

## **A Care-less State:**

### **Status of Persons with Disabilities and Access to Benefits in rural Rajasthan**

**RV Jayapadma & Kailas Kokare**

#### **Abstract**

1.56 million persons with disabilities, which is 5.83% of the 26.8 million persons with disabilities in India, residing in Rajasthan. As with the rest of India, in Rajasthan too, the number of disabled persons reside in rural areas are higher than in urban areas.

In February 2019, a study was undertaken by a few students of IIM Udaipur, as part of a Rural Immersion Program in the Course on Indian Social and Political Environment. The key objective of the study was to understand the status of people with disabilities in rural areas of Rajasthan and their access to various government schemes and support.

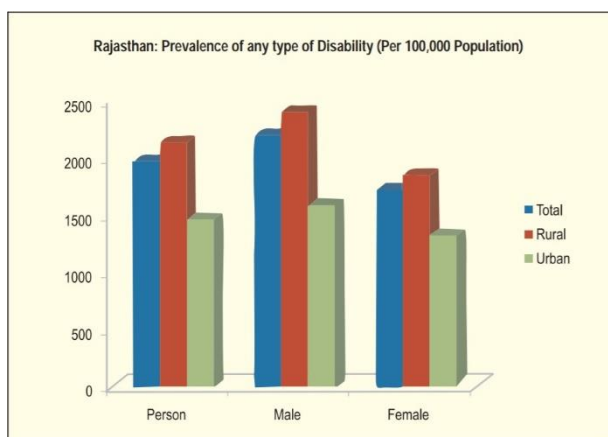
50 persons with disability and their families across 10 villages in rural areas of Udaipur were interviewed as part of the study. The study revealed that a large number of Persons with Disability, over 60% are illiterate. Overwhelmingly, 82% of the PwD work, 66% of them in agriculture and livestock care.

Rajasthan is one of the leading states in issuing UDID, however, it appears slow in reaching the villages surveyed. Only 38% of the respondents (18 men and 1 woman) had got Disability Certificates, and only 10% (5 men) have got UDID cards, pointing to the fact that penetration of UDID in rural areas is slow.

PwDs and their families, as well as representatives of local governments, have limited awareness of schemes and benefits available for PwDs. Most of them are left to their own devices and consider it their fate. A majority of PwDs interviewed shared that they have no aspirations, except to be treated with dignity.

#### **1. Introduction**

Persons with Disabilities refers to persons suffering from not less than 40% of any disability as certified by the Medical board. In India, approximately 26.8 million people are disabled (as per Census 2011), which is nearly 2.22% of the total population. There are 1.56 million persons with disabilities (PwD) in Rajasthan, which is 5.83% of the disabled population in India. Among them, 8.4 lakh are males and 7.1 lakh are females. As with the rest of India, a large percentage of disabled persons reside in rural areas, with implications on policies for public health systems and their responses.



Source: Annual Health Survey 2011-12 Fact Sheet Rajasthan - Vital Statistics Division, Office Of The Registrar General & Census Commissioner, India (Website: [www.censusindia.gov.in](http://www.censusindia.gov.in))

Key statistics related to persons with disability in Rajasthan are as follows:

- In the age group of 0-6 years, Rajasthan has 89,791 children with disabilities. This forms 5.74% of the PwD in Rajasthan and 4.4% of all India disabled children.
- In terms of the nature of the disability, about 3.1 lakh have problems in seeing, 2.1 lakh in hearing, 69,484 in speech, 4.2 lakh in movement while 2.1 lakh have multiple disabilities.
- In terms of literacy level among PwD, Rajasthan has the second lowest position in the country (40.16% in Rajasthan against 54.52% across India). Literacy among disabled females is even lower than males.
- The percentage of those working is 34.65%, which is also one of the lowest in the country. This is despite state government providing 3% reservation in government jobs.
- The State has the lowest population (31%) of unmarried PwD in the country.

The state enacted the Rajasthan Rights of Persons with Disabilities Rules, 2017 following the Rights of People with Disabilities Act 2016 enacted by the Government of India. The GoI Act expanded list of disabilities from 7 to 21. There has, however, been no comprehensive effort to update the list of PwD subsequent to the enactment of the Act, though it is estimated that the number of PwD would be much higher than the Census 2011 count.

To enable access to various benefits, Disability Certificates are issued to PwD, upon verification of the nature and extent of their disabilities. Disability Certificates were found to have a range of complexities in obtaining them, limiting the number of persons who received these certificates. Further, Disability Certificates issued in one state were not considered valid in others.

Towards eliminating these limitations, a national process of issuing Unique Disability ID (Swavlamban Cards) for Persons with Disability was initiated in 2016 under the Ministry of Social Justice and Empowerment. The UDID will also allow for direct transfers of scholarship, employment, and marriage allowance in the bank accounts of PwDs. Thus far, Rajasthan has been among the leading states, in issuing UDID cards covering 2.94 lakh PwD in the state. This accounts for less than 20% of PwDs in the state as per the 2011 Census data. It is second only to Madhya Pradesh which has issued 3.09 lakh UDID cards. Nationwide only 14,43,549 UDID Cards have been generated (data as of April 16<sup>th</sup> 2019 from <http://www.swavlambancard.gov.in/pwd/udidCardStatus>)

Currently, both Disability Certificates and UDID are being issued by the states.

A number of schemes and programs are implemented to support Persons with Disabilities.

- These include Rajasthan State Schemes for Persons with Disabilities by Directorate of Social Justice and Empowerment

- The State Disability Pension or the Social Security Pension are given on the basis of age criteria of the persons with disability. Indira Gandhi National Disability Pension Scheme is separately implemented in the state for persons who are BPL and with multiple disabilities or more than 80% disabilities.
- Financial assistance awards are extended to those who clear entrance exams and get admission in specified courses.
- Support for free travel is provided in the state to people with disabilities and their escort/attendant. For this, Smart Cards are issued by the Rajasthan State Road Transport at each district.
- The department of Social Justice and Empowerment sanctioned Rs. 25000 as incentive/grants in order to assist the people with disability to lead a happy married life.
- In addition, there are reservations for employment and provisions for inclusive education in schools.

## 2. The objective of the study:

There seems to be a limited understanding of the situation of persons with disabilities across the country and especially those residing in rural areas. In February 2019, a study was undertaken by a few students of IIM Udaipur, as part of a Rural Immersion Program in the Course on Indian Social and Political Environment.

The key objective of the study was to understand the status of people with disabilities in rural areas of Rajasthan and their access to various government schemes and support.

## 3. Methodology:

10 students participated in the study and collected data from 10 villages, 9 in Udaipur district and one in Rajsamand district.

In the villages where they stayed during the rural immersion, students identified persons with disabilities with the help of key informants from the village community. Each student met with and collected information from 5 persons with disability through interactions with the PwD and their families. Data of a total of 50 PwD were captured through the study.

Structured questionnaires were used to ask the PwD and /or guardian whether they know that the schemes exist and if they know what the procedures for obtaining benefits under them are. A subsidiary component of the exercise was also to meet the elected PRI Sarpanch or even the PRI Secretary to get an understanding of their awareness with regard to support for Persons with Disabilities and if they may have provided any help to them at any time.

## 4. Key findings from the study

### 4.1 Socio-economic status of respondents

	<12	12 to 18	19 to 35	35 to 60	>60
Female	2	3	6	1	
Male	2	6	18	3	9

Of the 50 respondents, 12 were women and 38 were men. While 9 men were over 60 years, a majority of respondents (6 women and 18 men) were in the age group 19 to 35 years.

Caste	General	OBC	SC	ST
Female		1		11
Male	3	5	4	26
Total	3	6	4	37

74 % of the PwD were from the ST, while 20% were from OBC and SC. 80% of the respondents live in *kutch* houses, indicative of their economic status.

Disability	Female	Male	Total
Hearing		2	2
Intellectual	3		3
Intellectual and Locomotor	1	2	3
Locomotor	7	32	39
Speech	1		1
Vision		1	1
Other		1	1
<b>Total</b>	<b>12</b>	<b>38</b>	<b>50</b>

Based on information related to types of disabilities, 84% of PwD reported Locomotor disabilities, of which 6% had intellectual disabilities as well.

Marital Status	Married	Never Married	Widow
Female	6	6	
Male	20	16	2
<b>Total</b>	<b>26</b>	<b>22</b>	<b>2</b>

Among the respondents, 5 F and 8 M are below 18 years. Therefore, 70% of PwD above marriageable age were married.

8 men, though above marriageable age, were never married, while 2 are widowed.

Education	Female	Male
Primary	4	9
Middle School	1	3
High School		2
Graduate		1
Illiterate		6
Not available	7	17
<b>Total</b>	<b>12</b>	<b>38</b>

Information regarding the education of respondents was sketchy at best, showing the limited access to education. Only one respondent was a graduate, and 2 had completed high school. 6 persons were illiterate, while data of 24 persons was not available, leading to the conclusion that nearly 60% of the PwDs may be illiterate. This can be correlated with the data for literacy rate of PwDs for the State of Rajasthan, which stands at 40%, as against the national average of 52%.

State efforts at inclusive education for PwDs seem to be not working in these villages. Children with disabilities are not seen to be present in anganwadis and primary schools in the villages.

	Agriculture	Daily Wage	Govt	Livestock	Not Working	Private
Female	6		1		3	2
Male	26	2		1	6	3
<b>Total</b>	<b>32</b>	<b>2</b>	<b>1</b>	<b>1</b>	<b>9</b>	<b>5</b>

82% of PwD reported that they were working. Only 9 respondents (3 F and 6 M) stated that they were not working. A majority of respondents (66%) work with the family in agriculture. It was not very clear if they were being compensated for this work, or if was only being notionally counted.

This presents quite a contrast when correlated with type of disability and level of education. A majority of respondents are found to have locomotor disabilities and have not had access to education, however they are all engaged in work, largely of the unskilled and wage labour type.

#### 4.2 Access to Disability Certificates, UDID and Government Schemes

	No	Yes	Total
Female	11	1	12
Male	20	18	38
Total	31	19	50

	No	Yes	Total
Female	12	0	12
Male	33	5	38
Total	45	5	50

38% of the respondents (18 men and 1 woman) had got Disability Certificates, while 32% of the respondents (12 men and 4 women) were Not Aware of Disability Certificates.

While 5 men said they had applied for Disability Certificates and it was 'In Process', 3 men and 7 women felt the application process for Disability Certificates was Complicated.

Only 10% of the respondents, all of them men, had received UDID cards. Three persons (2 women and 1 man) said their application was rejected as they did not have the required percentage of disability. A majority of respondents (76%) including 31 men and 7 women were not aware of the UDID. While Rajasthan prides itself in generating among the highest number of UDID cards in the country, it has been slow to reach PwDs in rural Rajasthan,

The above data presents a dismal picture in terms of inclusion of PwD and reaching benefits that are due to them.

#### 4.3 Access to government schemes

In line with the responses above 38% of the respondents said they were aware of government schemes. Of the 15 men who were aware of government schemes - 9 said they got to know from NGO, 3 from government officials, 1 from Sarpanch, 2 from Others. Only 4 women said were aware of Government Schemes – 3 said they got to know from NGOs, 1 from Anganwadi Worker

12 persons, all male, received Disability Pension (all of them had Disability Certificate), while 2 persons (1 boy, 1 girl) received Education Support. Only the Boy has Disability Certificate.

98% of the respondents said they did not receive any support from the *Sarpanch* or *Gram Sevak* in getting support from the Disability Schemes.

In seven villages where the Sarpanch, Panchayat members and Anganwadi workers were interviewed, 5 out of the 7 said that they were aware of government schemes. However, on being probed, they were able to only share information about the Disability Pension. Only two of them knew about UDID, while 2 Gram Panchayats kept records of the PwD.

There were no special arrangements made for education for PwDs, which is corroborated by the low literacy attainment of PwD respondents.

#### 4.3.1 Correlating remoteness with benefits

The farthest village was 90 km from the District Headquarters and 50km from the Block Office, and one village was 50km from the District Headquarters and 15km from the Block Office. The remaining villages were at a distance of 2 to 8 km from the Block Office and 5 to 40km from District Headquarters.

These distances have implications, especially in the identification of Persons with Disability and assessment for Disability Certificates and UDID. There is every likelihood that villages further away from the Block and District will have limited information with regard to schemes and programmes in support of PwD.

Further, both Disability Certificate and UDID require the PwD to be physically verified by a designated medical board which works on an appointed day each month to undertake verification of the PwD and provide an assessment of the percentage of disability, which has a crucial bearing on the type of benefits that can be availed by the PwD.

#### 4.4 Acceptance in families and aspirations

By and large, PwD felt accepted by their families. 86% of the respondents (34 men and 9 women) felt they were cared for and not discriminated against at least within the families. Four men and three women did not feel accepted by their families.

In terms of acceptance in society, however, the percentage was lower. 54% PwD (21 men and 6 women) feel accepted by society, while 17 men and 6 women feel not accepted by society

A majority of the PwD 60% (24 men and 6 women) said they had no aspirations. The other respondents spoke largely in terms of getting respect (5 men and 2 women), while 5 men had aspirations of getting a job.

***State of persons with disability in Ramela-Lakhmela village, Sawna Gram Panchayat, Udaipur District, Rajasthan - Case Study prepared by Sarkale Vaibhav Rajendra, PGP student, IIMU***

“Where is Mukesh?” we asked as we reached his house. His grandmother, in her 50s, smiled and replied “there he is”. And then we saw Mukesh, alone in the scorching sun, with a calf standing in the shade as companion, clothes and face full of mud, looking at the sky... with blank eyes. Mukesh and his family are one of the five People with Disabilities that I met as a part of the study on ‘Challenges faced by People with Disabilities (PwD) in getting welfare schemes in Rural Rajasthan’.



Mukesh suffers from Cerebral Palsy, which makes him incapable to movement on his own. “What can we do? Because of him, one person is tied up whole day, but we must go out for our daily work. We are helpless” said his grandmother. In the larger context, Mukesh is one of numerous children in the state of Rajasthan who are left to deal with their disability on their own.



Eight year old Nanalal is affected by 90% Cerebral Palsy. At his house, he was kept under the shade, while his father Kesulal was cleaning the cow shed. He cannot move and not surprisingly, has never seen a school. "This is all we have", says his father showing a laminated disability certificate signed by a doctor, neatly kept in a suitcase, when asked about what they do to help their son. We suggested to him to take Nanalal to Narayan Seva Sansthan Center, an NGO in Udaipur, where they help such children of Cerebral Palsy. "His mother does not

have some pension money though", he replied. They seem to have just accepted the state of the child and are not making any efforts towards improving it.

We then met the mother of Naru Ji on their family farm. Naru Ji is completely blind and was admitted to a blind school in Udaipur where he is studying in 9<sup>th</sup> standard. Naru Ji was lucky to be spotted by a government officer who provided the proper guidance and initial encouragement to his hesitant family. "My son is the most talented in his school" said his proud mother, with tears in her eyes. Cases like these are rare.



Meeting the Sarpanch on the penultimate day of the stay, we realized that he was not aware of either the Swavlamban card or any other scheme that the Government was offering for the disabled. "Jabhi jaroorat ho tabhi ek-adha hazaar rupaye de dete hain hum" was his reply on whether he had done anything to support the needs of disabled people in the Panchayat.

*Pic: L to R - Narendra Ji, Sahoo, Me, Sarpanch and Chaitanya after meeting with Sarpanch at his home.*

Not a single disabled person in the village had the UDID Swavlamban card. The total surrender to circumstances was ubiquitous among persons with disabilities and their families. A quiet acceptance of their fate, where there was neither the will nor the motivation to avail better care and support services from the government. The support from the government in its part is ad-hoc.

## 5. Conclusions

The study paints a dismal picture of persons with disabilities in remote and rural parts of Rajasthan. They are denied access to education, and receive little or no support from the government in terms of care, counselling or physical aids which can alleviate their immediate condition to an extent and provide them with better opportunities for the future.

**Limited coverage of PwDs under Disability Certificate and UDID:** The apathetic attitude is seen in the fact that only 38% of PwDs have Disability Certificates and 10% have UDID cards. Women fare dimly in this regard, as only 1 out of 12 women had a Disability Certificate. Applying for the Disability Certificates and UDID is purely based on the initiative of the PwDs and their care-givers. While many lack awareness regarding Disability Certificates and UDID, the complicated processes are also a deterrent.

Government at the local level, represented by Sarpanch and other officials are unaware of the various schemes and support that is laid out through Policies and Acts by the government for PwDs and lack capabilities to support PwDs.

**Illiteracy, work and continued dependence:** A large number of PwDs are illiterate, and will need to be dependant in more ways than one. This in turn has implications on their physical health and abilities, the type of work they can do, and the support they would need from their families. The families of PwD, as primary care-givers unconditionally accept their role and provide whatever care and nourishment they are capable of. Most PwDs make themselves useful in the family by taking up whatever work they can do, with a majority of them helping in the farms and in agriculture related activities.

**Aspirations of PwDs:** Most PwDs feel accepted and cared for by their families, though the same cannot be said for acceptance in the community, where they may still face discrimination. Their aspirations commensurately are with regard to getting respect, and also in terms of earning incomes and being independent. The care givers of PwDs wish for them to be married. A large number of PwDs (60%) said they have no aspirations, signifying how they have resigned to their fate and do not have the motivation or ability to improve their well-being.

By and large, PwDs in rural parts of India remain invisible and neglected as far as the government is concerned, and it remains to their families to provide whatever care and support they can through their lives.

## 6. Recommendations

Widespread awareness efforts are needed to spread information about the Rajasthan Rights of Persons with Disabilities Rules, 2017 and the Rights of People with Disabilities Act 2016 enacted by the Government of India as well as information about benefits and schemes of the state and national government.

Capacities of representatives of local governments and other functionaries need to be built with regard to schemes and benefits for PwDs, as well as the process for enrolment for Disability Certificate and UDID.

Proactive efforts must be made by Block Level Officials to identify PwDs in remote rural areas and extend relevant benefits to them. Collaboration with local NGOs, who have strong community connections may be beneficial in this regard.

Counselling services to PwDs and care-givers are of paramount importance to understand their needs and to provide solutions which are suited to their requirements.

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