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Title: Need to include Hemophilia and Thalassemia in the Disabilities Bill, 2012 so as to accord them the status of benchmark disability.

SHRI KABINDRA PURKAYASTHA (SILCHAR): The draft Right of Persons with Disabilities Bill, 2012 (section 39, chapter 6) released in September, 2012 by the Department of Disability Affairs, Ministry of Social Justice and Empowerment, Government of India, deals with facilities to be awarded to persons with benchmark disabilities. Under the abovementioned section there are 18 types of disabilities. Out of these 18 types only 16 have been included and two excluded from the Bill are Hemophilia and Thalassemia which are critical and life threatening. Hemophilia is a genetic and severe type of bleeding disorder and if not taken care of bleeding can turn into permanent severe disability or even can lead to death.

Hemophilia Federation India is a self help organization working for the welfare of people with Hemophilia. This organization has been trying hard for the last 29 years for inclusion of Hemophilia particularly in the persons with Disabilities Bill. But without any effect. As per survey it is observed that the numbers of Hemophilia affected patients are growing everyday causing threat.

I demand that the Government should seriously take care of the remaining two life threatening diseases and immediately include in the category of benchmark disability, so that the affected people may get equal benefit available to other 16 categories.