
Barriers to access physical workplace	27%
Support from family members for livelihood	83%

**Source: Author's Analysis based on the data collected for the study**

Shabir is a 40 year old man living in Shyam Nagar slums in Bhopal. He is affected by severe orthopaedic disability (foot and hand) which was detected 2 years after his birth. He lost his parents at the age of 16 and was left on his own. With no person in the family to support him, Shabir was forced to become daily wage labourer. At the age of 32 he got married and has one son. He says that due to his disability he does not get work regularly which has pushed the entire family to poverty. With very little awareness of the employment services provided by the government amongst persons with disabilities and the failure of these programs to reach deserving persons like Shabir, persons with disabilities are further marginalised. He also suggested that poor and marginalised persons with disabilities have no access to any skill development training, wage employment or loans for starting businesses and this means that they are forced to either remain unemployed or to do work that increases their physical disability.

The above table shows that the effectiveness of the government initiatives to help persons with disabilities access employment opportunities is very poor. Despite the provisions and state's

<sup>16</sup> <http://www.in.undp.org/content/dam/india/docs/pub-povertyreduction/livelihood-opportunities-for-persons-with-disabilities.pdf>

commitment of a fairly high reservation at 6%, the situation of employment of persons with disabilities in Government jobs due to reservation is a failure.

Another livelihood support provided to persons with disabilities is through the National Handicapped Finance and Development Corporation (NHFDC) which was set up by the Ministry of Social Justice & Empowerment.

NHFDC functions as an Apex institution for channelizing the funds to persons with disabilities through the State Channelizing Agencies (SCAs) nominated by the State Government(s). *In Bhopal district, 24 persons with disabilities have benefitted from the NHFDC loans from 1997 to 2012.*

## 5.7 Social Justice Entitlements

**Table 26: Entitlements provided to the persons with Disabilities by the Social Justice Department**

Name of the scheme	Service	No of beneficiaries benefitted	Amount spent in Bhopal
<b>Indira National pension</b>	<b>Gandhi disability</b> Rs 200 pension to ( persons with > 40% plus disability and Below Poverty Line ( BPL)	3114	58.01 lakhs
<b>Social Pension for the disabled</b>	<b>Security for the</b> Rs 150 pension to Non-BPL disabled	3965	
<b>Assistive devices provided</b>	<b>devices</b> Assistive/aiding devices provided to the disabled	1995	-
<b>Operations/Corrective Surgery</b>	Surgery/corrective operation support to disabled	Data on the recent camp conducted in Bhopal (J K hospital)	59 persons were identified out of which 23 were provided services
<b>Scholarship for disabled children</b>	Scholarship for disabled children		
<b>Pension for Mentally retarded individuals</b>	Rs 500 Pension to mentally retarded or multiple disabled	659 boys and 362 girls <sup>17</sup>	33,91,000
<b>Marriage incentive</b>	Marriage incentive if one of them is disabled Rs. 25000 and if both are disabled Rs. 50,000	28 persons	
<b>Higher education scholarship</b>	Scholarship for disabled to pursue higher education like medical, engineering, MCA, MBA etc	45	14 lakhs
<b>PSC scholarships</b>	Rs 20000 for passing prelims, Rs 30,000 for passing mains	3	Rs.70,000

<sup>17</sup> As on March 2012

	Rs 20000 for disabled who are successfully enrolled		
<b>Scholarships for school going disabled children</b>		1081	-
<b>NHFDC Loans</b>		24	-

**Source: Bhopal District Social Justice department, 2012**

The social justice department in Bhopal has provided 16138 disability certificates to persons with disabilities until November 2012. The total budget allocated for disability welfare activities to the department in the year 2011-2012 which excludes the disbursement of the centrally sponsored Indira Gandhi National Disability Pension is 200.59 lakhs and the department had spent Rs 184.85 lakh for disability activities that year.

### **5.7.1 Disability Pension: Failing to Reach the Majority of Beneficiaries**

According to the study findings only 42% of the persons with disabilities surveyed for the study had access to the disability pension. While the social justice department which is the agency responsible for the identification of the persons with disabilities and the Municipal Corporation of Bhopal which is responsible for disbursing these pensions, claim that the coverage is as high as 80%. The social justice department statistics show that only 3965 persons with disabilities who are non-BPL have access to social security pension of Rs150 every month. However, even if we assume out of the total 16870 registered persons with disabilities (registered with Sparsh Abhiyan) have disability certificate then the no. of beneficiaries should be 8435 which means 4470 persons with disabilities who are non-BPL are denied the pensions every month.

## **5.8 Barrier-free environment or Disabling Environment ?**

The goal of barrier free design is to provide an environment that supports the independent functioning of individuals so that they can participate without assistance. Central Public Works Department under the Ministry of Urban Development has issued guidelines in this regard. In MP, the Urban Administration and development department takes the responsibilities to provide barrier free environment to persons with disabilities. It has made necessary amendments to the MP Land development Act 1984. According to this Act, in all public places and public buildings, ramps and railings will be provided. Moreover it also ensures all that the drawing and proposal for new public building construction provides form ramps and railings. This responsibility is given to the municipal corporation commissioner. However, 76% persons with disabilities between age group of 6-18 yrs met during the survey said that the school infrastructure should be improved to meet their needs. Sixty three percent of persons with disabilities above 18 years who said that difficulty in travelling to and from workplace is one of the reasons for their unemployment

## **6. Governance Challenges towards Inclusion of Rights of persons with disabilities**

While the State Planning Commission has provided a fairly detailed process that would ensure participatory planning at the local level, the reality shows that planning in urban areas continues to be top-down with very little role played by the citizens and the elected representatives like the ward councillors.

Despite being identified as an important institution for local governance, the role of ULBs in the implementation of key services remains only in paper. The role of ULBs in planning and prioritising activities for the welfare of disabled is completely ignored in all the major disability related policies in India. As a result, municipal corporation is to disburse various state and central pension schemes and ensures barrier free access to urban public buildings with respect persons with disabilities.

### 6.3 Scheme based approach prohibits permanent system for inclusion

Much of the development in urban areas is today implemented through large schemes. These schemes are time bound and are implemented through projects. These schemes are most often found to be target oriented and therefore the leaving the steps of planning and program design to the technical experts rather than the beneficiaries. No role is played by elected representatives or the citizens in the design and implementation of large schemes like JNNURM and RaY. As a result, the development of the city today does not include the needs and aspirations of the persons with disabilities during the planning process.

### 6.4 Inadequate focus on Disability in the State and District Level Departmental Plans

There is no earmarking of specific budget for any of the key sectors like Health, education and skill development in the state level plan. While many of these sectors play a key role in providing services to the persons with disabilities, however there is no specific mention of activities or budget to ensure that the disability welfare related functions are delivered adequately. Using the examples of the Health and WCD department which play very important roles in prevention and early detection of disability, the below analysis will help in understanding the lack of consideration of disability as an important component while planning and funding for activities in key sectoral plans.

**Table 29: State Budgetary Allocations of the health department relevant to persons with disabilities in Urban areas**

	(in lakhs)					
	2011-2012 Budget Allocated	2011-2012 Expenditure	2010-2011 Budget	2010-2011 Exp	2009-2010 budget	2009-2010 Exp
Urban Health Service Allopathy 110 hospitals and dispensaries	6675	-	7288	7919.54	2234.54	2216.28
Prevention and Control of communicable diseases	1391	-	1071	1081	613.50	999.69
Health Infrastructure (Urban)	3035	-	0	0	0	0
Construction of Primary Health Centres	1989	-	250	1210	1200.11	567.74
Training Programme	200	-	0	0	0	0

Source: 12<sup>th</sup> Madhya Pradesh State Five Year Plan, 2012-2013 Annual Report

**Table 30: State budgetary allocations for Women and Child Development Department relevant to persons with disabilities**

	2011-2012 Budget Allocated	2011-2012 Expenditure	2010-2011 Budget	2010- 2011 Exp	2009- 2010 budget	2009- 2010 Exp
<b>Awareness camps</b>	105.68	-	212.59	212.59	73.22	70.07
<b>Construction of Anganwadi centres</b>	1	-	5000.00	5000.38	4000	4198.97
<b>Nutrition programme in urban slums</b>	0	0	0	0	0	0
<b>Atal Bihari Arogya Poshan</b>	18820.70	-	0	1724.19	0	0
<b>Training Programme</b>		-				

Source: 12<sup>th</sup> Madhya Pradesh State Five Year Plan, 2012-2013 Annual Report

There are no specific activities or earmarked budget for disability related activities in these departments. Thus, there is a complete neglect of disability welfare as a component while planning and budgeting of key sectors. There is a need to recognise disability is an important component like Schedule Caste Sub-Plan, Tribal Sub-plan and also Woman Component while budgeting for our activities.

## 6.5 Complex Inter-sectoral/departmental coordination

Disability is a complex social phenomenon and needs a multi-sectoral approach. There can be array of departments and ministries that may have direct implication for disabled such as Social Justice, education, Health and Family welfare, Women and Child Development (WCD), surface transport etc. While host of other departments such as Rural development, Vocational trainings, Sports and youth welfare play roles at different stages. Within the periphery of the department, there are several schemes, budget lines and programs that have direct implication for the persons with disabilities. For instance Anganwadi run by the WCD has a serious role in early intervention and prevention of disability or Road construction taken under NREGS may influence the connectivity of a disabled child to the school. A ramp may be built through Sarva Siksha Abhiyan (SSA), polio drops are administered through ANM and disability certificate are provided with the help of District Hospital. There are inherent challenges for any nodal ministry in such a multi-sectoral field as disability, to that extent, there is no “natural” nodal department for disability. The nodal agency for disability is the Ministry of Social Justice and Empowerment (MSJE). There is a complex institutional framework for operation of the disability sector in India. The MSJE-the nodal ministry for disability has an overall mandate to promote the interests of “disadvantaged and marginalised sections of society”. This includes Scheduled Castes, Backward Classes, minorities, Person with disability, aged persons, street children,



victims of drug abuse, and others. Therefore, persons with disabilities are a small constituent of the target group of the ministry. The other concerned ministries have been wary of the specific intervention or budgetary allocation. This is so in spite of the fact that the 11th Plan clearly mandated that “each concerned Ministry/Department shall reserve not less than 3 percent of their annual outlay for the benefit of disabled persons as enjoined in the Persons with Disabilities Act, 1995”.

There is a broader challenge of the ability/capacity of ministry of social justice to coordinate with several other ministries (in particular, education, health, transport and public works), with its low budgetary provisions, limited human resources available, lack of adequate sensitivity and training on disability issues. Therefore, planning for disability is challenging and governance framework is complex. Though there is no ideal solution to such an issue, but the unusual inter-sectoral and inter- institutional coordinating mechanisms asks for either a strong coordinating mechanism at the top or at the bottom.

## **6.6 Campaign based approach to Disability welfare service delivery**

While it is important to recognise that Sparsh Abhiyan and similar preceding campaigns have been positive efforts towards ensuring disability welfare, there is also a need to recognise that such campaigns have many shortfalls. Some of the key issues with Sparsh Campaign are:

1. The first issue is of over burdening of the Social Justice department. As seen earlier the Sparsh Campaign is designed to provide a multi-sectoral approach towards disability welfare. That is a number of departments play a key role in ensuring that disability needs are dealt with comprehensively. However, experiences of the Social Justice department shows that being the only department that manages the disability related activities, it is overburdened due to the responsibility of coordinating and monitoring of disability specific activities of 14 key departments
2. The second issue is the poor performance of the campaigns. For instance, the success rate of Sparsh campaign with respect to key activities like providing aids/ appliances for the disabled, linking them to specific entitlements and so on have been far from desired levels. Only 1995 of the total 20046 registered persons with disabilities in Bhopal have been issued aids and appliances under Sparsh Abhiyan.
3. The third issue is the absence of any monitoring mechanism that the Social Justice Department has put in place to evaluate the progress of the campaign. Since, the campaign is not target based, it is very difficult to assess whether the campaign has under-performed or outperformed its own plan.

## **7. Summary of Findings**

Both internationally and nationally, there is a shift in approach towards the persons with disabilities from being people who need to be cured to an approach that recognizes persons with disabilities as members of the society who could contribute to the growth of the nation if the State makes adequate efforts to ensure them equal rights and opportunities. There is an increasing recognition of the need to address disability using the Community Based Rehabilitation Model especially in a country like India where the role and power of community to improve the quality of life of marginalised people like the persons with disabilities is high. In this model concerted efforts are required from the persons with disabilities themselves, their families, their communities, ULBs, state and national governments.

The recognition of disability as an important issue at the policy level in India is evident in all the Plan documents since the 9<sup>th</sup> Five Year Plan provides hope to the disability rights advocates. While India has fairly progressive policies on disability rights, there are a few issues that have to be addressed so as to make them more sensitive to the needs and aspirations of the persons with disabilities. Following the popular model of approaching and evaluating disability policies suggested by DFID called the 'twin track model', it was revealed that the disability specific policies in India have attempted to address disability in a comprehensive way in its approach though much needs to be done to ensure that the implementation of these policies are effective. Some recurring bottlenecks in all these policies/legislations like a lack of recognition of the urban local bodies as a key unit for governance and service delivery for persons with disabilities. The other key issues that have resulted in poor implementation of the legislations are the issues related to the weak inter-sectoral coordination between the various departments that are entrusted with the responsibility for providing key services to the persons with disabilities. There is also a lack of clarity on the specific field level functionaries who would be responsible for delivering many services. For instance while the ANMs, Anganwadi workers and the ASHA are key local level functionaries who are crucial in ensuring prevention and early detection of disability, there are no efforts made by the Health, Woman and Child Development or the Social Justice department to provide them training and sensitise them to disability related issues. In case of the disability inclusive development policies in India, the analysis of the development policies in India revealed that the only sector that has addressed the issue of disability is the education sector. Through policies and schemes like National Educational Policy, Integrated Education for disabled children and Inclusive Education Programme of the Sarva Shiksha Abhiyan have been positive steps towards ensuring better education services for the CWSN.

Attempting to understand the extent to which the urban planning processes are inclusive of the rights of persons with disabilities, the study found that the initiatives for decentralised planning in Madhya Pradesh indeed provides hope for a more participatory and bottom up planning framework. The current guidelines for decentralised planning Madhya Pradesh recognise the persons with disabilities as an important stakeholder in the planning process. However, there are contradictions in the secondary and primary data collected for this study. On one hand the decentralised planning website reports that meetings were conducted in various wards of Bhopal as a part of decentralised urban planning and that aspects related to services provided for the persons with disabilities were a part of the 'State Problem Analysis', however the persons with disabilities living in the slums suggested that they were never consulted as a part of the planning process. Thus, it was found that the urban poor and the persons with disabilities living in slums are not included adequately in the planning processes and the procedures followed for such consultations need to be re-designed to ensure that the persons with disabilities living in poor conditions who largely depend on the government to access key services are consulted during the planning processes.

ULBs according to the 74<sup>th</sup> CAA and the 12<sup>th</sup> Schedule are the key agencies responsible for ensuring welfare of the marginalised population especially persons with disabilities. The study found that there are no specific activities identified, planned and budgeted for at the ward level or by the Municipal Corporation for the welfare of the disabled. Apart from construction of Sulabh complexes and disbursement of disability pension, no activities conducted by the wards and ULBs were found to be directly relevant to the persons with disabilities. There is no mention of any budget allocated for disability specific activities in the budget estimates of the Municipal Corporation in any of the years from 2009-2010 to 2011-2012. The same observation was made regarding the ward planning. The role of the ward councillors in matters related to planning and budgeting for activities at the ward level. There was a general opinion among the people and the ward councillors, zonal level officials that planning in urban areas continue to follow a top-down approach and that the role of the ward councillors are to implement the plan

that are handed over to them by the Municipal Corporation. Also, the emerging trend of 'project based urban development' approach has reduced the role of the ward councillors to a great extent. Much of the project design power is entrusted on technocrats and specialists who may not always understand the social underpinnings and the issues faced by the citizens. Apart from the Swarna Jayanti Shahari Rojgaar Yojna, there are no urban development schemes that have specific activities for the persons with disabilities. Thus much needs to be done to include persons with disabilities in our urban development planning and implementation.

There is a general consensus that the needs, rights and entitlements of the persons with disabilities cuts across Madhya Pradesh has been delivering its key services and entitlements to the persons with disabilities through large scale campaigns. Social Justice Department being the key agency responsible for the comprehensive welfare of the persons with disabilities is also responsible for conducting and coordinating the roles and activities of key departments in ensuring welfare of the disabled. While attempting to understand the issues faced by citizens while accessing various services offered by the government, the study found that there huge structural and procedural inadequacies in the framework for delivering services to the persons with disabilities. For instance the first and foremost responsibility of the government is towards prevention and early detection of disabilities. Two key departments in India are responsible for ensuring prevention and early detection of disability are the health department and woman and child development department. Through many activities like immunization, prenatal, perinatal and postnatal care of children, pregnant and lactating mothers and children below age of 6 years, the local level service providers like Anganwadi workers, ASHA and ANMs can to a large extent prevent disability caused due to polio, iodine deficiency and unsafe delivery and malnutrition among children. However, data shows that the effectiveness of the services provided by the Anganwadi and ASHA have been limited to immunisation and distribution of nutritious food pack. No proactive actions have been taken by them to prevent or detect disability. One of the major reasons for this is lack of training and sensitivity among these key field level functionaries about disability and the various services they are entitled to. The interviewed Anganwadi workers and ANM workers were found to have very little knowledge about disability and they claim that their only responsibility was to refer the disabled children to the nearest health centre. Thus the government fails to fulfil its first responsibility towards persons with disabilities. The next key responsibility of the government is the identification and registration of these persons. It was found that due to varying definition of disability by various authorities have resulted in the under-enumerated. This being a major issue, many persons with disabilities continue to be alienated from many of the services they would otherwise be entitled to. As a result, the percentage of persons with disabilities with disability certificate is also low. Of the persons with disabilities surveyed for the study only 60% had certificates. This is a major issue as the Social Justice Department mandates that only those persons with disability certificates can access the various rights and entitlements.

The next key stage of services the state provides the persons with disabilities is rehabilitational services. The study explores the quality of rehabilitation provided by the state in 3 types of services- medical, educational and vocational. The medical rehabilitational services include supply assistive aids and services depending on the type and intensity of disability and corrective surgeries. It was found that out of the 20046 registered persons with disabilities under the Sparsh Abhiyan only 1995 persons with disabilities were given assistive devices proving the failure of the campaign to reach out to the needy. In terms of educational services, it is important to recognise that the education department has taken progressive policy decisions for the inclusion of persons with disabilities in the mainstream education system, a milestone being the inclusive education programme under the Sarva Shiksha Abhiyan. The programme aims to provide holistic support to Children with special needs beginning from identification of CWSN by conducting regular identification and registration camps, providing assistive devices and also providing various types of educational support to CWSN depending on their needs and type of disability. However, the failure of the Zilla Shiksha Kendra to recruit crucial human

resources who implement the vision of Sarva Shisha Abhiyan at the field level like the mobile resource consultants especially in the urban areas raise serious concerns about the reach of the scheme. In the absence of MRCs in the urban areas, it is very likely that many CWSN are left unattended. A greater issue is a gross under-utilisation of funds by the Zilla Shiksha Kendra available to it for the Inclusive education program.

Finally, the commitments of the Madhya Pradesh government in terms of providing livelihood opportunities to the persons with disabilities through affirmative actions like reservation of 6% jobs to the persons with disabilities have been unmet. In the entire district of Bhopal, Sparsh Abhiyan website reports that only 6 people have been recruited in the government jobs. Thus despite many progressive policies and initiatives like Sparsh Abhiyan, persons with disabilities are denied many rights and entitlements due to loopholes in the governance framework like poor inter-sectoral coordination for comprehensive rehabilitation, under-resourcing of the social justice department despite it being the sole coordinating nodal agency for welfare services to persons with disabilities, poor implementation of the policies and the local level, lack of training provided to field level functionaries on disability related issues and the lack of recognition of the ULBs as a key unit for planning and delivering services to persons with disabilities in the governance framework. The study finds that while India is definitely on the positive track by embracing a rights based approach to disability and recognising disability as an important component that needs to be addresses during development planning through decentralised planning, many structural and procedural aspects should be addressed so as to ensure that the right of the persons with disabilities in our country are protected and promoted.

## **8. Recommendation**

### **8.1 Strengthening Decentralised Planning in Urban Areas by Creating Mohalla Samitis**

The decentralised planning in urban areas can be realised in spirit only when the people living in the wards are given a platform to participate regularly in the planning and also the governance of their ward. Currently more than 25000 people reside in a ward which makes it impossible for the technical support group to consult all these citizens during the planning process. It is in this context that the idea of Mohalla Samitis assumes huge importance. In the presence of Mohalla Samitis, persons with disabilities will have more opportunities to voice their concerns and issues more effectively

### **8.2 Strengthening ULBs to play crucial role in disability welfare**

The disability related policies should align themselves to the spirit of the 74<sup>th</sup> Constitutional amendment which envisions ULBs to be the lowest tier of governance that has many important functions including the welfare of the marginalised sections including the persons with disabilities. There is a need to strengthen the ULBs to play a more active role in the social development of the city. Being the unit of governance closest to the persons with disabilities, the ULBs would be most effective in reaching out to them. ULBs can be the key agency that works closely with the social justice department to ensure and monitor inter-departmental coordination.

### **8.3 Inclusion of 'disability component' while budgeting for departmental activities**

The advocates of rights of women, schedule caste and scheduled tribes have succeeded in successfully advocating for gender budgeting, creation of scheduled caste sub plan and tribal sub plan respectively. Similarly there is a need for allocation of funds by every setor/department to activities of their departments that enhance the quality of life of the disability. While the 11<sup>th</sup> five year plan has specifically mandated that all departments should allocate 3% of the departmental budget to disability, not much has been done to realise this mandate.

### **8.4 Training and Sensitization of key field level health related functionaries**

Field level functionaries of the Health/Woman and Child Development department play a key role in health promotion, prevention and early detection of disability. There is a need to providing training to them on disability related issues and the important interventions they could make to reduce instances of disability. Important knowledge, skills and attitude should be imparted to these important functionaries who interact with persons with disabilities on a daily basis.

### **8.5 Need to increase health centres to issue disability certificate**

Under the current system, only one district hospital is entrusted with the responsibility of issuing disability certificate. Considering the size of the district, it becomes very difficult for the persons with disabilities living in the peripheries find it difficult to reach these hospitals denying them the access to the most important document that ensures their eligibility to access various services and entitlements. There is a need to increase the number of hospitals where persons with disabilities can be issued certificates. Moreover the camps conducted under the Sparsh Abhiyan for identification and certification of persons with disabilities should be well advertised and conducted in every ward at least once a year.

### **8.6 Adequate Human Resource Allocation for inclusive Sarva Shiksha Abhiyan**

The failure to appoint mobile resource consultants and the poor remuneration provided to the MRCs under the Inclusive education program has resulted in many MRC posts left vacant. Being one of the most important field level functionary to provide educational rehabilitation services to CWSN, there is a need to increase the number of MRCs working in urban areas and also to revise the remuneration provided to them which gives due to the nature and magnitude of work they are expected to perform/ actually perform.

## **9. Annexure**

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**Annexure-1**

**Household tracking sheet/inventory**

Household Name	Caste	Presence of disability in the household		If yes, what type of disability	Whether from birth or acquired later	Age of the disabled	Going to school/employed ( as relevant)	Have disability certificate		Any other specialised services of State availed by persons with disabilities	Remarks ( challenges, facilities and suggestion )- by the disabled person /family members
		Yes	No					Yes	No		

**Interview guide district officials of Social justice department and health department**

Name of the official..... department/designation.....

Interviewer .....Date of Interview.....

1. What is the approximate number of identified persons with disabilities in the district
2. What is the process of identification
3. What challenges do the department face in identification of persons with disabilities
4. What is department doing for persons with disabilities at the district
5. What has been the impact of the program, say how many persons were employed after receiving the training, or if the assistive tools made any difference to the lives of persons with disabilities
6. Do they have any mechanism of taking feedback
7. What are challenges of persons with disabilities in the villages
8. Which are the critical areas of concern
9. What can be done at district , Panchayat or departmental planning to handle the issues of persons with disabilities
10. What are challenges in certification of persons with disabilities
11. What role can Panchayat play in facilitating department for improving the services towards persons with disabilities
12. What are the major role played by the district rehabilitation centre in your district
13. Do you think that rehabilitation centres adequately address the problems of persons with disabilities
14. What can be done to improve its services
15. What can be done to improve the medical boards
16. What are some critical challenges of persons with disabilities that are not covered by any of the departmental services or the major areas of intervention that are grey and not adequately addressed by any departmental services



## Interview guide President and CEO zilla Panchayat

Name ..... department/designation.....

Interviewer .....Date of Interview.....

1. In the process of Planning, how do you account for persons with disabilities
2. Are there any special budgetary provisions for persons with disabilities at the district level, if yes, what is it and with which departments
3. What has been the approximate expenditure on the persons with disabilities in the previous years?
4. Do the allocations made for the persons with disabilities usually spent? If yes which are the budget lines that are usually spent? Which are usually inadequately spent and why?
5. What are the challenges before the persons with disabilities?
6. What can be done by the State and department to resolve the same?
7. Do you think that departments are doing enough to improve the situation for persons with disabilities?
8. What can department do improve the same?
9. Do you think that many persons with disabilities are not certified as the certification process is very difficult?
10. What can be done to improve the accessibility and ease of certification process?
11. What difficulties do departments face in doing their job towards persons with disabilities?
12. What critical role can Panchayat play in planning and budgeting for persons with disabilities?
13. What can Panchayat do improve the services towards persons with disabilities?
14. What are the major role played by the district rehabilitation centre in your district
15. What can be done to improve its services
16. What are some critical challenges of persons with disabilities that are not covered by any of the departmental services or the major areas of intervention that are grey and not adequately addressed by any departmental services?

## Annexure-3

### Inclusion of Person with Disability in Rural and Urban Planning and Governance QUESTIONNAIRE PART-II FOR SCHOOL GOING CHILDREN (AGE 6 TO 18) –RURAL

A. Personal Information	
1. Name:	Total no of family members:
Village:	Panchayat:
Block:	District:
Age: Years <input style="width: 50px;" type="text"/>	Sex: Male <input style="width: 50px;" type="text"/> Female <input style="width: 50px;" type="text"/>
<b>2. Marital Status</b>	
Married <input style="width: 50px;" type="text"/>	Unmarried <input style="width: 50px;" type="text"/>
Seperated <input style="width: 50px;" type="text"/>	Deserted <input style="width: 50px;" type="text"/>
Widow <input style="width: 50px;" type="text"/>	Other.....
<b>3. Key Informant</b>	
Self <input style="width: 50px;" type="text"/>	Ward <input style="width: 50px;" type="text"/>
<b>4. Category</b>	
General <input style="width: 50px;" type="text"/>	OBC <input style="width: 50px;" type="text"/>
SC/ST <input style="width: 50px;" type="text"/>	Minority <input style="width: 50px;" type="text"/>
Studying.....( grade)	
<b>5. Type of Disability</b>	
Blindness/low vision <input style="width: 50px;" type="text"/>	Locomotive/Orthopadic <input style="width: 50px;" type="text"/>
Hearing Impairement <input style="width: 50px;" type="text"/>	Mental retardation <input style="width: 50px;" type="text"/>
Speech Impairment <input style="width: 50px;" type="text"/>	Other .....
<b>6. Severity of disability</b>	
High <input style="width: 50px;" type="text"/>	Very high <input style="width: 50px;" type="text"/>
Moderate <input style="width: 50px;" type="text"/>	Low <input style="width: 50px;" type="text"/>
<b>7.Begining of disability</b>	
By birth	accident,
lack of proper nederal attention	other reason( specify)
<b>8. What in your opinion was the reason for disability ?</b> ..... .....	
<b>9.Do you think it was preventable? Give reason for your answer.</b> ..... .....	
<b>10. If you thought it was preventable, How did your family try to prevent the disability?</b> ..... ..... .....	
<b>11. Did your family take help of any Village level service provider to identify or intervene at disability ?</b>	
Yes <input style="width: 50px;" type="text"/>	No <input style="width: 50px;" type="text"/>
<b>12. If Yes, what was the help and its outcome?</b> ..... ..... .....	
<b>13. Did your family take help of Panchayat to identify or intervene at disability ?</b>	

Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
<b>14. If Yes, what was it?</b>			
.....			
.....			
.....			
<b>15. In your opinion what can Panchayat or vilage level fonctionries do in identification/ prevention /intervention of disability?</b>			
.....			
.....			
....			
<b>B. Possession of Medical (Disability) Certificate</b>			
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
<b>16. If yes, how did you achieve this?</b>			
Govt health camp	<input type="checkbox"/>	Govt hospital	<input type="checkbox"/>
Private clinic	<input type="checkbox"/>	Other .....	
Other.....			
<b>17.If no, why?</b>			
Didn't try yet	<input type="checkbox"/>	No health camp organized	<input type="checkbox"/>
doctor asks for bribe	<input type="checkbox"/>	other,specify	<input type="checkbox"/>
<b>18 if yes, was it difficult to get the certificate</b>			
Not difficult		moderately difficult	<input type="checkbox"/>
very difficult		Other .....	
<b>C. Aid, Appliances and treatment received from the government</b>			
<b>19. Have you received aid or appliances from the government?</b>			
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
<b>20. If yes ? who facilitataed in the same</b>			
Panchayat	<input type="checkbox"/>	village level service providers	<input type="checkbox"/>
district hospital	<input type="checkbox"/>	Jilla Panchayat	<input type="checkbox"/>
agents etc	<input type="checkbox"/>	Other..... ( specify)	
<b>21. If no, why?</b>			
Applied but haven't been given yet	<input type="checkbox"/>	Didn't apply	<input type="checkbox"/>
Officers aks for bribe	<input type="checkbox"/>	Not needed	<input type="checkbox"/>
Applied but denied	<input type="checkbox"/>	Other .....	
<b>22. Have you received any teatment?</b>			
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
<b>23. If no, why?</b>			
No money	<input type="checkbox"/>	Not needed	<input type="checkbox"/>
No facility available	<input type="checkbox"/>	District hospital is unwilling to help	<input type="checkbox"/>
Other.....			
<b>24. Did you face any difficulty in receiving the treatment?</b>			
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
<b>If yes,specify.....</b>			
<b>25. Is your child enrolled in the school</b>			
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
<b>26. If yes,what specific experience does he have with respect his disability?</b>			
.....			
.....			
.....			

<b>27. If not enrolled, why have you not enrolled him/her?</b> ..... ..... .....	
<b>27. Is your child is enrolled, is he/she regular in school?</b>	
<b>Yes</b>	<b>No</b>
<b>29. If not, why is she/he not regular?</b> ..... .....	
<b>30. What support is required to make the child regular in school?</b> ..... ..... .....	
<b>31. Who are the village level persons/functionaries/institutions that can facilitate better schooling of child?</b> ..... ..... .....	
<b>32. What support can health or other relevant department provide to improve the schooling prospect of the child?</b> ..... ..... ..... ...	
<b>33 Have you availed benefit of any schemes and programme in school?</b>	
Yes <input type="checkbox"/>	No <input type="checkbox"/>
<b>34. If no, why?</b>	
Do not have proper information <input type="checkbox"/>	Applied but didn't get <input type="checkbox"/>
Do not have medical certificate <input type="checkbox"/>	Officer asks bribe <input type="checkbox"/>
<b>35. If yes, please list the benefits</b>	
1.	2.
3.	4.
<b>36. Where did you get information about the scheme?</b>	
Panchayat <input type="checkbox"/>	G teacher <input type="checkbox"/>
Newspaper <input type="checkbox"/>	Relatives/friends <input type="checkbox"/>
Other,specify .....	Other departmental functionaries
<b>37. What supportive tools/study material and other facilities available in school?</b> ..... .....	
<b>38. What are the other problems that your child faces in school?</b> ..... .....	
<b>39. How is the behavior of the teacher and other students with the child?</b> ..... ..... .....	

<p><b>40. What other support did you receive for rehabilitating your child?</b></p> <p>.....</p> <p>...</p> <p>.....</p> <p>.....</p>				
<p><b>41. What challenges did you face in finding the above support?</b></p> <p>.....</p> <p>.....</p>				
<p><b>42. What can be done to improve the delivery of these services?</b></p> <p>.....</p> <p>.....</p>				
<p><b>43. Who can play a critical role in connecting these support mechanism to disabled children?</b></p> <p>.....</p>				
<p><b>44. What can be done to improve the above services for the persons with disabilities?</b></p> <p>.....</p> <p>.....</p>				
<p><b>45. Which institutions near you can facilitate improved support services?</b></p> <p>.....</p> <p>.....</p>				
<p><b>46. Did you ever participate or made suggestion with regard to schooling difficulty while planning at village level?</b></p>				
<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 25%; padding: 2px;">Yes</td> <td style="width: 25%;"></td> <td style="width: 25%; padding: 2px;">No</td> <td style="width: 25%;"></td> </tr> </table>	Yes		No	
Yes		No		
<p><b>47. If yes, Who asked for the participation and what about?</b></p> <p>.....</p> <p>.....</p>				
<p><b>48. What was the output of the same?</b></p> <p>.....</p> <p>.....</p>				
<p><b>49. What will your suggestion be for better schooling for you ?</b></p> <p>.....</p> <p>.....</p> <p>....</p>				

**Inclusion of Person with Disability in Rural and Urban Planning and Governance  
QUESTIONNAIRE PART-1 FOR VERY YOUNG CHILDREN (AGE 0 TO 6)- RURAL**

A. Personal Information	
<b>1. Name:</b>	Total no of family members:
Village	Panchayat
Block:	District/city:
Age: Years <input type="text"/>	Sex: Male <input type="text"/> Female <input type="text"/>
<b>2. Marital Status</b>	
Married <input type="text"/>	Unmarried <input type="text"/>
Seperated <input type="text"/>	Deserted <input type="text"/>
Widow <input type="text"/>	Other.....
<b>3. Key Informant</b>	
Self <input type="text"/>	Ward <input type="text"/>
<b>4. Category</b>	
General <input type="text"/>	OBC <input type="text"/>
SC/ST <input type="text"/>	Minority <input type="text"/>
Studying.....( grade)	
<b>5. Type of Disability</b>	
Blindness/low vision <input type="text"/>	Locomotive/Orthopadic <input type="text"/>
Hearing Imparement <input type="text"/>	Mental retardation <input type="text"/>
Speech Impairment <input type="text"/>	Other .....
<b>6. Severity of disability</b>	
High <input type="text"/>	Very high <input type="text"/>
Moderate <input type="text"/>	Low <input type="text"/>
<b>7.Begining of disability</b>	
By birth	accident,
lack of proper nederal attention	other reason( specify)
<b>8. What in your opinion was the reason for disability</b> ..... .....	
<b>9.Do you think it was prevetable? Give reason for your answer</b> ..... .....	
<b>10.If you thought it was preventable, How did you try to prevent the disability?</b> ..... ..... .....	
<b>11. Did you take help of any Village level service provider to identify or intervene at disability ?</b>	
Yes <input type="text"/>	No <input type="text"/>
<b>12. If Yes, what was the help and its outcome?</b> ..... ..... .....	
<b>13. Did you take help of Panchayat to identify or intervene at disability ?</b>	
Yes <input type="text"/>	No <input type="text"/>
<b>14. If Yes, what was it?</b> ..... ..... .....	

<b>15. In your opinion what can Panchayat or village level functionaries do in identification/ prevention /intervention of disability?</b>	
.....	
.....	
....	
<b>B. Possession of Medical (Disability) Certificate</b>	
Yes <input type="checkbox"/>	No <input type="checkbox"/>
<b>16. If yes, how did you achieve this?</b>	
Govt health camp <input type="checkbox"/>	Govt hospital <input type="checkbox"/>
Private clinic <input type="checkbox"/>	Other.....
Other.....	
<b>17.If no, why?</b>	
Didn't try yet <input type="checkbox"/>	No health camp organized <input type="checkbox"/>
doctor asks for bribe <input type="checkbox"/>	other <input type="checkbox"/>
<b>18. if yes, was it difficult to get the certificate</b>	
Not difficult <input type="checkbox"/>	moderately difficult <input type="checkbox"/>
very difficult <input type="checkbox"/>	Other.....
<b>C. Aid, Appliances and Treatment received from the government</b>	
<b>19. Have you received any aid or appliances from the government?</b>	
Yes <input type="checkbox"/>	No <input type="checkbox"/>
<b>20. If yes? who facilitated in the same</b>	
Panchayat <input type="checkbox"/>	village level service providers <input type="checkbox"/>
district hospital <input type="checkbox"/>	Jilla Panchayat <input type="checkbox"/>
agents etc <input type="checkbox"/>	Other..... (specify)
<b>21. If no, why?</b>	
Applied but haven't been given yet <input type="checkbox"/>	Didn't apply <input type="checkbox"/>
Officers asks for bribe <input type="checkbox"/>	Not needed <input type="checkbox"/>
Applied but denied <input type="checkbox"/>	Other.....
<b>22. Have you received any treatment?</b>	
Yes <input type="checkbox"/>	No <input type="checkbox"/>
<b>23. If no, why?</b>	
No money <input type="checkbox"/>	Not needed <input type="checkbox"/>
No facility available <input type="checkbox"/>	District hospital is unwilling to help <input type="checkbox"/>
Other.....	
<b>24. Did you face any difficulty in receiving the treatment?</b>	
Yes <input type="checkbox"/>	No <input type="checkbox"/>
<b>25. If yes,specify.....</b>	
<b>26. Is your child enrolled in the school</b>	
yes <input type="checkbox"/>	No <input type="checkbox"/>
<b>27. If yes,what specific experience does he have with respect his disability?</b>	
.....	
.....	
....	
<b>28. If not enrolled, why have you not enrolled him/her?</b>	
.....	
.....	
....	
<b>29. Is your child is enrolled, is he/she regular in school?</b>	

Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
<b>30. If not, why is she/he not regular?</b>			
<b>31 Have you availed benefit of any schemes and programme in school?</b>			
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
<b>32. If no, why?</b>			
Do not have propoer information	<input type="checkbox"/>	Apppiled but did'nt get	<input type="checkbox"/>
Do not have medical certificate	<input type="checkbox"/>	Offcicer asks bribe	<input type="checkbox"/>
<b>33. If yes, please list the benefits</b>			
1.		2.	
3.		4.	
<b>34. Where did get information about the scheme?</b>			
Panchayat	<input type="checkbox"/>	G teacher	<input type="checkbox"/>
Newspaper	<input type="checkbox"/>	Relatives/friends	<input type="checkbox"/>
Other,specify .....		Other departmental functionaries	
<b>35. What other support did you receive for rehabilitating your child?</b>			
.....			
...			
<b>36. What challenges did you face in finding the above support?</b>			
.....			
.....			
<b>37. What can be done to improve the delivery of these services?</b>			
.....			
.....			
<b>38. Who can play a critical role in connecting these support mechanism to disabled children?</b>			
.....			
<b>39. What can be done to improve the above services for the persons with disabilities?</b>			
.....			
.....			
<b>40. Which institutions near you can facilitate improved support services?</b>			
.....			
.....			
<b>41. Did you ever participate or made suggestion with regard to your disabled child while planning at village level?</b>			
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
<b>42. Who asked for the participation and what about?</b>			
.....			
.....			
<b>43. Have you ever made suggestion in improving any public services from the perspective of disabled persons?</b>			



**44. What was the output of the same?**

.....

.....

**Inclusion of Person with Disability in Rural and Urban Planning and Governance  
QUESTIONNAIRE PART-III, FOR PERSONS WITH DISABILITIES IN EMPLOYABLE  
AGE GROUP [18 YEARS ONWARDS] - RURAL**

<b>A. Personal Information</b>	
<b>1. Name:</b>	Total no of family members:
Village:	Panchayat:
Block:	District:
Age: <input type="text"/> Years	Sex: Male <input type="text"/> Female <input type="text"/>
<b>2. Marital Status</b>	
Married <input type="text"/>	Unmarried <input type="text"/>
Seperated <input type="text"/>	Deserted <input type="text"/>
Widow <input type="text"/>	Other ..... <input type="text"/>
<b>3. Key Informant</b>	
Self <input type="text"/>	Ward <input type="text"/>
<b>4. Category</b>	
General <input type="text"/>	OBC <input type="text"/>
SC/ST <input type="text"/>	Minority <input type="text"/>
Studying.....( grade) <input type="text"/>	<input type="text"/>
<b>B. Type of Disability</b>	
Blindness/low vision <input type="text"/>	Locomotive/Orthopadic <input type="text"/>
Hearing Imparement <input type="text"/>	Mental retardation <input type="text"/>
Speech Impairment <input type="text"/>	Other ..... <input type="text"/>
<b>Severity of disability</b>	
High <input type="text"/>	Very high <input type="text"/>
Moderate <input type="text"/>	Low <input type="text"/>
<b>Begining of disability</b>	
By birth <input type="text"/>	By accident <input type="text"/>
lack of proper medical attention <input type="text"/>	other reason( specify)-----
<b>C. Possession of Medical (Disability) Certificate</b>	
Yes <input type="text"/>	No <input type="text"/>
<b>5. If yes, how did you achieve this?</b>	
Govt health camp <input type="text"/>	Govt hospital <input type="text"/>
Private clinic <input type="text"/>	Other ..... <input type="text"/>
Other..... <input type="text"/>	
<b>6. If no, why?</b>	
Didn't try yet <input type="text"/>	No health camp organized <input type="text"/>
doctor asks for bribe <input type="text"/>	Other <input type="text"/>
<b>7. Was it difficult to get the certificate</b>	
Not difficult <input type="text"/>	moderately difficult <input type="text"/>
very difficult <input type="text"/>	Other ..... <input type="text"/>
<b>D. Aid, Appliances and treatment received from the government</b>	
<b>8. Have you received any aid or appliances from the government?</b>	
Yes <input type="text"/>	No <input type="text"/>
<b>9. If yes ? who facilitataed in the same</b>	
Panchayat <input type="text"/>	village level service providers <input type="text"/>
district hospital <input type="text"/>	Jilla Panchayat <input type="text"/>
agents etc <input type="text"/>	Other ..... ( specify) <input type="text"/>
<b>10. If no, why?</b>	
Applied but haven't been given yet <input type="text"/>	Didn't apply <input type="text"/>

Officers asks for bribe	<input type="checkbox"/>	Not needed	<input type="checkbox"/>
Applied but denied	<input type="checkbox"/>	Other .....	
<b>11. Have you received any treatment?</b>			
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
<b>12. If no, why?</b>			
No money	<input type="checkbox"/>	Not needed	<input type="checkbox"/>
No facility available	<input type="checkbox"/>	District hospital is unwilling to help	<input type="checkbox"/>
Other.....			
<b>13. did you face any difficulty in receiving the treatment?</b>			
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
<b>14. If yes,specify.....</b>			
<b>E. Social Security Schemes and programmes</b>			
<b>15 Have you availed benefit of any schemes and programme?</b>			
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
<b>16. If No, why?</b>			
Do not have proper information	<input type="checkbox"/>	Applied but didn't get	<input type="checkbox"/>
Do not have medical certificate	<input type="checkbox"/>	Officer asks bribe	<input type="checkbox"/>
<b>17. If yes, please list the benefits</b>			
1.		2.	
3.		4.	
<b>18. From where you got information about the scheme?</b>			
Panchayat	<input type="checkbox"/>	Govt Department	<input type="checkbox"/>
Newspaper	<input type="checkbox"/>	Relatives/friends	<input type="checkbox"/>
Other,specify .....			
<b>F. Challenges in Employment</b>			
<b>19. Are you employed</b>			
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
<b>20. Have you availed any special training education?</b>			
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
<b>21. Yes, what was it?</b>			
.....			
<b>22. Was it useful?</b>			
.....			
Give reason for answer.....			
.....			
<b>23. What other support did you receive?</b>			
Quota in employment	<input type="checkbox"/>	Assistive devices	<input type="checkbox"/>
Cheaper loans	<input type="checkbox"/>	Others ,specify	<input type="checkbox"/>
<b>24. What challenges did you face in finding the above support?</b>			
.....			
.....			
<b>25. What can be done to improve the delivery of these services?</b>			
.....			
.....			
<b>26. Who can play a critical role in connecting these support mechanism to disabled persons?</b>			

<p>.....</p>	
<b>27. What challenges do you face in work situation?</b>	
Lack of adequate skills <input type="checkbox"/>	difficulty in reaching the work place <input type="checkbox"/>
Insensitivity of employer <input type="checkbox"/>	Insensitivity of co workers <input type="checkbox"/>
<b>28. What other services are critical to your smooth employment?</b>	
Public Transport <input type="checkbox"/>	PDS <input type="checkbox"/>
Health <input type="checkbox"/>	Other <input type="checkbox"/>
<b>29. What problems do you face in making use of the above services?</b>	
<p>.....</p> <p>.....</p>	
<b>30. What can be done to improve the above services for the Persons with Disabilities?</b>	
<p>.....</p> <p>.....</p>	
<b>31. Which institutions near you can facilitate improved support services?</b>	
<p>.....</p> <p>.....</p>	
<b>32. Is your family adequately supportive ? Give reason for your answer.</b>	
<p>.....</p> <p>.....</p> <p>.....</p>	
<b>33. Are you part of any network/ federation / group that can help in sharing experience?</b>	
Yes	No
<b>34. Did you ever participate or made suggestion with regard to planning at village level?</b>	
Yes	No
<b>35. Who asked for the participation and what about?</b>	
<p>.....</p> <p>.....</p>	
<b>36. Have you ever made suggestion in improving any public services from the perspective of disabled persons?</b>	
<p>.....</p> <p>.....</p>	
<b>37. What was the output of the same?</b>	
<p>.....</p> <p>.....</p>	

## Annexure-4

### Time involvement/ actual cost/ transaction costs: In-depth interview with one or two selected beneficiary

Track time and transaction cost

Particular	D ays	Ho urs	Transaction			
			Fe es	Tr ansacti on Cost	Sp eed money	Total money paid
1.						
2. Filling up form						
3. Organising necessary documents						
4. Submission of application						
5. Enquiry about status						
6. Receipt of document/ benefit						

Did you find that money spend by you was worth the getting that document/ service?

## **Annexure-4**

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### **Interview guide for village level service providers such as Anganwadi worker. ANM etc**

Name ..... department/designation.....

Interviewer.....Date of Interview.....

- 1. Do you have any training in recognising and preventing a possible disability in your field area**
- 2. Have you come across cases in your Panchayat , where a disability could have been prevented by timely medical intervention.**
- 3. Are you aware of the causes of different type of acquired disability, such as blindness etc.**
- 4. What support do you think that Health/ICDS and other relevant department make to prevent, intervene and rehabilitate disability?**
- 5. Do departmental budgets allocated to your centre ever have special provision for disability**
- 6. What type of disability is commonly seen in your area?**
- 7. What do you think is the cause for the same**
- 8. What can be done to prevent it**
- 9. What role can different institution such as Panchayat, Anganwadi center ,PHC, CHC etc in prevention and rehabilitation of disability**

**Guided interview schedule for Elected Representatives\***

**Name of the Member..... Ward Represented.....**

**Interviewer.....Date of Interview.....**

**Interview guide for elected representatives**

- **Have you made a village or Panchayat /slum annual plan, if yes, has the plan accounted for persons with disabilities in any way?**
- **If yes- how did it do it?**
- **What is done in your Panchayat for persons with disabilities - disbursement of scheme benefits, ramp etc in school or any other, facilitating the certification etc.**
- **What are the provisions for persons with disabilities, how does a Panchayat help in it?**
- **What can be done at planning level in Panchayat to improve the life of persons with disabilities?**
- **Do service provider at village level ever discuss the issues of persons with disabilities with you?**
- **Do the service provider take any special care of the persons with disabilities in your Panchayat?**
- **What challenges do you think that persons with disabilities face and where in Panchayat can play a critical role?**
- **What can departmental functionary with respect to persons with disabilities?**

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\* A total of 20 ward members, including the members from the wards in which the study slums are located, will be interviewed. At least 5 of those interviewed should be women. The list will also include the Chairperson/ Mayor of the Corporation.

## Annexure-6

### List of Government Officials Interviewed for the Study

Sl. No	Sample Population	Sample Size	Details
<b>State and District Level Officials</b>			
1	Madhya Pradesh State Planning Commission Officers	2	Sri. Yogesh Mahor, Planning Commission Officer -Social Advisor  Sri. Rishi Sharma, Planning Commission Officer, Joint Convergence Program
2	Commissioner for the Rights of Persons with disabilities	1	Sri. Deepankar Banerjee
3	District Officer, Social Justice Department - Bhopal	1	Sri. Manoj Batham
4	District Project Coordinator, Sarva Shiksha Abhiyan	1	Sri. R.K Pande
5	District Assistant Project Coordinator, Sarva Shiksha Abhiyan	1	Sri. Gangvare
6	District Urban Development and Administration	1	Smt. Lata Soni, Assistant Project Officer
7	Deputy Commissioner Municipal Corporation,	1	Sri. N.P Majhi
8	Bhopal JNNURM Project Manager	1	Mr. Subhodh Jain
9	Medical Board Member, 1250 District Hospital, Tulsi Nagar Bhopal	1	Dr. V.K. Jain
10	Ward Councillors	2	Smt. Chandramukhi Yadav- Ward Councillor of Baghmugalia  Smt. Nisha Khan- Ward councilor of Arif Nagar



<b>Field Level Functionaries</b>			
1	Mobile Resource Consultant, Berasia Block, Bhopal	1	Mr. Ravi
2	Anganwadi workers	3	Anganwadi Kendra No. 471 Anganwadi Kendra No. 751 Anganwadi Kendra No. 711