

# REPORT

## Inclusion of Person with Disability in Rural Planning and Governance



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## Abbreviation

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

# Inclusion of Persons with disability in Rural Planning and Governance

## 1. Introduction

The percentage of Persons with disabilities among the total population of any country would depend on the definition of 'disability' in that particular country, enumeration methodology as well as its accuracy. In India, the definition of disability used in the Census is very different from that in the 'Persons with Disabilities Act, 1995'. As per the definition of disability adopted in the census, the Indian census reports only 2.2 percent disabled persons in the country.

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 Persons with disability. Census 2001 has revealed that over 21 million people in India are impacted with one or the other kind of disability. This is equivalent to 2.1% of the population. Among the total Persons with disability in the country 12.6 million were males and 9.3 million were females as per the Census 2001. The number of Persons with disability is more in rural than in urban areas. There are more male Persons with disability than females (57-58 percent males as compared to 42-43 percent females).

Among the five types of disabilities on which data has been collected, visual disability is found at 48.5%. It emerges as the highest prevailing in the country. Others in decreasing order are: Locomotors disability (27.9%), Mental disability (10.3%), speech disability (7.5%), and hearing disability (5.8%). Across the country, the highest numbers of Persons with disability have been reported from the state of Uttar Pradesh (3.6 million). Significant numbers of Persons with disability 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 1: Number of Persons with disability population and type of disability**

Description	Population	Percentage (%)
Total population	1,028,610,328	100.0
Total Persons with disability population	21,906,769	2.1
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**

Estimated 2.3 percent disability is much lower than the most of our neighbouring countries. According to the United Nations, the proportion of Persons with disability people among the total population in the Asia-Pacific region varies from 0.7% (Cook Islands) to 20% (Australia and New Zealand). In our immediate neighbourhood, Bangladesh reports 5.6%; China 6.3%, whereas Sri Lanka reports 7% population as Persons with disability.

According to persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995, disability is defined when a person suffers not less than 40% of disability, as certified by a medical authority. It lists blindness, low vision, hearing impairment, leprosy cured, mental retardation, and other mental illness as disability. However while enumeration during the census; it is a challenge to correctly record the disability due to inability to measure the 40% or more criteria.

Owing to lack of a credible definition and a poor system of data collection and enumeration, disability data is incomplete and inaccurate. It can be reasonably assumed that Persons with disability constitute anywhere between 5 to 6% of our total population. Organisations with special focus on Persons with disability, estimate India's total Persons with disability population at approximately six per cent or 70 million.

Disability in Madhya Pradesh exists at an alarming level. According to Census 2001, the total population of Madhya Pradesh is 60,348,023; out of this 14,08,528 persons are living with disability. Currently, the department of Social Justice and Welfare is the authority responsible for the welfare of Persons with disability in Madhya Pradesh. There are 14,08,528 Persons with disability in Madhya Pradesh, making, 2.3% of the state's total population (Census 2001). The NSSO reported 11,66,856 Persons with disability in Madhya Pradesh. Visual disability is the most prevalent disability as per the Census 2001 while the NSSO data highlights that Ortho-disability as the most prevalent one. Persons with disability children number around 100,929. About 60% Persons with disability in the 6-14 age-groups are males.

**Table 2- Number of Persons with disability in India and Madhya Pradesh**

No of Persons with disability in India	10634881	1640868	1261722	6105477	226382	19869330
No of Persons with disability in MP	63613	75825	85354	495878	115257	835927

(Source: Sparsh Abhiyan, Department of Social Justice, M.P and Census India 2001)

## **Disability and Employment Status: Data from Madhya Pradesh**

As per the NSSO data, fifty percent of the total Persons with disability population in Madhya Pradesh is literate -- 45% in rural areas and 55% in urban areas. A majority (66%) of the literate Persons with disability have not progressed beyond primary school. The literacy rate (CENSUS 2001) for the Persons with disability (49.7%) is much lower than the literacy rate for the general population (64.11%). Only 37.6% of Persons with disability (529,648 people) are employed (main and marginal). The remaining 62.4% are not engaged in any income-generating activity. About 81% of total Persons with disability workers belong to rural areas, and 19% to urban areas. Nearly 52% of the total Persons with disability workforce in Madhya Pradesh belongs to the visually Persons with disability category. About 42% of total Persons with disability workers are cultivators, followed by agricultural labourers (27.5%).

## **Educational Institutions and Disability: Data from Madhya Pradesh**

About 12% of schools have ramps for barrier-free movement. Though financial assistance is given under various schemes for Persons with disability students, and to sensitize teachers on disability, only one college received financial assistance for higher education for the Persons with disability; no college has received a grant for teacher training. There are only six teachers for the Persons with disability in three universities in the state, and only 28 have been trained to teach in schools. About 207 special educators have been trained to teach the mentally retarded. There are six schools for physically and visually Persons with disability students, which have so far taught 289 students. (Source: Disability Audit-PACS).

## **2. Objective**

Samarthan, Bhopal has been commissioned to undertake a study on inclusion of Persons with disability in planning and governance process. The study has been commissioned by CBM Bangalore. The study will contribute to building a clear understanding of process of rural planning & governance from the perspective of the disability. Specifically, the study will objectively and comprehensively look into the planning and governance requirements of the persons with disability and suggest action agenda for advocacy.

### **Specific Objectives of the study:**

To understand the inclusion of Persons with disability and disability related issues in existing framework of developmental planning.

To see the trends of resource allocation, flow of funds and process bottlenecks in district budgeting and expenditures with respect to disability

Access of resources to Persons with disability and services provided to them at the local level? Issues involved in doing the same?

Though the study proposes to understand the flow of resources for Persons with disability and process bottlenecks in governance framework, it still upholds a closer examination of status of Persons with disability at ground level in terms of access to facilities from the State. Betul is the proposed district for studying the context specifically.



### 3. Methodology

Disability, a complex medical and social phenomenon, entails interplay of different departments and institutions. From prevention to employment or social rehabilitation, departments of Health, Education, Women and Child Development, Social Justice and Labour and Employment play different roles at different times. In fact, there are many more critical institutions involved in addressing disability at district level.

Therefore, it is not very appropriate to look at disability only within the framework of Department of Social Justice. Other departments and financial institutions like banks etc. also play an equally vital role. Though it is nearly impossible to look at each of these departments/ institutions, this study has tried to look at the departments and institutions that are most vital. A critical body of disability literature with reference to India in general, and Madhya Pradesh in particular includes policy and programme documents of the central and state governments. Unfortunately, there is very little data or discussion on disability in such documents. However, there are several other research reports of different organisations such the World Bank, UNDP, UNICEF that throws valuable light on the subject. These reports were examined to build stronger conceptual understanding and different perspectives on the issue.

Several other documents such as, district health plan, district decentralised plan, village plan under the decentralised plan, annual report of education department, budget documents of District Disability Rehabilitation Centre (DDRC) etc. were also examined to under the challenges in addressing disability.

#### **The process of secondary data generation has included:**

- Review and analysis of relevant national and state government documents
- Global, national, state and Bhopal, Betul and Panchayat level literature and reports on relevant information with respect to Persons with disability
- Secondary data such as guidelines for disability certification, report of rehabilitation council and other such documents that help in establishing the action on disability issues at the district level

**Primary data** on the other hand has been generated at two levels- first at the level of the Persons with disability and second at the level of service providers and policy makers. At both levels critical sub-sections have been identified in order to capture the dynamics of access, empowerment, and governance. An interview schedule with both open ended and closed ended questions was administered to the group of primary stakeholders. The primary data mainly comprised of: The interview schedules to Persons with disability in the two blocks of district of Betul.

In this context, a random sample methodology is used for collection of primary data as well as for interviews of village level functionaries. A sample is drawn randomly from the five villages of two blocks. Therefore, ten villages are taken up for primary data collection. Also only one village from a Panchayat (if village has ten or more Persons with disability) was considered for data collection to accommodate influence of Panchayat leadership at the local level. A total sample of 100 Persons with disability respondents was collected from the 10 villages of the 2 blocks of the district. A Few



village level service providers, elected representatives, block officials and district officials were also interviewed for the same purpose.

The blocks and preferably the villages are selected on the basis of concentration of disability in the village and the block so that meaningful insights are available for following the research. As indicated in our initial proposal, the data generated through FGDs and in-depth interviews with the primary stakeholders were documented as Field Notes and transcribed into structured output tables.

Additionally, the key findings from the preliminary analysis are presented to selected groups of users in order to triangulate the conclusions and thereafter, will be discussed with the supply side stakeholders. The final analysis and report will incorporate feedback and responses from the triangulations and discussions.

### **3.1 Sampling plan**

CBM has interventions in the Betul District through their partner, Naman Seva Samiti. The study has used their services in primary data collection, which has consequently resulted into building of capacities in the partner CSOs. Their team also facilitated the collection of secondary data from different departments, namely department of Social Justice, District Disability resource centres, Department of health, Department of Education etc. The study team of the partners also met different key stakeholders like elected representatives of Panchayats, Anganwadi workers, ANMs and other important district and block officials. They facilitated data collection and in-turn built a comprehensive understanding of the governance framework in disability.

The study proposed primary data collection from Betul while extensive state and district level literature like plan documents, budget etc. were reviewed to capture the different dimensions pertinent to disability.

Betul is among the poorest districts of Madhya Pradesh with a domination of tribal population. The district Betul is located at the southern border of Madhya Pradesh. According to the 2001 census, the total population of the district is 1394421 persons with 709525 males and 684896 females<sup>1</sup>. The total scheduled caste (SC) population of the district is 127438 and scheduled tribe (ST) population of the district is 443132 (1991 census). The literacy rate of the district is 57.4% (male) and 33.9% (female). The scheduled caste and scheduled tribe literacy rate of the district is 53.3% and 17.2% respectively. Betul is situated midway between Nagpur and Bhopal. It is covered under Schedule IV district for its predominant tribal characteristics. Of the 10,000 km area of the Betul, 4000 Km is forested.

Betul is representative of the situation in the state with its 1.07% population living with disability compared to state average of 1.06%. It has very high numbers of Persons with disability with complete blindness (2600) and severe orthopaedic disability (1000) as per a survey of Social Justice Department.

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<sup>1</sup> According to district census handbook, 1981, P-XIII-B (series-II), Directorate of Census operations Madhya Pradesh.

There are differences in the data provided by Census, NSSO and the Sparsh Abhiyan on the number of Persons with disability in the district. The difference originates due to the understanding of the enumerators and complexities in disability enumeration, whereby only the cases with high degree of disability (more than 40% disability) are supposed to be enumerated as Persons with disability.

Within the recognised cases of disability, their distribution in different age groups and type of disability is given below.

**Table -3 Distribution of Persons with disability in different age group in Betul**

<b>Age group/District</b>	<b>0-6 yrs</b>	<b>6-14 yrs</b>	<b>14-18 yrs</b>	<b>18-40 yrs</b>	<b>40- 60 yrs</b>	<b>60-80 yrs</b>	<b>More than 80 yrs</b>
Betul	297	2208	1685	8768	6561	3964	371

Source : Sparsh Abhiyan website, Department of Social Justice, M.P

It is evident that highest incidence of disability is reported in the adult population of the district i.e. in the age group of 18 to 40 years followed by the age group of 40 to 60 years. This may be interpreted as that a large number of working or potentially working population of the district is Persons with disability. Also the high incidence of disability reported in this age group may also be due to substantial population falling in this age group and easy enumeration possibility in the age group. The age group of 0 to 6 years is reported to have least incidence of disability. Enumeration of disability is quite challenging in this age group as disability is not easily recognisable. Also this is a 'data in progress' cited from the departmental website, which is still updating its records.

As far as type of disability is concerned loco-motor disability has the highest occurrence followed by mental illness and related disability. The occurrence of mental illness and related disorders is as high as 6729 cases. Visual disability is also highly prevalent in the district with 4555 Persons with disability recorded as visually impaired or blind.

**Table -4 Distribution of Persons with disability with respect to the type of disability**

<b>Type of disability</b>	<b>Visual or partial visual disability</b>	<b>Hearing impairment</b>	<b>Mental illness and related disability</b>	<b>Locomotor disability</b>	<b>Leprosy cured</b>	<b>Heart Valve problem</b>
Total numbers	4555	2603	6720	11759	75	70

Source : Sparsh Abhiyan website, Department of Social Justice, M.P

**Table -5 Villages selected for data collection from the two blocks of Betul District**

Name of Village	Name of Block	No. of Houses (approx)	Households with Disability
Timurni	Athner	260	24
Barkhed	Athner	98	9
Padurna	Athner	101	31
Rajola	Athner	82	14
Dehgud	Athner	147	22
Chargoan	Ghoradongri	116	18
Khakra koylari	Ghoradongri	111	14
Bansghodi	Ghoradongri	78	12
Sadakwada	Ghoradongri	105	11
Dhadgaon	Ghoradongri	99	16

Source : Sparsh Abhiyan website, Department of Social Justice, M.P

## 3.2 Survey tools

The following tools have been developed to generate data from both the supply and demand side stakeholders:

### 3.2.1 Household tracking sheet/inventory (Annexure-1)

A Household Tracking Sheet is used for collection of primary data at the level of the users. Ten randomly selected villages from the mentioned block villages were exhaustively surveyed to identify any disability. The Tracking Sheet also recorded any State services availed by the Persons with disability.

### 3.2.2 Interview schedule for the Persons with disability (Annexure-2)

The next tool used is an interview schedule with a few semi-structured questions, which recorded the status of access, service delivery and various other rehabilitation and prevention issues.

Three different types of interview schedules were administered to Persons with disability depending on their age, as different age groups required different and age specific services for intervention and rehabilitation. For instance a child in 0 to 6 years of age needs prevention and early detection while a 25-year-old adult would be interested in employment related issues. Similarly inclusive education would be pertinent for a 15-year-old child and pension schemes for the elderly Persons with

disability. Therefore three different interview schedules were prepared to cater to children below six years of age, children in school going age and adults above 18 years (employable) age.

### **3.2.3 Ranking of services in order of their desirability by Persons with disability**

Various state services such as transport, ration card, medical faculties were ranked as per their desirability or requirement for a PERSONS WITH DISABILITY. This is followed by a separate exercise to rank various State services - whether availed or otherwise - in order of preference by the Persons with disability.

### **3.2.4 Time and Cost Tracking for different services for Persons with disability (annexure 3)**

Respondents identified during filling of interview schedules were further interviewed specifically to ascertain the time and cost incurred in using the targeted services for Persons with disability, such as getting a disability certificate or assistive aids etc.

### **3.2.5 Semi Structured Interviews with all levels of the service providers (annexure 4)**

Semi-structured interviews are conducted with a range of grassroots functionaries and officials at the supervisory, managerial and decision making level. This will cover the vertical line of functionaries for several issues that are pertinent to the study.

### **3.2.6 Semi- structured interviews with elected representatives (annexure 5)**

Another set of semi-structured interview was conducted with elected representatives to ascertain their perspective as well as role on disability management. List of officials interviewed for the study is annexed in **Annexure- 6**

## **3.3 Challenges and limitations of the study**

Disability is a very complex social, economic, and medical phenomenon. It deals with different age groups, types of disabilities, reasons for disabilities, various ways of prevention, and several ways of rehabilitation. For instance, an eight-year-old blind child requires absolutely different rehabilitative measures as compared to a forty-year-old adult. In fact his rehabilitation, medical, social and infrastructure needs will be different from another child of the same age but who has a locomotors disability, or even low vision. The possibility of a combination of different types of disability with different types of age group multiplies the problem manifold. The complexity is further multiplied by different requirements at different stages of disability – from prevention, treatment, education, employment to other means of rehabilitation. This requires intensive coordination of different departments and different processes. Therefore, there is no simplified governance framework particularly at the ground level, which can be used to improve the response and entitlements of Persons with disability.

It is not sufficient to look at the expenditures of social justice department- the parent department dealing with disability, to see the trends of resource allocation, flow and process bottlenecks for addressing disability in district budgeting and spending. The budgets of health, education, and

several other departments are equally relevant. However, these departments neither get specified budgets on disability nor maintain record of activities and expenditure in the mentioned budget line. Many departments and programs such as Sarva Siksha Abhiyan, special employment exchanges for Persons with disability, vocational training centres for Persons with disability have been addressing the issues of disability but under a complex matrix of department and ministries (ranging from ministry of Human Resource Development to Ministry of Labour).

Poor and complex enumeration has contributed to the undermining of the problem, taking it away from the serious debate in planning and governance. Thus, disability is missed as a critical concern for planners, and not adequately addressed in planning and budgeting. Therefore, it is difficult to track down the budgeting and expenditure of the same. This study has faced challenges in probing an appropriate and adequate governance framework to understand the inclusion of Persons with disability in the existing developmental planning.

### 3.4 Organisation of the report

The findings of the study are organised in four sections. The first section undertakes a broader overview of various policies, acts, and legislations that may have an influence on addressing disability. It has not only reviewed Acts and policies specifically formulated to address disability, but also those provisions that can have strong influence on disability as an issue. Provisions of the 11<sup>th</sup> five year plan, provisions of Right to Education (RTE) or decentralised planning are some such provisions.

The second section of the report examines the district-level departmental framework for addressing different issues pertaining to disability. It deals specifically with health, education and employment of Persons with disability as critical components for prevention and rehabilitation of Persons with disability.

The third section summaries the challenges in governance of programs in addressing disability and related issues. The fourth section presents ways forward on the basis of the findings of the study.

## 4. Positive spaces - Review of the national bills, Acts and other relevant legislations on Disability

Persons with disabilities are often excluded from the mainstream activities of the society. The discrimination takes various forms: exclusion in education or employment and social discrimination (which can be more subtle such as isolation and segregation).

Table-6 Saparsh Abhiyan 2011 Madhya Pradesh	
Persons with disability identified under the Abhiyan	8,18,367
Camps held for disbursement of benefit	1025
Distribution of disability certificate ( in Lakh)	3.94

Distribution of assistive aids and tools	45,165
Multiple disability pension @ Rs.500 per month distributed to total number of beneficiaries	Rs. 24,382
Employment provided to by various departments	12.124
Employment provided by private sector to Persons with disability	2864
Barrier-free buildings constructed	91,219
NHFDC loans to Persons with disability	6774

Source : Saparsh Abhiyan 2011 Madhya Pradesh

of the Persons with disability, where largely the interventions as well as societal attitude are more of charity. In addition, they provide backbone for a legal environment to check discriminatory behaviour socially. Further, policies, international charters, and declaration provide reference points and frameworks for appropriate legislations. They put pressure on the State to enact appropriate legislation in accordance to its policy statement and international commitments.

#### **4.1 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 defined disability as one or more of the following: blindness, low vision, leprosy cured, hearing impairment, loco motor disability, mental retardation and mental illness. It says that to be considered Persons with disability, a person must suffer from not less than 40 per cent of any disability, as certified by a medical authority.

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act of 1995 has been on the statute book for nearly 15 years. This Act has been the basis of a largely empowering jurisprudence on the Rights of Persons with Disabilities. The Act has some binding entitlements and more general commitments. The binding commitments are mandatory or binding for the government irrespective of the economic status of the government, however, the general commitments are related to prevention and early interventions.

It details out the employment needs of Persons with disability. It talks of special employment exchanges for Persons with disability and proposes reservation up to 3% in jobs. The Act stipulates that the vacancies should be carried forward if a suitable persons with disability is not found for the job. Whilst the need to retain the empowering jurisprudence is unequivocally acknowledged, it is also recognized that the present Act, does not incorporate a number of rights deemed necessary for Persons with disability.

#### **4.2 Key entitlements and commitments under the Persons with disability Act, 1995**

The PERSONS WITH DISABILITY Act has both binding entitlements and more general commitments. The following commitments are binding on Government (i.e. not subject to economic factors):

## Education

- Governments shall ensure that every Persons with disability has access to free education “in an appropriate environment” until the age of eighteen.
- Governments “shall initiate or cause to be initiated” research by public and non-governmental agencies for development of both assistive devices and special learning materials for Persons with disability in order to promote equal opportunity in education.
- Government shall ensure teachers training that produce “the requisite manpower” for teaching of Persons with disability both in special schools and integrated settings.
- All public educational institutions and other receiving aid from Government shall reserve not less than 3 percent of seats for Persons with disability (i.e. for Persons with disability over 18 years).

Government should prepare a “comprehensive education scheme” for Persons with disability which includes transport or financial incentives, barrier free access, supply of books, uniforms and learning materials to Persons with disability, adjusts the examination system as necessary and adapts curriculum for Persons with disability.

## Employment

- The Government shall identify posts for Persons with disability in public establishments and update the list every three years and reserve not less than 3 percent of identified posts for PERSONS WITH DISABILITY, with 1 percentage point reserved for people with blindness/low vision, hearing impairment, loco motor 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 disability with a target of at least 5 percent of their workforce to be Persons with disability.
- Section 41 of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 provides incentives to employers to ensure that at least five percent of their work force is composed of persons with disabilities.
- Governments and local authorities shall formulate schemes for promotion of employment of Persons with disability which may provide for training of persons with disability relaxation of age limits in employment, measures related to OHS, provisions for financing such schemes and reservation of not less than 3 percent in all poverty alleviation schemes

The National Policy for Persons with Disabilities, which was adopted in 2006 also lays down that pro-active measures will be taken to provide incentives, awards, tax exemptions etc. to encourage employment of persons with disabilities in private sector. Accordingly, Finance Minister in his Budget Speech had announced a Scheme for employment of physically challenged in the organised sector. The act says that: Commitments “Within the limits of their economic capacity and development” of the states include:

- 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 Persons with disability:**

Provision of aids and appliances to PERSONS WITH DISABILITY, preferential allotment of land for housing, business, and recreation centres, special schools, research centres, and factories run by persons with disability entrepreneurs.

Non-discrimination in access: All commitments in this area are given with the provisional clause, “within the limits of their economic capacity and development.” Governments should: Adapt all forms of transport to make them accessible to Persons with disability and provide for a variety of assistive devices in the build environment, including auditory signals, ramps in public buildings and health facilities, Braille signage etc.

## **4.3 National policy for the Persons with disability**

National policy for Persons with disability was brought forth by ministry of Social justice and Empowerment in 2006 and has a comprehensive view on Persons with disability. It has several positive features for Persons with disability. Ministry of Social Justice is the nodal agency for coordination of the policy. It draws upon different departments and ministries to meet its vision on disability.

The policy specifically talks about 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 the disabilities, controllable by immunisation or improved nutrition. The policy provides for physical, economic, and educational rehabilitation and specifies specific measures to do the same. It clearly talks about inclusive education and educational rights of Persons with disability children. Ministry of Human Resource Development is the nodal ministry to ensure this. The policy is explicit on the development- suitable human resource to address the issues of Persons with disability

Employment being critical to dignified living, the policy reinforces the reservation in employment. It also provides for the encouragement of development of suitable skills in the Persons with disability for employment in the private sector. Rehabilitation and vocational training centres are supposed to play an expanded role in doing the same.

The policy lays special emphasis on women and children with disabilities. The policy talks about a barrier-free environment for ensuring access of the Persons with disability to the services. There is special mention of the social security measures to the persons with disability and states that the state government will be encouraged to bring out a comprehensive social security policy for the Persons with disability.<sup>2</sup>

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<sup>2</sup> National policy for the Persons with disability : Ministry of Social Justice and Empowerment, Website : [socialjustice.nic.in/nppde.php?pageid=2](http://socialjustice.nic.in/nppde.php?pageid=2)

## 4.4 Persons with disability act 2011-working draft

The Ministry of Social Justice and Empowerment- by notification F. No. 16-38/2006-DD.III dated 30th April 2010, constituted a Committee 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 ("PERSONS WITH DISABILITY Act").<sup>3</sup>

The proposed legislation guarantees equality and non-discrimination to all persons with disabilities and recognizes legal capacity of all persons with disabilities along with making provisions for support where it is required to exercise such legal capacity.

The proposed bill recognizes the multiple and aggravated discrimination faced by women with disabilities and creates a gendered understanding in both the rights and the programmatic interventions. It emphasizes the special vulnerabilities of children with disabilities and ensures that they are treated on an equal basis with other children.

It mandates the establishment of a National and State Disability Rights Authorities which facilitates 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. The government is supposed to take all necessary measures to facilitate and support employment of persons with disabilities, with special reference to self-employment and vocational training of persons with disabilities.

## 4.5 Rehabilitation Council of India Act -1992

The Act came into force for establishing rehabilitation councils in India to train and regulate rehabilitation professionals.<sup>4</sup>

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 (CBR) to enrol rehabilitation professionals who possess recognised rehabilitation qualifications. It seeks to ensure that Persons with disability are treated by qualified personnel. The council also acts as an accreditation and quality control facility. The Act provides an elaborate account on 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 institutions for rehabilitation professionals. A comprehensive list of recognised rehabilitation qualifications along with the names of courses and universities and institutions offering them has been provided in the Act. The Act also ascertains recognised qualifications of the rehabilitation professionals, and terms for holding post in Government or in any institution for practicing as rehabilitation professional. The key functions of

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<sup>3</sup> PERSONS WITH DISABILITY Act, 1995 The Persons with disabilities, ( Equal opportunities, Protection of Rights and full participation) Act, 1995, Ministry of Law, Justice and Company Affairs

<sup>4</sup> [www.rfhha.org/images/.../Rehabilitation\\_council\\_of\\_India\\_Act\\_1992.pdf](http://www.rfhha.org/images/.../Rehabilitation_council_of_India_Act_1992.pdf).

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.

The Act has envisaged important amendments including extension of the scope of work of RCI by adding components of monitoring the training of rehabilitation professionals and research in rehabilitation and special education

The Act provides recognition to the university and other institutions for training rehabilitation professionals and registers them. It aims to regulate the rehabilitation manpower.

#### **4.6 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 to the persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities.<sup>5</sup> 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.

#### **4.7 The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)**

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has undertaken the obligation to ensure and promote the full realization of all human rights and fundamental freedoms for all Persons with Disabilities without discrimination of any kind on the basis of disability. In fulfilment of this international commitment, India is obligated to enact suitable legislation in furtherance of the rights recognized in the UN Convention.

#### **4.8 National Education Policy and Right to Education Act**

An important legislation at the national level is policy on education and RTE. The policy has progressed significantly since the persons with disability Act. In particular, policy towards inclusion of persons with disability into mainstream education has become increasingly clear in policy statement of the MHRD. National education policy states a robust and concrete commitment to realizing the right to education of persons with disability.<sup>6</sup>

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<sup>5</sup> Ministry of Law, Justice and Company Affairs, Legislative Department, New Delhi, Website : <http://thenationaltrust.gov.in/images/stories/list/ntact%201999.pdf>

<sup>6</sup> Ministry of Human Resource Development, Government of India, <http://pib.nic.in/newsite/PrintRelease.aspx?relid=109929> New Delhi,

The Right of children to Free and Compulsory Education Act came into force on April 1, 2010 and mandated that the right to education 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 in 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.

The National Commission for Protection of Child Rights (NCPCR) has been mandated to monitor the implementation of this historic right. A special Division within NCPCR will undertake this huge and important task in the coming months and years.

RTE 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. And rights in Chapter 4 are not enforceable. For the first time in the history of India we have made this right enforceable by putting it in Chapter 3 of the Constitution as Article 21. This entitles children to have the right to education enforced as a fundamental right.

### **Inclusive education for the children with special needs (CWSN)**

The Scheme of Inclusive Education for Children with Special Needs (CWNS) at Secondary Stage has been launched from the year 2009-10. This Scheme replaces the earlier scheme of Integrated Education for CWNS and would provide assistance for the inclusive education of the CWNS from class IX-XII, and enables all students with disabilities, to pursue further four years of secondary schooling after completing eight years of elementary 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) <sup>7</sup>

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 Persons with disability 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 Persons with disability child per annum.

### **11th Five Year Plan and positive provisions for disability**

The 11<sup>th</sup> five year plan confirmed that the % of Persons with disability in NSSO and Census of 1.8-2.1% is very low and understated, even at a conservative level. It negated census and NSSO figures on disability and accepted far more prevalence of disability than that enumerated in census. Further

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<http://pib.nic.in/newsite/PrintRelease.aspx?relid=109929> Madhya Pradesh Rajya Shiksha Kendra, Bhopal

<sup>7</sup> Ministry of Human Resource Development, New Delhi, Madhya Pradesh Rajya Shiksha Kendra, Bhopal

it strengthened the shift from a “Welfare Approach” to a “Rights based approach” as a consequence of several Acts such as persons with disability Act and others enacted during the 9<sup>th</sup> and 10<sup>th</sup> Plan.

Therefore in the 11<sup>th</sup> Plan, the approach is more pragmatic and serious efforts are being made to empower the Persons with disability, focusing special attention on monitoring mechanisms.

#### **Four pronged approach in 11<sup>th</sup> year plan –**

- 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
- Set-up monitoring mechanisms at various levels and develop review systems

The 11<sup>th</sup> Plan recommended that 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 Persons with disability, 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 the grey areas such as disability certification and inclusive education.

### **4.11 District planning and decentralisation of planning process**

Zilla Yojna Samiti Adhinyam 1995 envisages a District Planning Committee (DPC) headed by Minister in Charge of district as chairman and elected members. District Planning Committee plays a key role in decentralised planning. It is supposed to provide leadership in collective vision building of the district wherein local priorities and expectations are a determining factor. It accommodates development priorities of the district.

Plans are prepared at village level with participation of the community and therefore they include local needs and local expectations. These plans are integrated to make a district plan. The decentralised planning process started in year 2001-02 with State Planning Commission as the nodal agency for the same. Gram Sabha is the smallest unit for planning in rural areas, while in urban areas it can be Mohalla Samiti or ward Sabha. It is after the initiation of district planning, the state budget was broken down to district budget. The district plan prepared at each district forms the basis of budgetary outlays for the district and delivery of the program.

The district planning process was unique and unprecedented for accommodating local priorities and participation of community. It has potentials to integrate the aspirations and priorities of Persons with disability 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.

**Table -7 Summaries of positive spaces and bottlenecks in different legal instruments**

<b>Policy and Legislations</b>	<b>Positive Spaces</b>	<b>Bottlenecks</b>
11 <sup>th</sup> Five Year Plan	<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> <li>• Approach and focus shifted from 'Welfare 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>• Makes district planning mandatory to access the funds of 11<sup>th</sup> five year plan</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> <li>• District planning is sketchy and weak</li> <li>• Disability doesn't figure in village planning format.</li> <li>• Slow progress on rights-based approach</li> </ul>
National Policy on Disability	<ul style="list-style-type: none"> <li>• Amends building by-laws to promote barrier free access</li> <li>• Incentive to promote jobs in Private sector</li> <li>• Identifies and encourages prevention and early intervention with the help of village level service providers from other departments</li> <li>• Clearly articulates physical, economic and educational rehabilitation</li> </ul>	<ul style="list-style-type: none"> <li>• Poor integration and implementation at the ground level</li> <li>• Grass root functionaries are poorly trained on disability</li> <li>• Panchayats have been neglected for providing downward linkage</li> </ul>
PERSONS WITH DISABILITY Act 1995	<ul style="list-style-type: none"> <li>• Right based approach</li> <li>• Schemes and reservation in employment</li> <li>• Affirmative action such as provision of assistive aid &amp; technologies, preferential allotments in land housing ,loans etc</li> <li>• Advocates non-discriminatory access, equal opportunities and equal participation of Persons with disability</li> <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 plan</li> </ul>	<ul style="list-style-type: none"> <li>• 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.</li> <li>• Poor budgetary allocation to justify the agenda of the act.</li> <li>• Relies on census data for identifying the - the data is inadequate</li> <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> </ul>

National Education policy and Right to education act- RTE	<ul style="list-style-type: none"> <li>• Strongly promotes inclusive education</li> </ul>	<ul style="list-style-type: none"> <li>• Insensitive implementation of RTE in relation to disability provisions</li> </ul>
District planning and decentralised planning	<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>	<ul style="list-style-type: none"> <li>• Poor aggregation</li> <li>• Department budgets may have mismatch with village plan</li> <li>• No specific focus on disability</li> <li>• No way to figure out disability centric allocations</li> <li>• Process of district planning and village planning still very sketchy</li> </ul>

## 5. Addressing Disability – crosscutting framework of departments and village level institutions

Disability is complex problem and involves various sectors, departments and agencies, even different ministries. Prevention and early detection of disability have a strong role of Health and Women & Child Development Department. Education of Persons with disability children involves interplay of Department of Education and Department of Social Justice. Rehabilitative measures for Persons with disability are also vast and include physical rehabilitation, skill building, employment, marriage and other societal roles. This large array of rehabilitative measures also has a complex interplay of the departments. Physical rehabilitation involves specialized services of various therapists, while skill building is undertaken by department of Social Justice through several NGOs. Similarly, the Ministry of Labour is setting up vocation rehabilitation centers for building vocational skills. Employment, as one of the most critical rehabilitative measure for Persons with disability also involves a large number of departments and institutions. Special employment exchanges have been set up by Ministry of Labour to register Persons with disability for the purpose of providing employment. There is a reservation of 3% in central government jobs and 6% in the state. There is also a provision of subsidies to employers in the private sector for employing Persons with disability. Last, but not the least, are specific departmental schemes such as disability pension and activities like distribution of assistive aids to by the department of Social Justice. They are normally referred to as ADIP schemes.

There is a complex interplay of different departments and institutions that constitute the framework for governance on issues related to Persons with disability. While for prevention and early detection, village-level institutions can play the best role, rehabilitation mechanism requires convergence of services of several departments depending on the issue and agenda.

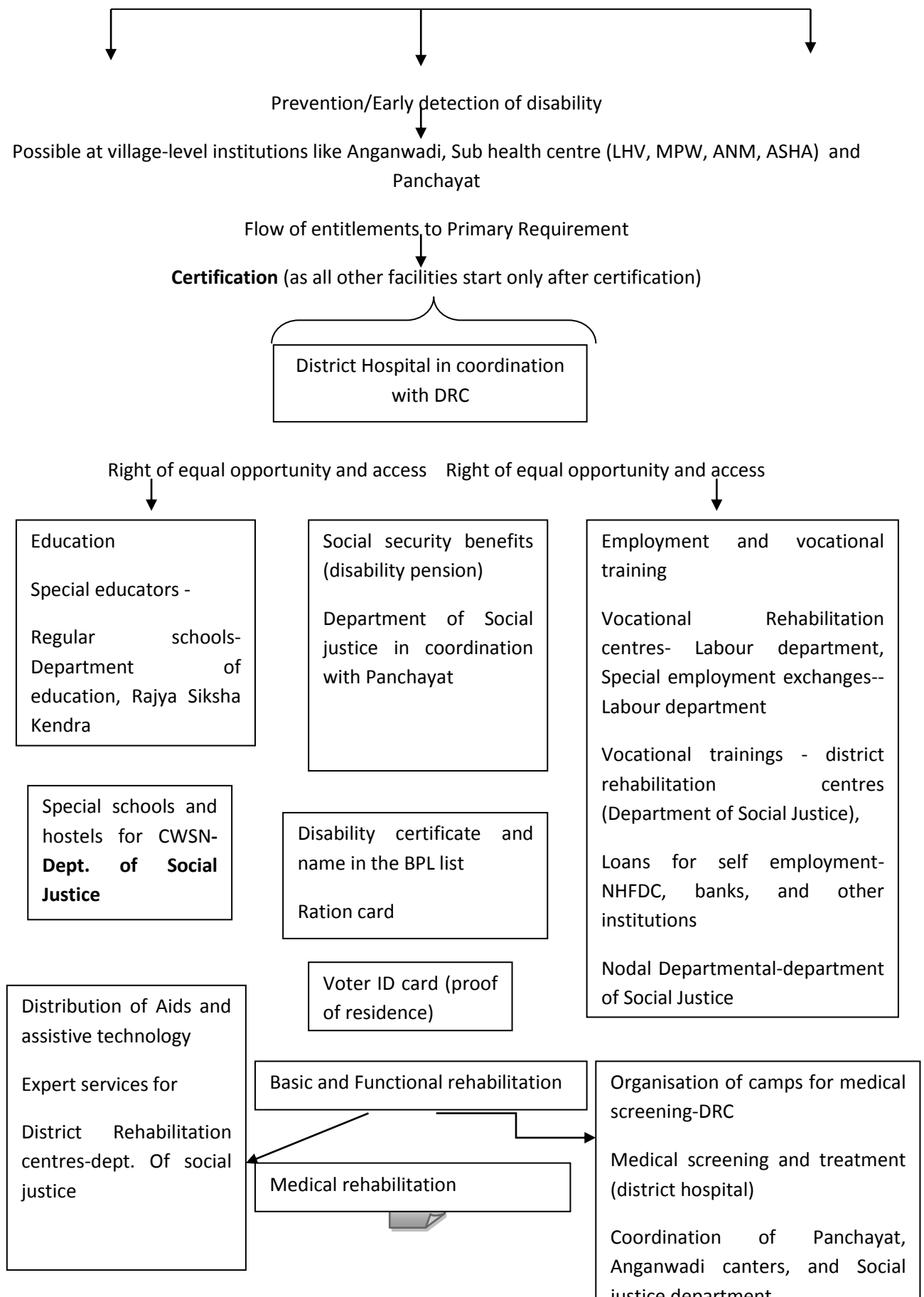
### Critical nested rights for Persons with disability

The set of rights/entitlements and services provided by the government, too have a nested relationship. Critical rights that influence all kind of entitlement and rights to Persons with disability identified with Panchayat and departments were listing of names in the BPL register, voter ID cards, ration cards and having a disability certificate. The disability certificate was identified as the most



critical for accessing any service and entitlements to Persons with disability. Voter ID and ration cards serve as proof of address and identity even for getting a disability certificate, while disability certificate is necessary to access various entitlements particularly the disability pensions. However, complex interplay of institutions without a clear line of control and specific allocations for the Persons with disability blurs the issue and thereby the rights and entitlements of Persons with disability.

## Relationship of PERSONS WITH DISABILITY oriented services with different departments and institutions at district level



## 5.1 Department of Social Justice- Pioneering on disability interventions

Madhya Pradesh has been a pioneer state to take up disability in an upfront manner. It has conducted door-to-door surveys at different stages to recognise and build a database of the Persons with disability in the state. Utthan Abhiyan, Indira Sahara Abhiyan, Sparsh Abhiyan are some of the campaigns undertaken by the department for this purpose. The campaigns undertook door-to-door survey for identification of the Persons with disability with the help of NGO's and other district level agencies. Further the collected data was computerised and is available on the department's website. The data collected in these campaigns were used for strengthening schools, hostels for Persons with disability children and facilitate the access of the various government schemes to identified . Block and district level camps were further organised for the assessment of disability with the support of specialists and speed the process of certification of the Persons with disability. These camps were also used for distribution of benefits, linking of schemes and organising easy access to various government schemes.

The department of Social Justice, Madhya Pradesh is the nodal agency for intervening towards disability. It carries out different campaigns to cater to the needs of Persons with disability. It is currently carrying out the Sparsh Abhiyan, whereby it is trying to identify the Persons with disability and facilitate the delivery of benefits as well as establish linkages with the other departments. The Abhiyan takes the help of Panchayat secretary and other service providers to inform the villagers, of the timing and date of the camps that department organises from time to time. The scheduled camps are attended by a host of functionaries from different departments, such as education, health etc. The disability certificates are also distributed in the camps. The camps mandate that school dropouts will get re- enrolled, or those requiring surgeries will be listed and operated later. The assistive tools, technological aids, railway passes too are distributed in the camps. The departments that have other specific scheme for Persons with disability such as disbursement of loan by Khadi and village industries department or district industrial department, or disbursements of scholarships to the school going children is also undertaken in camp. It is supposed to be department's way of coordination and integrating with other departments. However such camps have several shortfalls. The foremost problem is of the poor delivery of benefits itself. The table below shows that from 24054 Persons with disability who were registered in Betul, only 2347 have been provided disability certificate and only 766 have been provided any other schematic benefit as social security pensions.

Poor certification, not having the name in the BPL list, lack of or errors in other documentary evidences required for disability pensions, cost involved in repeated visit of department , unattractive amount in pensions, difficulty in reaching banks to get pensions are some of the reasons for extremely poor performance of disability pensions in Betul district.

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**Table 8 - Registered beneficiaries and disbursement of benefits**

Disability certification in Betul	2347/24000 (approx. 14%)
Disability pensions	19 beneficiaries in state's Social security pensions and 738 in Indira Gandhi national disability pensions (less than 5% )

Source : Department Social Justice, M.P

### Office of the deputy registrar –Department of Social Justice

There are several critical units at the district level that influence the practices and outcomes at the district level. First and the foremost is the office of the deputy registrar, Department of Social Justice. It provides overall coordination and supervision to the disability interventions at the district level. It facilitates building of the projects for appointment of DDRC and coordination with DDRC for improved functioning. It also coordinates with other NGOs at district level that are appointed for training of the Persons with disability for employment generation, running the hostels /centres for and CWSN etc.

### District Disability rehabilitation centre (DDRC)

The DDRCs are commissioned by the state department coordinated by Deputy Director of the department located at the district. The bidding organisation puts forward a proposal for the work plan which is sanctioned by the state's department of Social Justice. It is supposed to undertake activities. The fund is released as per the activities proposed.

DDRCs in the district, on the other hand, provide specialised services to Persons with disability. It has positions for physiotherapists, occupational therapists, vocational teachers, rehabilitation workers, social workers, speech therapists, medical doctors, mobile instructors etc. In fact, a DDRC can provide an array of services depending on the project commissioned to it. DDRCs are run differently in different district. For instance many DDRC are commissioned to Indian Red Cross society, while many other are run by different NGOs. Some of the DDRCs are directly run by the office of Deputy Director in coordination with the District Collector. The DDRCs are funded by the 'Nirashrit Nidhi' collected as tax from Mandis and markets of the districts.

### Certification for disability-Barriers of cost and inefficiency

Disability certification is complex, and needs the support of skilled medical professionals-usually a certified medical board. In absence of such skilled staff to be dedicated for boards, doctors of district hospitals are given the right of medical board and power to certify disability. The certification usually takes place in camps organised by the district unit of the Social Justice Department, with the support of DDRC. Panchayats and other village-level institutions play a critical role in mobilising the Persons with disability for the camp. The camp usually starts in the morning hours, while most of the Persons with disability arrive late. Several documents are required for complete certification besides the medical examination. There is no prior screening or submission of the documents, resulting into errors or incomplete documentation at the camp.

The medical board is usually not able to attend to 50% of the Persons with disability that come in for certification in a particular camp. Their timing gets over even before most of the target population arrives.

Consequently, a PERSONS WITH DISABILITY with a family member makes minimum of three trips for certification. Most make even more than three trips. The preparation of required documents also makes for an expenditure of approximately two hundred rupees. Each trip also costs approximately 3 to 4 hundred rupees, as transport of Persons with disability is costlier. Bribing is also common in these camps. About Rs. 500 is paid on an average as bribe for certification to different functionaries. Therefore a certificate usually costs minimum three thousand rupees. Many poor families either do not have required documents or have errors in the documents. Also they do not have that kind of money to invest in logistics, and therefore do not bother about disability certification. Even after the documents are submitted, one is not sure whether and when will one get the certificate. Many respondents in the survey had applied for the certificates but haven't received them even after a year. Sometimes even Panchayat representatives are reported to have asked for bribe to hand over the certificate. The benefit of certification is only perceived in the disability pensions. If the person is entitled for only 200 rupees, then it is not feasible as making a trip to bank itself costs them about hundred rupees. Most bank functionaries also ask for 20 to 30 rupees for filling up of the form. Therefore, the poorest and neediest of the Persons with disability may not have the disability certificate. Disability certification being the most critical of the 'nested right', all the subsequent entitlements of the Persons with disability are then jeopardised.

#### **Human resource constraints in DDRC**

The functioning of DDRCs is much below expectations. Several factors contribute to the poor functioning. Most DDRCs are cash strapped and have a dearth of trained staff. For instance the DDRC at Betul has only one skilled staff while the other eight positions are lying vacant. Similarly the DDRC in Sehore district has appointed only 4 staff mostly in administrative positions. First and foremost reason for shortage of the skilled manpower in DDRCs is the non availability of such skilled staff at the district level, particularly as per the criterion laid out by the Department.

The last instalment for the DDRC in Sehore was Rs. 9 lakh released about five years back. Similarly Betul DDRC has been receiving an approximate budget of 3.5 lakhs annually for past several years. The Betul DDRC has two technical staff against the 9 sanctioned positions. Budgets continuously lapse due to poor staffing and activities.

**Source : DDRC, Sehore and DDRC Betul**

Adding to the problem is remuneration stipulated to the skilled staff at the DDRCs. The stipulated salaries are too low to attract the required staff, particularly at districts.

A list of potentially authorised positions with the required qualifications and mandated honorarium is given in the table below.

**Table-9 : List of potentially authorised positions with the required qualifications and mandated honorarium.**

Sl. No.	Posts	Proposed honorarium (in Rs.)	Potential Market rate	Qualification
	Technical Staff			
2	Medical Doctor (Paediatrician/ Psychiatrist/ ENT Specialist/ Neurologist/ Orthopaedic Surgeon/etc.)	8200	40.000 or more	MD or PG Diploma in area of Specialization
3	Nurse	3800	6 to 8 thousand	Degree or Diploma in nursing
4	Senior Occupational Therapist	8200	8 to 10 thousand	Post Graduate in related field with 5 Years experience
7	Senior Physiotherapist	8200	Approximately 15 thousand	Post Graduate in related field with 5 years experience
12	Senior Speech Therapist	8200	Approximately 15 thousand	Post Graduate in related field with 2 years experience
15	Audiometrician	5800	Approximately 12 thousand	DHLS with 2 years experience
18	Clinical Psychologist	8200	Approximately 15 to 25 thousand	M. Phil in Clinical Psychology or Ph.D. in Clinical Psychology
20	Braille Instructor	5800	Approximately 12 thousand	Graduate from Recognized University and sound knowledge of Braille

## Inadequacy of DDRC to support an entire district

A district with approximately 20 to 25 thousand Persons with disability spread across five to ten thousand square kilometre area is supposed to be serviced with one DDRC. Though there is provision for mobile service for DDRC, the remoteness of the villages, diversity in the requirement of services makes it virtually impossible for any centralised unit to service and rehabilitate the vast number of in a district. In absence of potential work plan and agenda, most DDRC are acting as assistants to Deputy Directors, taking day to day orders from them. They help the department in carrying out the surveys and organising the service and certification camps for the District

District	Staff in DDRC
Betul	Only 2*
*usually works on the instruction of Deputy director and mostly facilitates the functioning of disability camps	

The performance is further affected by the limited and sketchy staff that most DDRCs are operating on. One or two technical staff at a DDRC is completely lost as it is used as an additional hand to district offices of the department.

## 5.2 Critical missing linkage of health services with prevention of disability

Of the one thousand households surveyed for disability in the district of Betul under the study, a large number of households reported disability and significant numbers reported catching disability after birth or contracting disability at birth from apparently preventable factors such as delayed crying of the child at the time of birth, or very low birth weight, incomplete immunisation, anaemic mothers, or mothers consuming alcohol during pregnancy.

Nearly 40 % households surveyed for disability reported the PERSONS WITH DISABILITY having acquired disability after birth, either due to progressive congenital disorders, illness or accident. There have been many instances of progressing low vision leading to near blindness or persistent ear infections leading to hearing impairment. However, locomotor disability is most common kind of disability acquired after birth. Accidents, injuries, and paralysis were common reasons cited. Though substantial number of reasons remained undiagnosed, a couple of cases are discussed below.

**Sandip Patil**, An 11-year-old boy from Betul suffers from Cerebral Palsy. His mother, an illiterate agriculture labour, had delivered the boy at home with the help of a local birth attendant. Delivery at a hospital was unaffordable and government health infrastructure was perceived even worse. The new-born baby had not cried even several minutes after the birth. She is still clueless that such a seemingly common and harmless incident may also result in cerebral palsy or that damage could have been prevented.

**Gunia** from the same district had repeated occurrence of ear infection which involved constant discharge from ear accompanied with pain. She obviously couldn't afford to a visit to private doctor. Slowly she stopped



Table 10 –Status of household with disability and disability certificates			
Total households surveyed	Households with disability	HH with Disability Certificate	% of with the disability certificates ( approximate)
1092	166	61	18%

Source : Sparsh Abhiyan, website: Ministry of Social Justice, M.P

Madhya Pradesh, a predominantly tribal state presents a grim picture on various health indicators. Madhya Pradesh with a population of 7.25 crore, fairs poorly on most Infant and maternal Health indicators. Significantly these indicators have a direct relationship with the occurrence of disability. Infant Mortality Rate of M.P at 72 (SRS-20007), is much higher than the National average of 55. Similarly the Maternal Mortality Ratio (MMR) of M.P is 335 compared to the national average of 254.

Poor literacy rate in females (50.3% as per 2001 census) and a large percentage of population living in poverty (37.43 % living BPL compared to national average of 26.10) exacerbate health problems and therefore disability. Betul being predominantly tribal and among the poorest districts takes a higher hit on the issue.

Households in - primary survey- Betul	Disability from birth	Disability after birth
166	92	74
Source : Primary survey		

Despite the poor performance on most health indicators, the health infrastructure in Madhya Pradesh is still grossly inadequate-particularly at the village and Panchayat levels.

S.No	Health infrastructure/functionaries	Requirement of health infrastructure/functionaries	health infrastructure/ functionaries in position	Shortfall in infrastructure/ functionaries
1	Sub-centres	10402	8843	1568
2	CHC	417	270	147
	PHC	1670	1149	521
3	ANM at Sub-centres	9983	8718	1265
5	Obcs. & gynec. Specialist at PHC	270	53	217

(Source-RHS bulletin, March-2008,MOH-GOI)

The situation is only worsened by inadequate immunisation coverage (73% Betul, 57% M.P) and poor rate of institutional deliveries (40% Betul, 47% MP). To make matters worse, there is continued poor absorption of health budgets at ground level. Fund allocation for ASHA was poor, but its utilisation was poorer at 33%. The Project implementation plan under RCH in 2008-9 has remarkably low expenditure on institutional strengthening (22%), Training (3.85%), and IEC (55%).

Integrated District Health Action Plan or Project implementation plan, a kind of decentralised plan of the department prepared at districts for interventions at district level is not only limited by the lack of health infrastructure but also by capacity to build the same and be able to utilize the allocated funds.

The interventions at village even at their best performance are limited to pre-natal check-ups, universal immunisation, and supplementary nutrition. Village-level institutions or functionaries have neither the vision nor the skill to scan or prevent disability in any other way. They have been witnessing cases of low vision progressing to total loss of vision or a persistent ear infection leading to loss of hearing, or delayed respirations in new born leading to cerebral palsy or child unable to see properly due to refractive index errors, but intervention in these kind of cases is probably visualised as out of the scope of the work of department. The shortage of health personnel coupled with poor training reduces their routine job to mundane outputs.

The ASHA workers, Anganwadi workers, ANMs, and Panchayat representatives interviewed during the course of the study have never received any training on early detection and prevention of disability. Significantly, they universally connect nutrition and complete immunisation to prevent disability. In fact, one Anganwadi worker in Betul herself turned deaf after a prolonged ear infection. Most of these institutions have information in their respective village, as they are engaged in surveys or mobilisation for camps etc., however, they do not perceive their role in its prevention and early detection. They have never been asked to do so from their own supervisors and have not received specific trainings with respect understanding causes of disability and preventive measures.

Inadequate health infrastructure coupled with shortage of health personnel not only reflects in poor health indicators, but also has a fallout on increasing numbers of children born with disability or many more contracting disability after birth from a possibly preventable reason.

Only 9.1 % of the expecting mothers had undergone complete ante natal check-ups in the district of Betul. The institutional delivery rate was also as low as 22.5%. The complete immunisation is also grim for the district at 30%. None of the PERSONS WITH DISABILITY respondent in primary survey had received any corrective surgery from the state, though 40% felt their disability can be either prevented or minimised by a suitable medical treatment.

The situation is far more complex for poor families. The NRHM state plan states that IMR is five times more for poor families and only 12% of children in poor households are completely immunised. Only 17% of such households have deliveries assisted by trained birth attendants. These grim indicators on health have strong consequences for occurrences of disability.

**Source-NRHM Program implementation plan-2005-06 and primary**  
**SURVEY**

## Criticality of supportive infrastructure and services for Persons with disability

Amongst the surveyed respondents, health was identified as the most critical support service needed by the Persons with disability. Their health priorities range from preventive measures to subsidized treatment. After health, there was the need for effective public transport which allows Persons with disability to travel with relative ease. The next in line was vocational training for building employable skills. Education was also seen by the parents as critical to school going Children with Special Needs (CWSN). Education, they felt, had a critical role in confidence building and social rehabilitation of the child. Though Persons with disability and their families perceive role of several institutions in their well being, most village level functionaries have very fragmented view of their role in addressing disability.

Demand for supportive services by Persons with disability in decreasing order of preference- ( from primary survey of the Persons with disability)
Health
Transport
Vocational training for employment
Education
Rehabilitative services
Other demand were more need specific

ASHA	Aanganwai worker	ANM
<ul style="list-style-type: none"> <li>• can relate the disability to poor nutrition of mother during pregnancy, and incomplete immunisation of child</li> <li>• Never directly intervened to prevent disability</li> </ul>	<ul style="list-style-type: none"> <li>• can relate the disability to poor nutrition of mother during pregnancy, and incomplete immunisation of child</li> <li>• Identifies the CWSN and PWDs during the surveys and informs them of the departmental disability camp</li> <li>• Has very little technical skills to identify a potential case for early detection and prevention of disability for referral to skilled units</li> <li>• Has never received any specific training for early detection or in dealing with CWSN in Anganawadis</li> <li>• Occasionally consulted for medication and occasionally asked a family with PWD to visit a doctor, however, her advice is not taken seriously and community prefers to see a 'Bhagat' i.e a traditional healer.</li> <li>• Never received any specific budget for CWSN</li> </ul>	<ul style="list-style-type: none"> <li>• Undertakes immunisation, however doesn't scan cases for early detection, despite reasonable technical competence.</li> <li>• Has poor vision and goals towards prevention and early detection of disability besides immunisation</li> <li>• Do not educate the mothers ( families ) towards causes and preventive methods</li> <li>• Has not received training for scanning cases for early detection say progressing low vision, or progressing hearing impairment, or potential orthopedic handicaps</li> <li>• Is in a way indifferent towards prevention detection and rehabilitation and is primarily concerned with immunisation only</li> <li>• Has not received any budget at subcentres for disability</li> </ul>

## Decentralised planning in Health - missing on disability

The scope of district plan depends upon what data is used in planning and how priorities are selected. National Rural Health Mission envisages decentralised and bottom up planning in health sector. The department undertakes District Level Health Survey (DLHS) which appraises the department of health issues in the district. Based on the data collected in DLHS, integrated district health action plan is prepared at the district level. The district plans are further compiled to form the Project implementation plan at the state level. The DLHS should have data on disability from the district and the planning at the district and state level must integrate disability as an area of

intervention. Despite the positive provisions, unfortunately the state PIP is significantly 'Disability blind' and doesn't make any reference of disability.

The concept of decentralised planning is based on understanding local priorities and addressing the same through budgetary allocation to reach maximum expenditure efficiency. Obviously the district health planning in practice currently has overlooked local needs in general and disability in particular. It is practiced every year like a ritual, without much relevance and gains. Obviously, there is no question of budgetary allocations on the local priorities of the community.

### 5.3 Education - a critical rehabilitation measure

SSA provides up to Rs.3000/- per child for the inclusion of CWSN, as per specific proposal, per year. District plan for children with special needs is formulated within the limit of Rs.3000/- per child norm. The interventions under SSA for inclusive education are identification, functional and formal assessment, appropriate educational placement, and preparation of Individualized Educational Plan, provision of aids and appliances, teacher training, resource support, removal of physical barriers. There is a provision for research, monitoring, and evaluation with a special focus on girl child. 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 'zero rejection' policy so that no child is left out of the education system". In order to implement the zero rejection policy- SSA provides for a multi-option model- regular school, ESG/AIE and home based. Thus SSA provides for one of the best examples of schemes that have very comprehensive framework for addressing the needs of the CWSN.

The Department of Education-Government of Madhya Pradesh has adopted and based its work plan on the Government of India's policy on Inclusive Education particularly with respect to the CWSN. The Rajya Shiksha Kendra (RSK), Govt. of MP has made significant effort in the implementation of the Inclusive Education Programme in the state, the mandate being- inclusion of all children with disabilities into the mainstream.

The RSK has launched several very significant steps to promote inclusion of the CWSN in mainstream education.

#### Difference in disability data of different departments

The children assessed at the district level for inclusive education is nearly half of the children identified under Sparsh Abhiyan in district of Betul. The Primary survey conducted in five Panchayats of the Betul district, identified 17 children with special needs. Ten of the surveyed children were registered in schools, but seven of them were irregular. The reasons cited for irregularity was lack of interest of the child in school because of incompatible schooling, difficulties in commuting, physical challenges to child in school, no learning in school. Physical challenges in dropping the child to school was most frequent reason cited by parents in providing education to 'such a child'. Significantly only two of them had received any assistive aid from any department or camp, however, 8 of them had certificate for disability.

## **A foundation course for teachers**

A foundation course for teachers enables teachers to get orientation about all disabilities, their basic features, needs, and basic methods to address their needs. They also get inputs about the various Acts, rights, benefits and other specific issues of Persons with disability and CWSN. They are given special inputs on the prevalent methods of assessing a CWSN and approaches to teach them in a mainstream classroom. The course is taught in a distance learning mode having duration of three months.

### **Identification, assessment and distribution of Aids & Appliances to the CWSN**

Identification, assessment and distribution of Aids & Appliances to the CWSN – In association with the local administration, NGOs and other agencies is the second step towards providing education to the Persons with disability children.

It has attempted to strengthen infrastructure for improved access. The Annual Work Plans of the government has systematically made provisions to make the existing schools more accessible by building ramps. It has also made provisions to establish resource centres in the respective districts for the benefit of the children.

Despite, a policy framework there is a Poor Response of CWSN towards these measures. Lack of Awareness coupled with difficulties in access, many CWSNs are unable to attend the camp. There is generally a large gap between the children assessed through IED program and CWSN children identified in the Sparsh Abhiyan.

The professionals are limited and the available professional are reluctant for field based jobs/projects. Experts are not easily available especially for the assessment of MR, Autism, Low Vision and Learning Disabilities. Such CWSNs are often undiagnosed and not included<sup>8</sup>.

### **Mobile consultants-insufficient and inadequately trained**

Mobile consultants are special educators, who are given the responsibility of Identification of CWSNs and organising them in assessment camps with the objective of admitting the CWSN in the school. They also extend support to the teachers in the school for planning and teaching the CWSN in a mainstream classroom and coordinate with the Department, the school and the local community.

Under the educational rehabilitation the focus is given to the education of Persons with disability people based on their context. As per the norm

Retired teachers have been trained with some foundation course and appointed for CWNS in Betul district. Most of the professionals in disability felt that, these teachers are not equipped with new techniques and content curriculum. Facilities and educational material also needed to adapt to CWSN. Data on home based education to CWSN is not available in the district.

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<sup>8</sup> situation analysis on inclusive education program in Madhya Pradesh-Sumit Roy-for Sight savers)

there should be one special educator for every 8 CWSN. Data on home based education to CWSN is not available in the district.

### **Inadequate Co-ordination between NGOs and SSA department**

While enquiring about the number of aids and appliances distributed to the CWSN in Betul district, it was found that the responsibility of procuring the aids from ALIMCO and distributing among children lies with NGOs. The education department is responsible to ensure the proper implementation of the scheme. Ideally it should have a record of the work of the NGO in this matter. However, it was found that there is no updated information on many of the activities implemented by NGOs at the SSA district office.

### **Poor rate of expenditure of funds available for IEC under SSA**

Much of the funds available to the Betul district for the implementation of IEC 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.

### **Parallel planning in education, department of Social Justice and decentralised district planning**

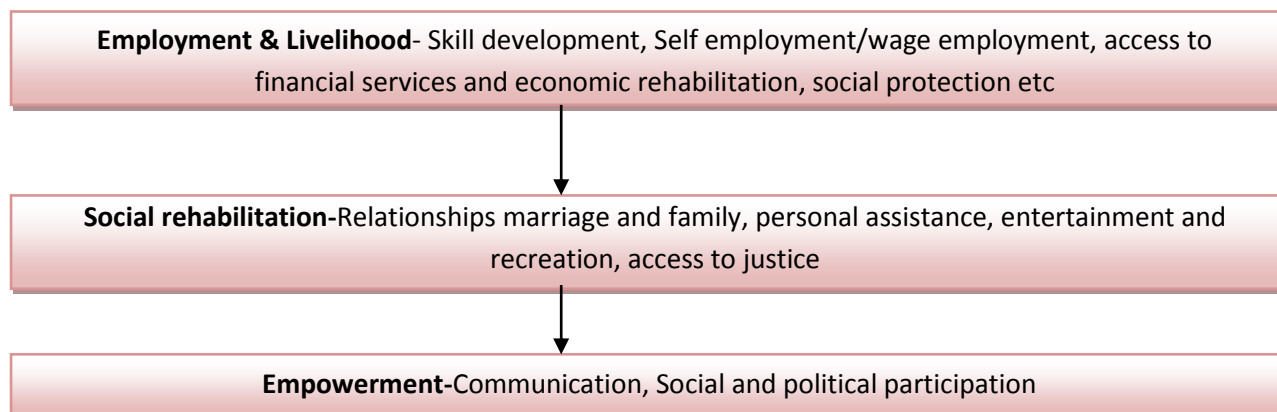
There is a parallel survey being conducted by IEDC department under RSK and Department of Social Justice. This results in duplication of activities. Further, Planning Commission, Madhya Pradesh carries out a comprehensive decentralised planning at the district level. The education is also part of the prepared district plan. This process is duplicated by the Rajya Siksha Kendra that prepares independent education. Neither the decentralised plan of the district nor the education plan of the education department has any focus on disability. Therefore another survey for CWSN is carried by the RSK, which in turn gets duplicated with the disability survey of the department of social justice. There is duplication of survey and planning at several levels, however implementation is in bad shape even after couple of rounds of planning.

## **5.4 Employment among Persons with disability - a critical factor for rehabilitation (CBR matrix)**

The employment is the most critical challenge with the Persons with disability. Among the adult Persons with disability in the employable age group, employment challenges are varied. Ranging from their own attitude, to the attitude and support of their family members, to skill development for a meaningful employment or access to credit and finance for self employment. Other conditions such as public transport, medical facilities also play an important role in employment of the Persons with disability.

Employment gives not just the economic security but also earns the critical social cushion and family support. In fact Employment plays a critical role in holistic rehabilitation of a PERSONS WITH DISABILITY. The comprehensive rehabilitation matrix lays particular emphasis on employment of the Persons with disability for a sustainable rehabilitation of the Persons with disability.

### The Employment for rehabilitation measure with respect to CBR matrix



Howsoever critical, the toughest rehabilitation challenge faced by the Persons with disability is with respect to gainful employment. Their employment prospects are influenced by several factors like their own attitude towards their own potential and capabilities, the support of the family for facilitating and supporting employment, the role of institutions such as primary schools to those engaged in skill development, access to finance and timely financial support and other subsidiary services like transport etc.

The primary data collected from 100 households and interview of 30 Persons with disability in the potentially employable age group brings forth different situations and challenges with respect to their employment.

#### Four Scenarios of Persons with disability and with respect to potential gainful employment

There is problem in employability of the Persons with disability both from the demand side for employment and supply institutions. During the course of survey different type of Persons with disability were found in the potentially employable conditions. First and most commonly found are the Persons with disability that have attitudinal block towards their own ability to work and be gainfully employed.

1. With their own attitude, as being incapable of productive employment	2. Willing for employment but families either do not consider them capable of employment or not willing to support them in the employment they are capable off
3. Capable of employment and have family support but do not have either the skills or the financial assistance required for employment	4. Willing Persons with disability have found employment and are leading independent and empowered lives; however some of them may find challenges in transport or other necessary services.



They feel that they won't be able to work due to their disability and therefore do not make an effort for employment. They become financially dependent on their families or even community. The second is the category of where the individual is open to working but does not have necessary family support for the same. Family does not make the necessary effort to overcome the PERSONS WITH DISABILITY employment challenges, be it investment in education, skill development or effort required in transport. The family lacks belief in the capacities of the Persons with disability or are

The primary survey in Betul district collected data from 43 adults in the employable (18 to 60) age group. From 43 adult Persons with disability in the employable age, only 9 had meaningful employment while the 33 persons were totally unemployed. Only 19 were married. Of these 43 respondents, only three had received any assistive aids, though none of them found any utility of these aids and have abandoned them by and large. Significantly, none received any training for skill building.

1. Twenty three year old Ashok of Bijori village in Sehore district has multiple disability. He can't speak and his right hand and leg have orthopaedic disability and do not function properly. His family is into small business and owns few shops in and around the village. Though he is mentally stable, his family has little confidence in his mental ability. They have neither employed him in the shop nor do they let him start any other livelihood pursuits such as Poultry etc... They feel that he may not be able to handle the money transactions. The other 'doable' 'livelihood' options such as poultry etc., being perceived socially low are unacceptable to the family. He is keen to learn and work but is unable to do so in absence of family support. They feel that the family will be able to take care of basic needs. Many respondents during the survey were keen to work, however did not have adequate family support to rehabilitate them in a productive employment.
2. While Bandhu of the same village is completely blind. The forty year old gets the disability pension of Rs. 200 to meet his cash needs. For his basic needs, he is dependent on the village community which provides him food and other basic provisions. He believes that a blind person can't be of any use and can't possibly earn a livelihood. Like him. Many adult Persons with disability have very low estimation of their capacities and feel that they can't earn a livelihood.
3. Mukesh is also from the same village, and was a carpenter by profession. Two year back he lost the motor activity of his right arm following an injection he was administered at the district hospital. With the loss of movement of arm, he lost employment potential as it required extensive use of arms. He wants to open a small shop for his livelihood but doesn't have access to credit for the same. He is already in debts owing to medical expenses incurred by him. A very large number of potentially employable Persons with disability are part of this category. They can't start a livelihood in absence of a skill or finance etc.

unable to make required effort due to physical and financial constraints. At the same time, many are unable to find a suitable employment, in absence of required finances or skill development.

However, a positive attitude and a little support from the family has been most effective instrument in employment generation for the Persons with disability, particularly in absence of well laid out programs from the department. Many families make investment in skill building of the PERSONS WITH DISABILITY, individually mobilise finances for employment and sustainable financial



independence to the PERSONS WITH DISABILITY in their families. Many of them get self employed in the family owned small enterprises. For instance 15 year old Vikas from Dolidhana village in Betul block of the Betul district is studying in class sixth. His father is encouraging him in 'murgi palan' i.e. poultry'. Today he has 7 hens and chicks and earns approximately five hundred every month from the same. He is also finishing his studies. His orthopaedic disability is not a big constraint in the enterprise. Similarly speech impaired Muddasir is working with his maternal uncle, at his car/motorcycle's tube repair shop. He was trained by the uncle in the trait. Dhorram works at a brick kiln despite his orthopaedic handicap. He earns Rs 300 a day by working in the adjoining village of his residence. His brother drops him to the site every day.

A closer examination of both the surveyed blocks, it is clear that many Persons with disability get employed if they could get some skills and family support.

### **Supply side constraints in Potentials for employment among Persons with disability**

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 loco motor disability or cerebral palsy) in the Government establishments including the Public Sector Undertakings. Madhya Pradesh Government has gone ahead further and announced the reservation to be raised to 6% in formal sector.

<b>District</b>	<b>Total number of PERSONS WITH DISABILITY</b>	<b>Number of provided Government jobs</b>
<b>Betul</b>	23000	1
<b>Sehore</b>	18319	12
<b>Bhopal</b>	19748	6
<b>Source- Sparsh Abhiyan Website Department of Social Justice, M.P</b>		

### **Poor status check on employment of Persons with disability in the reserved provisions**

Despite the provisions and state's commitment of a fairly high reservation at 6%, the situation of employment of Persons with disability in Government jobs due to reservation is grim. Betul with twenty thousand Persons with disability have provided government job to only one person with disability. Further, no concrete data is maintained either at district level or at the State to provide a status check. The jobs declared at district level from different departments have very little coordination with the Social Justice department. The department also does not have any control on the department to push the employment of the Persons with disability. The departmental heads at the district make a vague assessment of the employment at the district. Most employment for Persons with disability is pushed through the District Collectors.

As per a vague assessment made by district unit of Social Justice department in Betul, hundred and nine vacancies were to be filled by Persons with disability, similarly the Sehore's unit of the department claim that one hundred thirty four vacancies have been filled with suitable Persons with disability. However, there is hardly any substantial record to prove the same.

### **Nearly defunct Vocational rehabilitation centres and special employment exchanges**

Run by Ministry of Labour and Employment for vocational training, skill building and rehabilitation of the handicapped, the vocational rehabilitation centres are supposed to provide skill building training to Persons with disability for their economic rehabilitation. Such centres should be there in every

district considering the mobility challenge of Persons with disability. However, there is only one centre in Jabalpur for both MP and Chhattisgarh, with an annual budget of approximately 80 lakh. The discussion with staff of VRC revealed that the budget of VRC is spent largely on salaries. It runs in a rented building meant to be running shops. The machines and equipments are defunct. Negligible numbers get trained. The staffs say that Persons with disability do not want to go to, too far off places for training. Besides, there is no facility for stay and food for the trainees, making it nearly impossible for Persons with disability to register here. Most Persons with disability can't afford large expenditures they would incur in making arrangements for stay.

A PERSONS WITH DISABILITY is suppose to be registered here and make visit regularly for a month for assessment of his/her capacities for skill building trainings that he may receive later. After registration and assessment, a PERSONS WITH DISABILITY may be given trainings and may be facilitated in employment. The employment generation and loan disbursement through institute has been negligible in the past decade

### **Special employment exchanges for Persons with disability; Insignificant role in employment**

Special employment exchange has also been set up in the Ministry of Labour and Employment for registering and providing employment to Persons with disability. Unfortunately there is only one such exchange in Madhya Pradesh. This institution is also defunct since government jobs are getting advertised openly for most the districts. The applicants apply directly and selection is also made directly. The institution lies defunct by and large.

Kamal has impairment in hearing. He is graduate and has done a certificate course in computers. He is also employed in voluntary organisation as a field level worker. He has applied for different government jobs like teacher, lower div. Clerk, Rozgar Sahayak, and even a peon through open vacancies advertised in different news papers, but never qualified for one. He says that departments are biased. Besides, money changes hands in appointments

To complicate the matter further, Special employment exchanges have been set up by the government for the Persons with disability to procure the employment. A PERSONS WITH DISABILITY is required to register at this special employment exchange for getting a job. Unfortunately, there is only one exchange in Madhya Pradesh, that too only in Jabalpur. Awareness about this employment exchange is virtually non existing. It has staff of 5 persons presently, and registers 30 to 40 Persons with disability per month. The centre organises employment fairs where it tries to connect the Persons with disability to the potential employer. The special employment exchange has not been able to provide any to job to any PERSONS WITH DISABILITY in the last year. A total of nine hundred Persons with disability were called for such camps and forty were provided employment through these camps. However, only three to four persons continued in the employment. They have not provided a single job in the reserved category, as department advertise the vacancies independently.

### Vocational Rehabilitation center for handicapped

- Run by Ministry of Labour and Employment for vocational training, skill building and rehabilitation of the handicapped. There is one center in Jabalpur for both MP and Chhatisgarh, with an annual budget of approximately 80 lakh spent largely on salaries. A PWD is supposed to be registered here and make visit regularly for a month for assessment of his/her capacities for skill building trainings that he may receive later. After registration and assessment, a PWD may be given trainings and may be facilitated in employment
- The employment generation and loan disbursement through institute has been negligible in the past decade

### NGOs undertaking vocational training

- NGOs are funded by the department and conduct vocational trainings of the PWDs. Some of the districts are performing very poorly and have hardly conducted any trainings such as Betul. However, there is any methodical need assessment of the trainings requirements or scoping study for the feasibility of the employment avenues in the district. A negligible number of PWDs that have been trained manage to get a sustainable employment. Most of the trainings are only used to display the products in exhibitions, that have very little sale beyond the buying in the exhibitions by sensitive consumers.

## 6. Challenges in streamlining governance framework for Persons with disability

Disability is a complex social phenomenon and needs a multi-sectoral approach. There can be a range of departments and ministries that may have direct implication for the Persons with disability as they play a role at different stages of life cycle of a PERSONS WITH DISABILITY.

### 6.1 Inter-sectoral and inter-ministry coordination – A Challenge

Besides a host of departments engaged in addressing disability in some or the other way, there are several schemes, budget lines, and programs within the ambit of the departments that have direct implication for addressing

Department of Social Justice identified during Sparsh Abhiyan more than eight lakh Persons with disability in 2011. They organise camps to the needs of the Persons with disability. The camps are usually convened at district headquarters and Gram Panchayat secretary are usually asked to inform the / families to bring the Persons with disability persons to the camp. The camp usually has staff from various concerned departments such as health, education, rehabilitation centres, pension disbursement etc. The Persons with disability are supposed to articulate their needs at these camps and different departments try to fulfil them on that

disability. There are inherent challenges in such a multi-sectoral field as disability, to the extent that there is no supreme and identified “natural” nodal department for disability.

There is a complex institutional framework for operation of the disability sector in India. The MJSE- 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, PERSONS WITH DISABILITY, aged persons, street children, victims of drug abuse, and others. Therefore, Persons with disability 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 Persons with disability as enjoined in the Persons with Disabilities Act, 1995”.

## 6.2 Misplaced budgetary allocations of ministry of Social Justice

If we take the last Five Year Plan, the total outlay of the Ministry of Social Justice and Empowerment (M.S.J.E.) was Rs. 1900 cores.

The analysis of the total expenditure incurred by M.S.J.E., the nodal Ministry on disability, in the 11th Five Year Plan reveals that it was able to allocate only 75.98 percent of the recommended allocations for people with disabilities. Ironically, most of the budgetary allocations of the department have been spent on running and maintaining institutions that can at best cater to a few thousands of people with disabilities. For instance, the number of out-patients treated in ‘Institute of Physically Handicapped’- New Delhi in the year 2004-05 was 34,000. This is an insignificant number compared to the number of Persons with disability in the country. Ironically, these institutes have very poor outreach program and therefore can’t cater to large population of Persons with disability, preferring to stay locally for any interventions.<sup>9</sup>

Year	No. Of outpatients treated in Institute of physically handicapped--new Delhi
2003-04	39,000
2004-2005	34,000

**Source-Annual report 2007, Institute of physically handicapped, New Delhi**

In the period 1998-2003, just under Rs. 1042 crores was spent by MSJE on the 'welfare of PERSONS WITH DISABILITY', with the largest expenditure category the national institutions and corporations for disability. However, several other ministries such as education and health also contribute directly to disability. Unfortunately such cross-ministerial data is not available for interpretation.

Analysis of various programmes and schemes of M.S.J.E. reveals lack of allocation for ensuring

Assuming that the pensions, assistive aids and loans to Persons with disability persons are the only direct benefit reaching the poor in the far flung districts, forty rupees per month ( Rs. 40/month) is the contribution of MJSE in the respective budget lines. This calculation too is based on census data on disability which is claimed to be far lower than the actual level. Disability @ 6% of population, this amount would be reduced to one third at Rs. 13 per month.

<sup>9</sup> (Source: 13 Five Year Plan document).

facilitation and rehabilitation at community level towards holistic development. The table above shows that less than half of the budget of the ministry provides any direct relief to the Persons with disability. At this rate of benefit disbursement, it is not only inappropriate but also unfair to look for any governance framework only within the Ministry of Social justice.

**Table -10: Expenditure in 11<sup>th</sup> Five Year Plan on schemes disbursing direct benefit to PERSONS WITH DISABILITY**

<b>Total expenditure in 11 Five Year Plan ( in INR and in crore)</b>	<b>Schemes following the Persons with disability Act,1995</b>	<b>ADIP scheme</b>	<b>NHFDC</b>
<b>191</b>	9.5	49	10
<b>208</b>	8	60	18
<b>197</b>	10.8	67.3	9
<b>314</b>	50.4	69.6	50
<b>292</b>	34.9	75.9	25
<b>1202</b>	113.6	321.8	102

Source : 11th five year plan allocations, website: Ministry of Social Justice, New Delhi

### 6.3 Virtual neglect of PRIs in planning and execution

Panchayats are a critical unit for the convergence of program deliveries of all relevant departments. Being the constitutionally-mandated lowest tier of governance, it has the right for surveillance of the programs being implemented in their areas of jurisdiction. They can monitor village-level institutions such as Anganwadi, sub health centres, sanitation campaigns, water supply programs and supervise the functioning of village-level functionaries. They also have strong abilities to alter the health seeking behaviour of the community in their village.

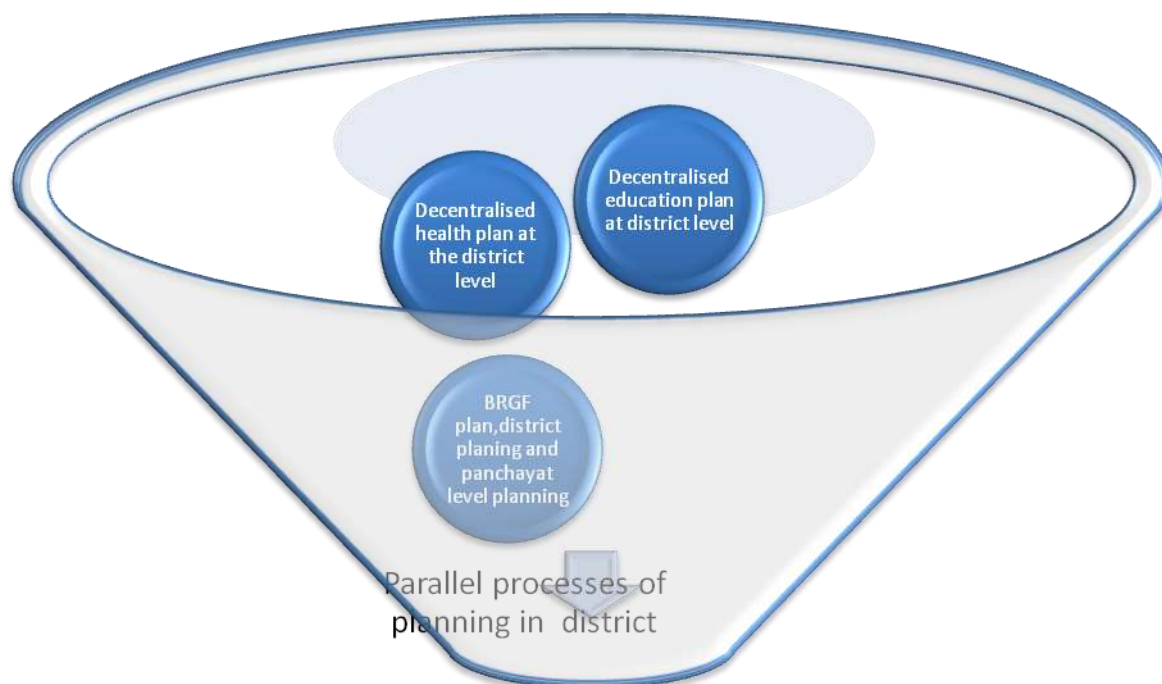
However critical, Panchayats are largely absent from the Act and therefore the current institutional framework for disability, is increasingly out of line with the constitutionally-mandated decentralization of developments and governance. Lack of attention to PRIs continues in the National Policy, reflecting the limited downward reach of the disability institutional network. The institutions from which PERSONS WITH DISABILITY most often reported receiving services and benefits are at district-level administrative machinery-though Panchayat exists as a constitutionally-mandated body. Panchayats are used by the district machinery as a cheap agent for passing information on camps, surveys etc. They are also used for disbursement of disability pensions.

Downward integration with departmental convergence at the ground level with proactive intervention from PRIs is necessary to provide a robust framework for inclusion and participation in decision making. Village planning and district planning provide a constitutionally-mandated framework for planning at lowest units such as village, Gram Sabha and Municipality. There is scope to identify and integrate the needs and aspirations of each PERSONS WITH DISABILITY and respond to it at this level.



## 6.4 Planning of departments in concentric circles; missing comprehensiveness in approach

Decentralised planning is being undertaken in concentric circles with no single department doing it comprehensively for all the necessary components and focus. Health department undertakes health planning while education department builds its own decentralised plan. The NREGS builds perspective annual plan on right to employment issues. The Panchayats too, build their own plan for the year and get it approved by Gram Sabha. Further, the backward districts build Backward District Grant Fund (BRGF) plan with a bottom-up approach. To top it all, the process of decentralised planning is mandated by the 74<sup>th</sup> Constitutional Amendment.



Concentric levels of planning dilute the objective, waste resources besides being hardly integrative or comprehensive. They handle only one dimension of the issue and overlook associated other critical issues. For instance, the education plan focuses on enrolments but not on the approach road to school, critical for regularity. Health plan will have a component on blindness control but not proper nutrition.

District plans that are supposed to be integrated into the village plan, are largely infrastructure plans limited to construction of roads and drains.

Budgetary transfers being largely tied with different schemes, local priorities are taken over by the budget availability in central schemes. The process of planning is half-hearted and sketchy besides being duplicated by several departments.

The indicators on disability are composite of nutrition, sanitation, women literacy, immunisation, early childhood development as well as hospitals and functional health systems. However, planning process of related departments undertakes planning with departmental priorities in the mind, and not the integration challenges for addressing disability

## 6.5 Bottom up planning commitment - mere eye wash

Decentralised planning is a new development. This is phase of experimentation, trials and errors in decentralized planning. Therefore, several methods are being tried and fine tuned. Health department collects the data from five villages and extrapolates the need of the district on the basis of the data. Education department too carries out half-hearted bottom-up planning. The district planning which is supposed to be most comprehensive of all is difficult to integrate at block and district level.

Decentralised planning also started in response to the push by the 11th five year plan, which makes it mandatory precondition for accessing the plan resources. Therefore, there has always been a poor commitment to the process, instead it is undertaken to meet the statutory requirements. The final district plan is essentially a 'mark up' plan for demanding budgets. It is impossible to find the pathway of integration at the block and district level.

Panchayat builds their own plan for NREGS as well as other activities. However, cash strapped Panchayats end up planning their priorities in accordance with the availability of funds in different schemes, instead of being the other way round.

The households with disability were neither aware of decentralised planning process, nor had ever participated in decentralised planning. They either take help from Panchayat or Anganwadi for any intervention for disability. This support is mostly limited to disability pensions and certification.

Panch and the Panchayat make an annual plan of the village but do not have an idea on decentralised plan for their Panchayat. They have tried to maximise access of disability pensions as only redressal mechanism.

Significantly format for decentralised planning does have mention of, but fills up the response as all necessary intervention undertaken-quite contradictory to ground reality. One such format is annexed with the report.

These planning exercises undertaken by different departments have no point of convergence. Further the bottom up plan collects the demand but there is not much else to planning than collection of demand. There is no set mechanism of setting priorities or responding at block and sub block level. In this method, it is difficult to make out if the budgets are allocated as per the priorities of the village.

## 6.6 No focus on disability in planning

Although disability is found in alarmingly high proportions in the surveyed villages, the decentralised plan prepared at the district level has no focus on disability. A village Dhadgaon has 19 households with disability among the total 99 households in the village. The plan and the filled-up planning format of the village is given in annexure-5 for assessing the disability insensitivity in the planning process. The formats carry no

The planning formats for the district planning mention of all services available to Persons with disability as a standard response.

Twenty percent of the surveyed households in the villages surveyed for household survey had a PERSONS WITH DISABILITY in their family. However, the planning undertaken at the district level doesn't even mention

details on the Persons with disability. Instead, it misleads by reporting no problems for Persons with disability

## **7. Ways forward**

The above issues contextualize the challenges in governance framework and multi-sectoral coordination required in addressing disability. The discussion with the different stakeholders and departments put forward following points for addressing in improving governance of PERSONS WITH DISABILITY centric program deliveries.

### **7.1 Strengthening bottom up planning process**

Bottom up planning needs to be strengthened with integrative and comprehensive approach. Departments have to strengthen district-level planning by merging their data and priorities with each other. There has to be an absolute abandonment of several mutually-exclusive district planning process undertaken by several departments, instead a comprehensive plan needs to be developed integrating the needs of different sector. This plan may, therefore, be funded by different departments.

Further the fund allocations have to look beyond the schematic budgets and respond purely to the local priorities. Therefore, data collection for the planning has to be further strengthened addressing the need and aspirations of different section of the society.

#### **7.1.1 Identifying issues for sub district block and cluster level response**

Many issues including disability need to be addressed at sub-district level. Given the vastness and variability in disability sector, it is not possible to address disability at the individual PERSONS WITH DISABILITY level in each village. For instance, it is not possible to establish a vocational training unit at the cluster of villages, but not at village level due to small number of the interested individuals, nor it is feasible at district level, as most of the needy individuals may not be able to commute.

Same goes for special educational need of the CWSN. These children can be supplemented for their special needs at cluster level for the same reason.

### **7.2 Priority allocation of budgets on disability**

11th Five Year Plan has specifically mandated that departments should allocate 3% of the departmental budget to disability sector. However, this has not become a priority for departments. The budgetary allocations have not been provided by most departments.

Education department has made steady advances with respect to CWSN. However, hardly any other department has recognised and responded to disability. As is clear from the survey, disability (may or may not be 40%) exists at much alarming proportions compared to existing census data. However, prevention and rehabilitation of disability do not find mention in the budgeting priority of the critical departments. Health department needs to allocate special funds in training of functionaries on prevention of disability. Further, all the health institutions need to be strengthened with respect to disability.

Some of budgetary priorities mentioned by service providers and Persons with disability are as follows:



- Conduct access audits in all critical health and educational institutions and build necessary infrastructure
- Priority treatment to all the Persons with disability in the health institutions
- Extra allocation for medical facilities and treatment, including free medicine at the district hospitals for all the Persons with disability
- Substantial medical and accident insurance for the Persons with disability
- Strengthening sub-centres for preventing and screening of disability
- Cluster-level vocational training centres for Persons with disability
- Expenditure on decentralisation of the process of certification at the block level
- Investment in good quality assistive aids and technology as currently too few Persons with disability have accessed them and almost a negligible number uses them due poor quality of the tools and aids
- Investment in training of the village level service providers like teachers, Anganwadi workers, ANM etc. on different relevant aspects in management of disability
- Strengthening of DDRC by substantial increase in salaries of the staff
- Investment by the State in developing human resource specialising in disability rehabilitation
- Increase in the number and amount of disability pensions and scholarships
- Start district disability centres where applications are taken for disability certification and disability pensions on a regular basis.
- Allocate special budgets for in the loan disbursement for self employment
- Constitute a district-level fund from 'Nirashrit Nidhi' for extending credit access to Persons with disability

#### **7.4 Bring disability in focus of departmental functioning**

Despite a large proportion of the population with disability, the departmental focus on disability is non-existing. For instance the state's project implementation plan of the department of health must address on building health infrastructure for prevention and rehabilitation of disability.

#### **7.5 Ensuring employment of Persons with disability for committed reserved seats**

There is a positive provision about the reservation Persons with disability, however practice needs to be strengthened. An employment register should be maintained at all the departments for all the vacancies advertised and recruitments made. The Social Justice department should coordinate the updating of the registers. The department should build a list of appropriate Persons with disability at the district level so that vacancies may be filled up at the district level.

Since most positions being advertised are ad hoc and contractual, they are being advertised and filled up at district level. Therefore, it is important to sensitise the officials at the district level for employment of Persons with disability so that they may be adequately absorbed at the appropriate time

#### **7.6 Ensuring useful vocational trainings at the district level**

Many trades have been identified by the community, as suitable for Persons with disability. In fact many of the Persons with disability are already working on these trades, if they have been trained by somebody in the family. A listing of viable trades for self employment should be undertaken, and market potential of trained manpower should be carefully assessed at the district level. Further,

Persons with disability in the different categories of disability should be assessed for competencies and potential in the listed trades.

**Table- 11: Identified trades as suggested by different categories of stakeholders and PERSONS WITH DISABILITY households**

<b>Low Vision and visually impaired</b>	<b>Hearing and speech impairment</b>	<b>Orthopaedic and loco motor disability</b>
<b>Basket making, packaging of spices and other grocery items etc.</b>	Puncture repair, automobile repair, goat and poultry farming, cattle raising, tailoring, beauty parlour, shop assistants, weighing and small labour work, masonry	Motor winding, Mobile repair, TV Repair, shop assistants

## **7.7 Easy and reliable credit access to Persons with disability for self employment**

There is substantial fund collected at the district level as 'Nirashrit Nidhi' from the tax collected on Mandis (market places) and 'local hats'. A part of this fund should be dedicated to vocational trainings and credit access to Persons with disability. Functional disability should necessarily form the basis of such loan disbursement. A data bank should be prepared on the testimonies and guarantees of Panchayats and credit should be facilitated without much complication and procedures.

## **7.8 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 field functionaries on disability related issues and the important interventions for prevention of disability at birth and childhood. They could be critical support to the poor families to reduce instances of disability. Important knowledge, skills, and attitude should be imparted to these important functionaries who interact with Persons with disability on a daily basis.

## **7.9 Increase the role of Panchayat on disability issues**

Panchayats have been entrusted with the responsibilities of economic planning and social justice, besides being the constitutionally mandated lowest tier of governance. Panchayat should be trained in surveillance of village functionaries and village-level institutions. They should be adequately and repeatedly trained by the department of Social Justice to capture their potential in bringing meaningful convergence of different programs at the ground level for the interests of Persons with disability. Further Panchayat leaders with their leadership potential can be trained for altering behaviour of families and care givers towards Persons with disability.

**Table – 12: Potential role of Panchayati Raj Institutions in prevention, control and rehabilitation of disability**

<b>Potential role in program management</b>	<ol style="list-style-type: none"> <li>1. Increasing surveillance of village functionaries and village level institutions</li> <li>2. Increasing programmatic convergence of different programs for addressing disability</li> <li>3. Monitoring of Immunisation, nutrition and early childhood care for preventing disability</li> <li>4. Increasing the access of disability certification and disability pensions</li> <li>5. Increasing the access of obstetrics care</li> <li>6. Ensuring schooling of the children with disability</li> <li>7. Forming networks to build pressure on district administration for better implementation of disability related programs such as vocational training, loan disbursement , employment etc.</li> </ol>
<b>Potential role in altering behaviour of households and community towards disability</b>	<p>Altering the health-seeking behaviour of the community so that disability can be addressed appropriately by a trained medical practitioners</p> <p>Altering the attitude of and their families towards capacities and employability of so that families encourage skill building and employment of PERSONS WITH DISABILITY</p> <p>Altering the attitude of the community towards the education of Persons with disability children</p>

## Annexure

### 1. Household tracking sheet/inventory

House hold Name	Caste	Presence of disability (Persons with disability) in the household		If yes, what type of disability	Weather from birth or acquired later	Age of the Persons with disability	Going to school/employed (as relevant)	Have disability certificate		Any other specialised services of State availed by PERSONS WITH DISABILITY	Remarks ( challenges, facilities and suggestion )- by the Persons with disability person /family members
		yes	no					yes	no		

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## **2. Interview guide district officials of Social justice department and health department**

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

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

What the approximate number is of identified in the district?

What is the process of identification?

What challenges do the department face in identification of Persons with disability?

What is department doing for Persons with disability at the district?

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 disability?

Do they have any mechanism of taking feedback?

What are challenges for Persons with disability in the villages or places where they live?

Which are the critical areas of concern?

What can be done at district , Panchayat or departmental planning to handle the issues of

What are challenges in certification of Persons with disability?

What role can Panchayat play in facilitating department for improving the services towards Persons with disability?

What is the major role played by the district rehabilitation centre in your district?

Do you think that rehabilitation centres adequately address the problems of Persons with disability?

What can be done to improve its services?

What can be done to improve the medical boards?

What are some critical challenges of 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?

### 3. Interview guide for President and CEO Zilla Panchayat

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

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

**In the process of Planning, how do you account for Persons with disability**

**Are there any special budgetary provisions for Persons with disability at the district level, if yes, what is it and with which departments?**

**What has been the approximate expenditure on Persons with disability the in the previous years?**

**Do the allocations made for the Persons with disability is usually spent? If yes which are the budget lines that are usually spent? Which are usually inadequately spent and why?**

**What can be done by the State and department to resolve the challenges of the Persons with disability?**

**Do you think that departments are doing enough to improve the situation for Persons with disability?**

**What needs to be done by the department to improve the same?**

**Do you think that many are not certified as the certification process is very difficult?**

**What can be done to improve the accessibility and ease of certification process?**

**What difficulties do departments face in doing their job towards Persons with disability?**

**What critical role can Panchayat play in planning and budgeting for Persons with disability?**

**What can Panchayat do improve the services towards Persons with disability**

**What are the major roles played by the district rehabilitation centre in your district?**

**What can be done to improve its services?**

**What are some critical challenges of 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?**

#### 4. 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 type="text"/>	Sex: Male <input type="text"/> Female <input type="text"/>
2. Marital Status	
Married <input type="text"/>	Unmarried <input type="text"/>
Seperated <input type="text"/>	Deserted <input type="text"/>
Widow <input type="text"/>	Other.....
3. Key Informant	
Self <input type="text"/>	Ward <input type="text"/>
4. Category	
General <input type="text"/>	OBC <input type="text"/>
SC/ST <input type="text"/>	Minority <input type="text"/>
Studying.....( grade)	
5. Type of Disability	
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.....
6. Severity of disability	
High <input type="text"/>	Very high <input type="text"/>
Moderate <input type="text"/>	Low



<b>7.Begining of disability</b>	
By birth	accident,
lack of proper medical 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 type="checkbox"/>	No <input type="checkbox"/>
<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 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,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 any 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 receved 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"/>
If yes,specify.....	
<input type="checkbox"/> ..... <input type="checkbox"/> .....	
<b>25. Is your child enrolled in the school</b>	
Yes	No
<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>	
Yes	No
<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/instituttions that can facilittae better shooling 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> ..... .....	

<b>40. What other support did you receive for rehabilitating your child?</b> ..... ..... .....	
<b>41. What challenges did you face in finding the above support?</b> ..... .....	
<b>42. What can be done to improve the delivery of these services?</b> ..... .....	
<b>43. Who can play a critical role in connecting these support mechanism to Persons with disability chilren?</b> .....	
<b>44. What can be done to improve the above services for the CWNS?</b> ..... .....	
<b>45. Which institutions near you can facilitate improved support services?</b> ..... .....	
<b>46. Did you ever participate or made suggestion with regard to schooling difficulty while planning at village level?</b>	
<b>Yes</b>	<b>No</b>

x

**47. If yes, Who asked for the participation and what about?**

.....  
.....

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

.....  
.....

**49. What will your suggestion be for better schooling for you?**

.....  
.....

## Inclusion of Person with Disability in Rural and Urban Planning and Governance

### QUESTIONNAIRE PART-1 FOR 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 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 Imparement <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
<b>7.Begining of disability</b>	

By birth	accident,
lack of proper medical 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 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="checkbox"/>	No <input type="checkbox"/>
<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="checkbox"/>	No <input type="checkbox"/>
<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	moderately difficult <input type="checkbox"/>
very difficult	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 ask 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"/>	Appiled but didn't 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 Persons with disability children?</b> .....	
<b>39. What can be done to improve the above services for the ?</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 Persons with disability child while planning at village level?</b>	
Yes <input type="checkbox"/>	No <input type="checkbox"/>

<p><b>42. Who asked for the participation and what about?</b></p> <p>.....</p> <p>.....</p>
<p><b>43. Have you ever made suggestion in improving any public services from the perspective of Persons with disability?</b></p>
<p><b>44. What was the output of the same?</b></p> <p>.....</p> <p>.....</p>

## Inclusion of Person with Disability in Rural and Urban Planning and Governance

### QUESTIONNAIRE PART-III, FOR IN EMPLOYABLE AGE GROUP [18 YEARS ONWARDS] – RURAL

<b>A. Personal Information</b>	
1. Name:	Total no of family members:
Village:	Panchayat:
Block:	District:
Age:    Years <input style="width: 50px;" type="text"/>	Sex:    Male                      Female <div style="text-align: center;"> <input style="width: 50px;" type="text"/>                      <input style="width: 50px;" type="text"/> </div>
<b>2. Marital Status</b>	
Married	Unmarried
Seperated <input style="width: 50px;" type="text"/>	Deserted <input style="width: 50px;" type="text"/>
Widow <input style="width: 50px;" type="text"/>	Other..... <input style="width: 50px;" type="text"/>
<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	Minority
Studying.....( grade)	<input style="width: 50px;" type="text"/>
<b>B. Type of Disability</b>	
Blindness/low vision <input style="width: 50px;" type="text"/>	Locomotive/Orthopadic
Hearing Imparement <input style="width: 50px;" type="text"/>	Mental retardation <input style="width: 50px;" type="text"/>
Speech Impairment <input style="width: 50px;" type="text"/>	Other.....
<b>Severity of disability</b>	
High	Very high <input style="width: 50px;" type="text"/>
Moderate <input style="width: 50px;" type="text"/>	Low
<b>Beginning of disability</b>	
By birth <input style="width: 50px;" type="text"/>	By accident <input style="width: 50px;" type="text"/>

lack of proper medical attention	other reason( specify)-----
<b>C. Possession of Medical (Disability) Certificate</b>	
Yes <input type="checkbox"/>	No <input type="checkbox"/>
<b>5. 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>6. If no, why?</b>	
Didn't try yet	No health camp organized
doctor asks for bribe <input type="checkbox"/>	Other <input type="checkbox"/>
<b>7. 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>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="checkbox"/>	No <input type="checkbox"/>
<b>9. 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>10. If no, why?</b>	
Applied but haven't been given yet <input type="checkbox"/>	Didn't apply <input type="checkbox"/>
Officers ask 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</b>	
<input type="checkbox"/>	

education?		
Yes	<input type="text"/>	No
<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="text"/>	Assistive devices <input type="text"/>
Cheaper loans	<input type="text"/>	Others ,specify <input type="text"/>
<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 Persons with disability?</b> ..... 		



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

<p>.....</p> <p>.....</p>
<p><b>36. Have you ever made suggestion in improving any public services from the perspective of Persons with disability?</b></p>
<p><b>37. What was the output of the same?</b></p> <p>.....</p> <p>.....</p>

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

Track time and transaction cost

Particular	Days	Hours	Transaction			
			Fees	Transat ion Cost	Speed money	Total money paid
1. Filling up form						
2. Organising necessary documents						
3. Submission of application						
4. Enquiry about status						
5. Receipt of document/ benefit						

## 6. Interview guide for village level service providers such as Anganwadi worker, ANM

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

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

Do you have any training in recognising and preventing a possible disability in your field area  
Have you come across cases in your Panchayat, where a disability could have been prevented by timely medical intervention?

Are you aware of the causes of different type of acquired disability, such as blindness etc.

What support do you think that Health/ICDS and other relevant department make to prevent, intervene, and rehabilitate disability?

Do departmental budgets allocated to your centre ever have special provision for disability

What type of disability is commonly seen in your area?

What do you think is the cause for the same?

What can be done to prevent it?

What role can different institution such as Panchayat, Anganwadi center, PHC, CHC etc in prevention and rehabilitation of disability?

## 7. 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 in any way?

If yes- how did it do it?

What is done in your Panchayat for PERSONS WITH DISABILITY's- disbursement of scheme benefits, ramp etc in school or any other, facilitating the certification etc.

What are the provisions for Persons with disability , how does a Panchayat help in it?

What can be done at planning level in Panchayat to improve the life of PERSONS WITH DISABILITY's

Do service providers at village level ever discuss the issues of PERSONS WITH DISABILITY's with you?

Does the service provider take any special care of the Persons with disability in your Panchayat?

What challenges do you think that face and where in Panchayat can play a critical role?

What can departmental functionary do with respect to disability?

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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.

## 8. Interview schedule of officials

State Officials	
1	Mr B.K. Batham Commissioner Department of Social Justice Govt. of M.P
2	Ms. Geeta Kamte Director- Department of Social Justice Govt. of M.P Bhopal
3	Mr. Yogesh Mahor Social development expert M.P State Planning Commission Govt. of M.P Bhopal
4	Mr. Rishi State Project Coordinator Govt. of India-Joint Convergence Program State Planning Commission-MP
5	Mr. Mangesh Tayagi Under Secretary M.P State Planning Commission Bhopal
Members of the Panchayat	
1	Mr. Rajesh Rathore Sarpanch Panchayat-Rajola Sehore
2	Ms. Rekha Dhurve Sarpanch Panchayat-Timurni Sehore
3	Mr. Bablu Uike Sarpanch Panchayat-Dehgud Sehore
4	Mr. Raju Sahu Panch Panchayat-Paduna
5	Mr. Santosh Barkhede Panch

	Khakra Kolilari
<b>6</b>	Gopal Bhadavi Sarpanch Panchayat-Dhard Gaon
<b>Anganwadi workers/ANMs-District Betul</b>	
<b>1</b>	Rajkumari Srivastava
<b>2</b>	Chandrakala Soni
<b>3</b>	Chandrakala dhurve
	Anita Jharbare
	GeetaMathrankar
<b>District Officials</b>	
<b>1</b>	Deputy Director Social Justice department Betul
<b>2</b>	Mr. G.L. Sahu District Project Cordinator Sarva Siksha Abiyan Betul
<b>3</b>	Ms. Zafia Javed Deputy Director Social Justice Department Sehore
<b>4</b>	Dr. Maravi CHMO Sehore
<b>5</b>	Mr. Dharmendra Sharma District Officer Education Department Sehore
<b>6</b>	Mr. Rampal Special Educator Social Justice Department Betul