

GOVERNMENT OF INDIA  
MINISTRY OF SOCIAL JUSTICE AND EMPOWERMENT  
DEPARTMENT OF EMPOWERMENT OF PERSONS WITH DISABILITIES

**RAJYA SABHA**

**UNSTARRED QUESTION NO.2832**  
TO BE ANSWERED ON: 22.12.2021

**PERMANENT DISABILITY CERTIFICATE TO PEOPLE SUFFERING FROM SICKLE CELL DISEASE**

2832. SHRI SAMIR ORAON:

Will the Minister of Social Justice and Empowerment be pleased to state:

- (a) whether sickle cell is a chronic/incurable disease, if so, whether Government proposes to give permanent disability certificate instead of temporary disability certificate to the people suffering from it;
- (b) the number of people suffering from sickle cell in India out of that the and number of people from tribal community out of that;
- (c) whether Government is contemplating on setting up a 'Centre of Excellence' in all the States to provide timely and proper treatment to sickle cell patients; and
- (d) whether Government is considering any pension scheme for these patients?

**ANSWER**

MINISTER OF STATE FOR SOCIAL JUSTICE & EMPOWERMENT  
(SUSHRI PRATIMA BHOUMIK)

(a): As per the Rights of Persons with Disabilities (RPwD), Act 2016, sickle cell disease means a hemolytic disorder characterised by chronic anemia, painful events, and various complications due to associated tissue and organ damage; "haemolytic" refers to the destruction of the red blood cells which leads to the release of haemoglobin from within the red blood cells into the blood plasma. The Ministry notified guidelines for assessment of various specified disabilities including disability caused due to blood disorders such as sickle cell disease on 04.01.2018. It was initially prescribed in these guidelines that in case of sickle cell disease, in patients with severe disability with score above 80%, permanent certificate could be issued. In other cases it was required to be reviewed periodically with at least one year of interval as these diseases are progressive in nature. Review of these guidelines is a continuous process. These guidelines were last amended with respect to assessment of disability caused due to blood disorders on 03.08.2021 vide which it is now stipulated that the process of evaluation is dynamic and to be reviewed periodically at an interval of three years instead of one year as stipulated earlier.

(b): The Ministry relies on Census 2011 data with respect to persons with disabilities. The last Census 2011 does not provide data regarding persons with sickle cell disease as this disability was not included under the repealed Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995. The Ministry implements Unique Disability Identity Project (UDID) to create a national database of persons with disabilities. As per information available on UDID portal, so far 13677 certificates of disability have been issued for persons with sickle cell disease.

Further, Ministry of Tribal Affairs has informed that though several States and organisations have conducted surveys on incidence and prevalence of sickle cell disease, there is no repository at State or Central level giving the exact number of persons having sickle cell disease.

(c): Public health and hospitals being a state subject, the primary responsibility of management of patients suffering from sickle cell disease including setting up of specialized centers lies with the respective State Governments. The Ministry does not have any proposal to set up Centre of Excellence in all the States/UTs.

(d): Ministry of Rural Development implements Indira Gandhi National Disability Pension Scheme under National Social Assistance Programme. Under this scheme, central assistance is provided to all States/UTs @ Rs. 300/- per month per person with severe or multiple disabilities aged 18-79 years and belonging to family living below poverty line as per the criteria prescribed by the Government. The scheme is applicable to persons with disabilities covered under the repealed Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 and the National Trust Act, 1999. On reaching the age of 80 years, the beneficiaries are paid enhanced central assistance of Rs. 500/- per month. The States/UTs also top up on central assistance depending on their economic capacity. The States/UTs have been advised to provide disability pension to all categories of persons with benchmark disabilities covered under the RPwD Act, 2016.

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