1436. SHRIMATI KANIMOZHI KARUNANIDHI:
Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state:

(a) the number of people affected by Hemophilia in the country especially children, State/UT-wise and number out of them in Tamil Nadu, district-wise especially in the Thoothukudi district;

(b) the measures/policies taken/proposed to be taken by the Government to provide affordable and efficient treatment to Hemophilia patients;

(c) the reasons for not providing PwD (Person with Disability) reservations in Government jobs for people affected by Hemophilia; and

(d) the measures taken/proposed to be taken by the Government to promote the representation of Hemophilia patients in Government jobs and Sports?

ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY WELFARE
(PROF. S. P. SINGH BAGHEL)

(a) to (b)
Health is State subject. The epidemiological data on number of people including children affected by hemophilia in the country is not available centrally.

Under NHM, Government of India provides financial support to the States to strengthen their health care systems along with system of handling blood disorders including Hemophilia based on the proposals submitted by the State/UT Governments in their Programme Implementation Plans. Support is provided for optimal care for hemophilia patients including provision of medicines like anti hemophilic factor and other necessary medicines in coordination with the state health department, training of the required staff and carrying out awareness activities.
As per the guidelines issued by Blood Transfusion services (BTS) division of MoHFW, It is mandatory for all blood centres (Government supported and non-Government supported) to provide blood/blood components free of cost to hemophilia patients.

(c) to (d)

The hemophilia is included under the specified disability category caused due to blood disorder under the Rights of Person with Disability (RPDA) Act, 2016 and disability certificates are provided to persons affected by Haemophilia as per the provisions of this Act.

Under RPDA, every appropriate Government shall appoint in every Government establishment, not less than four per cent of the total number of vacancies in the cadre strength, in each group of posts meant to be filled, with persons with benchmark disabilities. The Act also has a provision for appropriate Government to constitute an expert committee with representation of persons with benchmark disabilities for identification of such posts; and undertake periodic review of the identified posts at an interval not exceeding three years.