

Disability Bulletin

Developments in Disability Law & Policy

Edition 4

Policy Developments

1) Developments in Issuance of a Permanent Disability Certificate for Persons with Sickle Cell Disease

The Ministry of Health and Family Welfare and the National Health Mission released the [Guidelines for Guidelines for National Programme For Prevention and Management Of Sickle Cell Disease: National Sickle Cell Anaemia Elimination Mission 2023](#) with a goal to eliminate the disease by 2047. The three strategic pillars defined for elimination are:

1. Primary prevention strategies,
2. Secondary prevention and screening strategies,
3. Holistic management and continuum of care.

When Sickle Cell Disease (SCD) was included in the list of disabilities under the RPWD Act, 2016, patients could avail of disability certificates with a one-year validity. Given the nature of the disease (i.e., one of permanency - being both chronic and progressive), the Department of Empowerment of Persons with Disability (DEPwD) increased the validity of the certificate for SCD for [3 years](#) and lowering the minimum percentage of disability to 25% after great push from the Department of Tribal Affairs.

Disability identification and care is defined under the Ministry of Health, and the Department of Social Justice and Empowerment actually issues the disability certificate. The Ministry of Tribal Affairs, due to the large prevalence of SCD among the tribal population (1 in 86 births), is keen to review the [guidelines](#) for the disability certificates. Despite the chronicity of the disease, the Ministry of Health and Family Welfare insists on the detection of the disease rather than focusing on the issuance of permanent disability certificates. This dissonance creates gaps in the implementation

of policies and ideologies around disability. However, [talks are ongoing](#) between the Ministry of Social Justice and the Ministry of Health to issue permanent disability certificates to those with SCD above the age of 5 years and who meet the criteria as decided by the Ministry of Health and Family Welfare.

2) The Indian Sign Language Research and Training Center Introduces an Online Self-Learning Course

On the day of the International Day of Sign Language, September 23rd, the [Indian Sign Language Research and Training Center](#) (ISLRTC), DEPwD, Ministry of Social Justice and Empowerment, launched an online self-learning course and a comprehensive dictionary containing 10,000 ISL terms. The online resource will serve as a valuable tool for individuals seeking to expand their vocabulary and fluency in [Indian Sign Language](#).

Additionally, the Indian Sign Language Research and Training Center in collaboration with [Societe Generale](#) and [V-Shesh](#), introduced a significant initiative by launching 260 signs for financial terms in Indian Sign Language. This initiative is aimed at bridging communication gaps between hearing impaired and hearing individuals working in the financial and banking sectors. It will also improve the employment opportunities for deaf/hearing impaired job-seeking youths. The online course has 10 modules which comprise 30 essential topics that cover basic everyday communication. The course can be accessed on

1. www.isirtc.nic.in under 'Resources' - Online Basic Indian Sign Language in Course in Self-Learning Mode, And/or
2. Access through the official [YouTube channel](#)

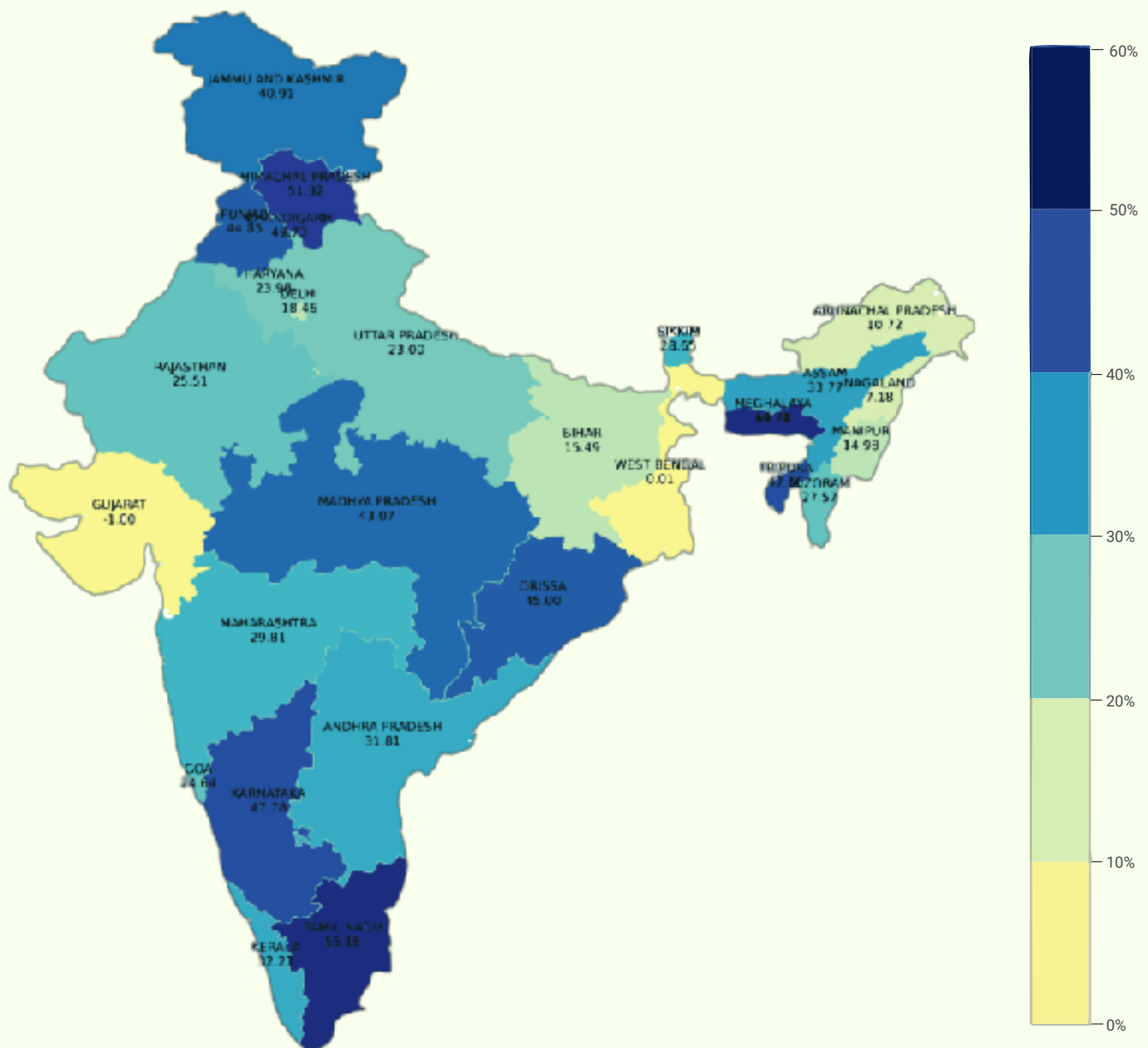
Other initiatives by the ISLRTC include the signing of an MoU with the National Council of Educational Research and Training (NCERT) on October 6, 2020, for converting NCERT textbooks from classes 1 to 12 into Indian Sign Language (digital format) to make the textbooks accessible to children, teachers, teacher educators, parents and others from the with hearing impaired community.

3) Where to Obtain Aggregated Data on Issued UDID Cards?

[Aggregate data on UDID](#) can be obtained under the Swavalamban website. However, the department has [removed](#) all socioeconomic indicators such as household income, employment status, education, and caste in the database. Currently, the data on the cards issued are given based on a district-wise breakdown of UDID per State distributed across disability type, age group, and gender.

Early analysis of the coverage of the UDID cards per proportion of population was done by Pacta. Below is the map indicating how states are fairing on UDID.

Mapping Percentage of UDID Registration among Person with Disabilities (PwDs) in Indian States as of September, 2023



Note: For more information on the data and accessibility (for those using screen readers) data can be found [here](#).

The legend on the right side shows the percentage of UDID coverage, the states with lighter shades of yellow and green have lower UDID coverage while the states with darker shades of blue have better coverage of UDID. The map shows state-wise differences in UDID coverage which can be attributed to state-specific implementation challenges.

The map above shows the state-wise coverage of Unique Disability IDs for persons with disabilities (PWDs) in India. The data on UDID coverage published by the Government of India is mapped in proportion to the estimated/projected number of persons with disability in each state. The estimation of the state-wise population of PWDs in 2023 is arrived at through the following steps:

Step 1. Using [Population Projection Report 2011 - 2036](#) by the Ministry of Health and Family Welfare to arrive at a state-wise projection of the total population of 2023

Step 2. Using [Census 2011 data](#) on state-wise disability prevalence, the present estimate of the total population of persons with disability in each state is calculated. (Prevalence rate/100 * State population of PWDs from Step 1

Legal Developments

1) Supreme Court Reduces Financial Penalty for Student Who Gave Up Medical Admission Seat

In August 2023, the Supreme Court reduced the fee paid to the government medical college in Tamil Nadu (TN) after the student gave up her admission seat due to her disability.

Facts of the case - The petitioner was a medical student with a disability suffering from post-polio residual paralysis with 63% disability. The student sought admission to a post-graduate medical degree as a student with a disability at a government medical college in TN. The petitioner obtained admission after the mop-up and counseling round, but thereafter left the seat and was penalized financially. The TN State rules lay down that a candidate will pay an amount of 15 lakhs if the candidate vacates a seat. This is because the State believes a person is depriving another deserving candidate of the seat in the government medical college. The State additionally requires a bond from all medical students

to serve in rural health care clinics for a stipulated period.

Issue - With stringent rules laid by the State for students taking up admissions in Government Medical Colleges, the student with a disability was asked to pay a heavy fine of INR 15 Lakhs.

Judgment - The court having regarded the peculiar facts of the case directed the petitioner to pay the State INR 5 lakhs and return all documents belonging to the student. The Supreme Court granted the candidate permission to participate in further rounds of counseling for future academic sessions providing her an opportunity to continue her education

2) Anomalies in The Mediation Act, 2023 for Persons with Disabilities

Section 6 read with the First Schedule of the [Mediation Act, 2023](#) excludes disputes involving claims of persons with intellectual disabilities, persons of unsound mind, and persons with disabilities having high support needs deeming them “not fit for mediation.” This exclusion sweeps broadly, encompassing individuals with intellectual disabilities as mentioned in the RPWD Act 2016, those with high support needs under section 2(t), and even persons with benchmark disabilities requiring intensive support for daily life, decision-making, access, and participation. It also extends to individuals diagnosed with mental illness under the Mental Healthcare Act, 2017 and persons deemed of unsound mind. However, this exclusion is discriminatory and denies these individuals easy access to justice.

There are a number of reasons why mediation can be a beneficial dispute resolution process for these individuals.

1. First, mediation is voluntary, so the individual can choose whether or not to participate.
2. Second, mediation is confidential, so the individual's privacy is protected.
3. Third, mediation is a process that is designed to help the parties reach a mutually agreeable resolution, which can be beneficial for all parties involved.

Therefore, based on the basic rights of all individuals having legal capacity (per the UNCRPD, 2007 and the RPWD, 2016), persons with disabilities should not be discriminated against under particular provisions of the Mediation Act, 2023, and should be provided the opportunity to avail such rights with reasonable accommodation.

3) Anomalies between Right of Persons with Disability Act, 2016 and the New Digital Personal Data Protection Act, 2023

The [Digital Personal Data Protection Act, 2023](#) (DPDP Act) and the Right to Persons with Disabilities Act, 2016 (RPWD Act) have inconsistencies in recognition of legal capacity for the rights of persons with disabilities.

The key inconsistency is in the area of consent. Section 9(1) of the DPDP Act requires data fiduciaries to obtain verifiable consent from the lawful guardian in the situation where the person with a disability has a lawful guardian before processing their personal data. However, this is not in line with recognizing the legal capacity of persons with disabilities under Section 13 of the RPWD Act, which provides that persons with disabilities have the right to equal recognition everywhere as any other person before the law.

Furthermore, Section 38 of the DPDP Act provides that in the event of a conflict between the DPDP Act and any other law, the DPDP Act will prevail to the extent of such a conflict. This means that even if the RPWD Act recognizes the legal capacity of persons with disabilities, the DPDP Act could potentially override this recognition.

These inconsistencies create uncertainty for persons with disabilities and their guardians. It is not clear whether the consent of guardians would always be needed, and whether the legal capacity of the person would be considered valid under certain circumstances. This can lead to discrimination against persons with disabilities and prevent them from exercising their rights under the law.

Therefore, it is important to harmoniously interpret the DPDP Act and the RPWD Act in a way that protects the rights of persons with disabilities.