2. Sickle Cell - Science & Technology

India has revised guidelines to recognize Sickle Cell Disease (SCD) as a disability, granting access to welfare schemes under the RPWD Act, 2016. However, this recognition is symbolic as it excludes SCD patients from the crucial 4% government job reservation quota.

Introduction - Revised Guidelines for Sickle Cell Disease

In a significant policy update in March 2024, the Government of India issued revised guidelines under the Rights of Persons with Disabilities (RPWD) Act, 2016. These guidelines are designed to standardize the assessment and certification of disability for individuals suffering from Sickle Cell Disease (SCD) and other related genetic blood disorders, aiming to integrate them into the national welfare framework.

Understanding Sickle Cell Disease (SCD)

Sickle Cell Disease is a complex condition with severe health and social implications, particularly for marginalized communities in India.

Medical Profile - It is a hereditary blood disorder resulting from a genetic mutation that leads to the production of abnormal haemoglobin, called Haemoglobin S (HbS).

Impact on Red Blood Cells - This mutation causes normally round and flexible red blood cells to become rigid and adopt a sickle or crescent shape. These abnormal cells have a shorter lifespan, leading to anaemia, and can block blood flow in small vessels.

Symptoms and Health Effects - Patients frequently experience a range of debilitating symptoms, including -

1. Severe and unpredictable pain episodes (known as vaso-occlusive crises).
2. Chronic fatigue and anaemia.
3. Progressive organ damage (affecting kidneys, lungs, and spleen).
4. Increased susceptibility to infections and a reduced life expectancy.

Social Dimensions in India - SCD disproportionately affects Scheduled Tribe (Adivasi) and other marginalized communities. This makes it not only a major public health issue but also a profound social justice challenge, intertwined with poverty and lack of access to healthcare.

Government Initiative - Recognizing its severity, the Government of India launched the National Sickle Cell Anaemia Elimination Mission (2023–2030). The mission focuses on strengthening screening, prevention, and management mechanisms to combat the disease.

Details of the Revised Disability Guidelines for SCD

The new guidelines provide a structured framework for recognizing SCD as a disability and enabling access to welfare benefits, though with certain limitations.

Coverage of Individuals - The guidelines explicitly cover individuals with specific genetic markers, including -

1. Persons with two sickle cell genes (HbSS).
2. Those with a combination of SCD and Beta Thalassaemia.
3. Those with a combination of SCD and Haemoglobin D (Hb D).

Recognition and Entitlements under RPWD Act - This formal recognition allows affected individuals to claim benefits under the Act, such as -

1. Free school education.
2. Access to various development schemes.
3. Enhanced healthcare services.
4. Housing support and reservation in agricultural land allocation.

Significant Exclusion from Job Quota - Despite this recognition, SCD patients have been excluded from the 4% government job reservation quota. This quota is reserved for persons with "benchmark disabilities," which currently include vision impairment, hearing loss, locomotor disability, and intellectual disability.

Certification Process - The assessment continues to rely on a biomedical and score-based system. This model primarily quantifies visible and measurable complications like the frequency of pain crises, blood transfusion needs, and organ damage, while largely ignoring the profound social, emotional, and economic impacts of the disease.

The Broader Challenge of Disability Certification in India

The issues faced by SCD patients are reflective of deeper systemic problems within India's disability certification framework.

Purpose of a Disability Certificate - It is the foundational document for Persons with Disabilities (PwDs), serving as a gateway to access **constitutional and statutory entitlements**, including government schemes, job and education reservations, healthcare benefits, and pensions.

Current Status (as per 2013–14 Data) -

1. **National Scenario -** A significant gap exists, with only 39.28% of the 2.68 crore disabled persons in India possessing a disability certificate.
2. **State-wise Variations** - Performance varies drastically. States like Tripura (97.72%) and Tamil Nadu (84%) show high coverage, while Nagaland (5.7%), Arunachal Pradesh (7%), and Delhi (21%) lag significantly.

Key Issues in the Certification Process -

1. **Narrow Medicalised Approach -** Medical boards often focus on a single, primary disability, ignoring the reality of multiple or coexisting conditions.
2. **Arbitrary Assessment -** The percentage of disability assigned can be inconsistent and subjective, varying between doctors and institutions.
3. **Accessibility Gap -** PwDs in rural and marginalized communities face immense difficulty in reaching designated government hospitals and medical boards for assessment.
4. **Exclusionary 40% Threshold -** As highlighted by West Bengal’s Social Welfare Minister Sashi Panja, individuals with a disability assessed at less than 40% are denied a certificate, even though they face significant social and economic barriers.
5. **Denial of Rights -** Activists like Shampa Sengupta emphasize that without certification, the rights and reservations guaranteed by law become meaningless and inaccessible.

Systemic Flaws for 'Invisible' and 'Episodic' Disabilities like SCD

The current framework is particularly ill-suited for conditions like SCD, where disability is not always visible or constant.

The "Benchmark Disability" Hurdle - The RPWD Act's requirement of 40% or more impairment to be classified as a "benchmark disability" is a major barrier for SCD patients, whose symptoms are often episodic and fluctuating.

Failure to Capture Lived Reality - The framework fails to account for the true burden of the disease, including chronic pain, severe fatigue, frequent hospitalizations, and the resulting disruption to education and employment.

Accessibility Barriers to Certification - The need for specialized diagnostic tests and travel to district hospitals poses a significant challenge for Adivasi and rural patients who are most affected.

Risk of Symbolic Recognition - By granting recognition under the Act but denying access to the employment quota, the policy risks becoming an act of "exclusion disguised as inclusion," offering symbolic validation without tangible economic empowerment.

Way Forward and Recommended Reforms

A comprehensive, rights-based approach is needed to ensure that the inclusion of SCD translates into meaningful change.

Extend Job Reservations - SCD and related blood disorders must be included under the 4% government job reservation quota to acknowledge their lifelong disabling impact.

Reform the Certification Process - The assessment framework must evolve beyond rigid biomedical scoring. It should incorporate metrics that reflect the lived reality of the disease, such as episodic pain, school/work absenteeism, and socio-economic burdens.

Decentralize Certification - To improve access, certification authority should be extended to Primary Health Centres (PHCs), block hospitals, and mobile medical boards that can reach remote communities.

Adopt a Rights-Based Approach - As scholars like Gargi Mishra and Sarojini Nadimpally argue, disability must be understood as a complex interplay of a medical condition with social exclusion and structural barriers. Policy should reflect this understanding.

Strengthen Digital Integration - The UDID (Unique Disability ID) Card program should be expanded to ensure portability, reduce paperwork, and improve transparency.

Awareness and Stigma Reduction - Targeted campaigns are crucial to reduce the stigma and discrimination faced by SCD patients, particularly those from Adivasi and Dalit communities.

World Sickle Cell Day

Date - Observed annually on June 19th.

Objective - Formally recognized by the United Nations in 2008, the day aims to raise global awareness about SCD as a significant public health challenge and to promote better screening, treatment, and care while reducing social stigma.

Source - [https - //www.thehindu.com/opinion/op-ed/sickle-cell-the-battle-for-disability-justice/article70005373.ece](https://www.thehindu.com/opinion/op-ed/sickle-cell-the-battle-for-disability-justice/article70005373.ece)