CRITICAL ANALYSIS OF SECTION 25, 26 AND 34 OF RIGHTS OF PERSONS WITH DISABILITY ACT, 2016 WITH RESPECT TO RIGHTS OF HEMOPHILIC PEOPLE

SUMIT TAK¹, ASHISH DESHPANDE^{2*}, KSHITIJ NAIKADE³. APARAJITA MOHANTY⁴, ATMARAM SHELKE⁵

¹LLM Scholar, Symbiosis Law School (SLS)

² Assistant Professor, Symbiosis Law School (SLS)

³Assistant Professor, Symbiosis Law School (SLS)

⁴Associate Professor, Symbiosis Law School (SLS)

⁵Associate Professor, Symbiosis Law School (SLS)

Symbiosis International (Deemed University) (SIU), Vimannagar, Pune, Maharashtra, India

*E-mail: profashish@symlaw.ac.in

Abstract: Having a healthy life is the right of every human being. The State has to help people live a healthy life and support people suffering from any disease. In this article, the researcher focuses on one of the diseases called Hemophilia. Hemophilia is a bleeding and genetic disorder. It is included in the Rights of People with Disability Act, 2016. It is a highly neglected disease. There is no research from a legal perspective on this topic. This research paper will help understand hemophilia and gaps under the Rights of Persons with Disability Act, 2016. The researcher will analyse sections 25, 26 and 34 of the Act. After studying and analysing all these things, the researcher will apply the doctrinal method and examine some Conventions, Acts, Case Laws, etc. The researcher finds that these sections do not achieve the purpose of this Act or various conventions done to protect disabled people.

Keywords: State Health Care System, Hemophilia, Bleeding disorder, Genetic disorder, Disability, Benchmark Disability, Discrimination, Equality, Socio-Economic Upliftment, Insurance Policies, Reservation.

Table of Contents

Introduction

- 1. What is hemophilia?1
 - 1.1 According to World Hemophilia Federation:²
 - 1.2 According to Hemophilia Federation India:3
 - 1.3 How do people get hemophilia?
- 2. Objectives of this research
 - 2.1 Research Question:
 - 2.2 Method and Methodology
 - 2.3 Limitation of Research:
- 3. Laws on disabled people
 - 3.1. PwD Act, 1995:
 - 3.2 Objectives of Convention and RPwD Act:
- 4. Laws on Hemophilia and Need to Reform
 - 4.1 Hemophilia: Newly Added in the Disability Act:

¹ "Centers for disease control and prevention", CDC 24/7 saving lives, protecting people, U.S department of health and human services available at

 $www.cdc.gov/ncbddd/hemophilia/facts.html \#: \sim : text = Hemophilia \% 20 is \% 20 usually \% 20 an \% 20 inherited, can \% 20 help \% 20 to \% 20 stop \% 20 bleeding$

² https://wfh.org/humanitarian-aid/

³ https://www.hemophilia.in/index.php/hemophilia/about-hemophilia



- 4.2 RPwD Act, 2016:
- 5. Recommendations
- 6. Conclusion
- 7. Acknowledgement

Introduction

As Human beings, we are blessed to have such a life beyond imagination. Human beings can do anything which others can't. Humans can think, speak, protect themselves, walk, run, jump, learn, hear, sense, feel, eat, prepare, produce food, etc. Other animals don't have any choice way they live. From one point of view, it is very normal, but it makes a vast difference between human beings and other animals. They can't prepare or produce food, can't enjoy the melody of music, taste of food, joy of celebrations, etc. Human beings have the capacity to enjoy it and have the ability to create new things for our betterment. We can live every moment of our life.

These are some aspects for which we should treat ourselves as most gifted to be born as a human. We all need to realise that the fundamental truth we fail to understand is that we are still searching for happiness outside. Many people live human life as punishment, but it is not punishment; it is the ultimate blessing. Human beings can live their lives happily, but in today's world, most humans live their lives in tension, stress, and unhappily with their own created artificial things. This includes disputes relating to family, religion, culture, caste, property, economic, and conflicts between humans due to these reasons being the primary source of unhappiness.

The primary purpose of human life is to live their life happily, which they can as we discussed previously, human beings could think, speak, see, eat, prepare and produce food, walk, run, hear, jump sense, feels, emotions, etc. these things make human unique and blessed. Happiness and human life are closely connected. Generally, human beings don't respect their abilities unless they lose them. The person can speak, see, walk, run, etc.; if a person is met with an accident and loses one of the abilities, and only they can understand the importance of that organ. For example, a person loses his sight afterwards, that person realises the ability to see is a blessing. Therefore, having ability, these abilities for human beings are blessing. Unfortunately, many people are born without these abilities may lose any of these abilities afterwards. People lack the ability; we call them with different terminology like exceptionally able, differently able, disabled etc.

Human beings have some characteristics, and one of the crucial characteristics is to help others, if they can, and to behave with humanity. So as being humans is our primary responsibility to help and support others, especially those who have any disability. People having all these abilities are blessed. Health plays a vital role if people want to live their life happily. Health is one of the essential factors in everyone's life. Good health can carry happiness. Good health means what? World Health Organization defines it.

'World Health Organization' (WHO) defined in 1948,4

"Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity."

WHO Defines Wellness,⁵

"Wellness is the optimal State of health of individuals and groups. There are two focal concerns: the realisation of the fullest potential of an individual physically, psychologically, socially, spiritually and economically and fulfilment of one's roles and expectations in the family, community, place of worship, and other settings."

The human body is a combination of various components. Each organ has its specific work to function the body properly. If any organs do not function correctly, it will create health issues. The human body

⁴ https://www.who.int/about/governance/constitution

⁵ https://www.who.int/data/gho/data/major-themes/health-and-well-

 $being \#: \sim : text = The \%20 WHO \%20 constitution \%20 states \%3A \%20 \%22 Health, of \%20 mental \%20 disorders \%20 or \%20 disabilities.$



has functions to repair some infection or other attack on the body by itself. Still, some organ injuries or infections

Several reasons affect health, for any reason, that can disturb the person's health. Any defect in the functioning system of the body is called a disease. If a person is suffering from any disease, a person's body indicates that something is wrong with the body or the body's functioning system is not well. These indications and signs help to diagnose that particular disease.

There are several reasons that the human body gets affected and will face health issues. Health Science classified these diseases in different categories such as 'Physical, Mental, Inherited, transferable, degenerative, etc. Some diseases are common, some are rare, and some may be transferable to another person. Some disorders are severe, such as Hemophilia; if the proper medication is not taken on time, it can cause death or permanent physical disability. This article is based on hemophilia; the researcher will explain in detail about hemophilia further.⁶

According to 'the U.S. Department of Health & Human Services' stated that,

"Mental health also depends on a person's ability to enjoy life, feel safe and secure, different balance elements of life, such as family and finance and society."

In general case a low socio-economic status reduces access to health care.

According to one study, which was done in 2018 "Frontiers Pharmacology" says that, "People living in developed countries, their life expectancies are more than other underdeveloped or developing countries." They easily have access to health care.

This is State's responsibility to take care of its people. State's Health Care system should help people to maintain their optimal State of health. The life expectancy of people depends on the Nation's health care system, including access to health care and having a healthy lifestyle. Receiving medical treatment on time helps to maintain good health. Physical health will help to maintain mental health. Physical health and mental health are strongly connected. For example, if a person, due to chronic illness, can't do their regular tasks, it may lead to stress or depression. These feelings could be due to accessibility, mobility, social acceptance etc.

Whenever a person suffers from the disease, the person becomes dependent on other people; therefore, that person feels helpless and weak in society. But the Government and society always stand with people suffering from any disease. The Government runs various programmes for the upliftment of those people. Society also supports it.⁸

As we all know, there is no system, which is perfect; we have to work on everything to improve any system. People suffering from diseases and some diseases are recognised as a disability in India. The Rights of Persons with Disability Act, 2016 was enacted in India to protect and give them special rights and reservations to minimise social, economic, and cultural problems. This research paper focuses on one of the diseases called hemophilia bleeding disorder.

1. What is hemophilia?9

"Hemophilia is usually an inherited bleeding disorder in which the blood does not clot properly. This can lead to spontaneous bleeding and bleeding following injuries or surgery. Blood contains many proteins called clotting factors that can help to stop bleeding. People with hemophilia have a low level of either factor VIII or Factor IX. The amount of blood factors determine the severity of a person's haemophilia. The lower the amount of the factor, the more likely it is that bleeding will occur, which can lead to serious health problems."

⁶ https://www.who.int/data/gho/data/major-themes/health-and-well-

 $being \#: \sim : text = The \%20 WHO \%20 constitution \%20 states \%3A \%20 \%22 Health, of \%20 mental \%20 disorders \%20 or \%20 disabilities.$

⁷ https://www.nimh.nih.gov/health/statistics/mental-illness

⁸ https://www.scientificworldinfo.com/2019/12/importance-of-good-health-in-our-life.html

⁹ "Centers for disease control and prevention", CDC 24/7 saving lives, protecting people, U.S department of health and human services available at

 $www.cdc.gov/ncbddd/hemophilia/facts.html \#: \sim : text = Hemophilia \% 20 is \% 20 usually \% 20 an \% 20 inherited, can \% 20 help \% 20 to \% 20 stop \% 20 bleeding$



1.1 According to World Hemophilia Federation: 10

"Hemophilia is a bleeding problem. People with hemophilia do not bleed any faster than normal, but they can bleed for a longer time. Their blood does not have enough clotting factors. The clotting factor is a problem in the blood that controls bleeding. It is quite rare; about 1 in 10,000 people are born with it."

1.2 According to Hemophilia Federation India: 11

"Hemophilia is a genetic disorder in which the patient tends to bleed excessively. The peculiar thing about the transmission of this disease is that only the male suffers from it. The females are only carriers. Unless and until the sufferer bleeds into a vital organ and dies, hemophilia is not a killing disease. However, the type of life, it compels the effected man to limbs, not a small number of hemophiliacs have been known to end their life immaturely. The cause of hemophilia is the inability of the body to produce the anti-hemophilic factor in the required quantity. There is no known cure for this disorder."

In simple words: Person who has a deficiency of factor VIII and factor IX in the blood will suffer from internal and external bleeding episodes.

1.3 How do people get hemophilia?

According to Hemophilia Federation India (HFI):

"Hemophilia is usually inherited, and about 1 in every 5,000 males is born with the disorder. It cannot be caught or transmitted except through inheritance but can sometimes occur with no family history of hemophilia. About one-third of new cases are caused by a new gene mutation in the mother or the child. There is no previous history of hemophilia in the family in these cases. Women who have the hemophilia gene are called carriers, and they can pass it on to their children. When the mother is a carrier, and the father does not have hemophilia, for each child there is a 50% chance that a son will have hemophilia and a 50% chance that a daughter will be a carrier."

Hemophilia is a disease where a person suffering from this disease needs support from the State and society. As we discussed in our introductory part, we discussed how physical and mental health are connected. A person suffering from any disease needs special support to live his life happily.

Many diseases are declared as a disability in 2016's Act for Persons with Disability Act. Hemophilia is also added as one of the disability. There are some provisions of the Act are excluded hemophilia from getting benefits. Somewhere it's discriminatory as compared to other diseases and disabilities. Therefore researcher is trying to cover that gap from the present article.

2. Objectives of this research:

a) To study the application of section 25, 26 and 34 of RPwD Act, in the case of Hemophilia.

2.1 Research Question:

Whether sections 25, 26 and 34 of the Act are discriminatory in the case of hemophilia?

2.2 Method and Methodology

The first step in developing the analytical framework involved identifying whether the signatory states are trying to achieve objectives of the Convention on Rights of disabled people? India has ratified this Convention and is trying to achieve its goals; therefore, India frames the RPwD Act law.

In this research, researchers are trying to determine whether these objectives are achievable or not in hemophilia. In this research, the researcher followed an analytical and critical approach. This research is based on library base material.

The methodology adopted in this research is Doctrinal, in which the researcher has analysed existing laws. Doctrinal research is a suitable method for the present research because it involves the study of

¹⁰ https://wfh.org/humanitarian-aid/

¹¹ https://www.hemophilia.in/index.php/hemophilia/about-hemophilia

¹² https://www.hemophilia.in/index.php/hemophilia/about-hemophilia



various legislations like 'The PwD Act', RPwD Act, Convention, case laws and multiple articles to answer the research question.

2.3 Limitation of Research:

Within the given time frame of the available resources, this research paper covered limited sections of this Act, such as sections 25,26 and 34. The researcher tried to analyse these sections and their application in the case of hemophilia.

3. Laws on disabled people:

Convention was held in New York in the year 2006. As per 'Article 1' of this Convention, "The Purpose of the present Convention is to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and promote respect for their inherent dignity.

Persons with disabilities include those who have physical, mental, intellectual or sensory impairments which faced various barriers may hold back their full and effective contribution in society on an equal basis with others."¹³

Convention signed by India and afterwards ratified it on 1st October 2007. After ratification, it is binding on India to change its National Law relating to Persons with Disability and try to achieve the purpose of the Convention. RPwD Bill, 2014' was introduced on 7th February 2014 in "Rajya Sabha" then it was referred to Standing Committee on 24th February 2014.

Standing Committee produced a report on 7th May 2015; then it was passed on 16th December 2016 in "Rajya Sabha" and afterwards passed in "Lok Sabha" on 16h Dec 2016. The bill replaces 'the PwD Act 1995'. The number of disabilities increased from seven to twenty-one, and Hemophilia is also newly added with other disabilities.

Art. 253 of the Indian Constitution gives the power to enact legislation and effect an international treaty. Parliament had introduced this bill to fulfil the obligation under the Convention that India ratified. And this bill became the Act after it was passed in both houses. Now the question before us is whether this Act can fulfil the purpose of the Convention? Through this research, the paper researcher is trying to find the answer to this question. Hemophilia was newly added in RPwD Act; previously, it was not part of the PwD Act, 1995.

3.1. PwD Act, 1995:

This Act provides equal opportunities to disabled people. The Indian Government has put an Act for the disabled to make sure the disabled can also be a part of or contribute to society. This Act promotes the promotional aspects of rehabilitation to disabled people such as vocational training, education, unemployment allowances, appropriate or suitable employment, houses for severely disabled people etc.

It is ironic that PwD Act. As per Sec. 2(t), "Disable Person means a person suffering from not less than 40% of any disability as certified by a medical authority". Further, the meaning of disabilities is discussed in Sec. 2 (i) in table no. 1

| Sr.No. | Name of Disability | Sr.No | Name of Disability |
|--------|--------------------|-------|----------------------|
| 1. | Blindness | 5. | Locomotor Disability |
| 2. | Low vision | 6. | Mental retardation |
| 3. | Leprosy-cured | 7. | Mental illness |
| 4. | Hearing impairment | | |

Table Number: 1 - Disabilities as per PwD Act, 1995. 14

_

 $^{^{13}}$ Convention on the Rights of Persons with Disabilities (CRPD) (2006) available at un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

¹⁴ Persons with Disability Act 1995 Section 2



These disabilities were part of the PwD Act, but authorities and people still consider these disabilities as disabilities mentioned in table number 1. Other than these disabilities, they have not considered disabilities.

After the Convention, the Convention was mainly held to safeguard disabled people's human rights. They have expanded the definition of disability; based on this Convention, RPwD Act was framed, and this Act has been added more categories of disabilities, which are given below.

Sr.No. Name of Disability Sr.No. Name of Disability Sr.No. Name of Disability Blindness 8. Cerebral Palsy 15. Multiple Sclerosis 1. 2. Low Vision 9. Specific Learning 16. Thalassemia Disabilities 3. 10. 17. **Leprosy Cured Persons** Speech and Language Hemophilia Disability 4. 11. **Impairment** 18. Sickle Cell disease Locomotor Disability Hearing (Deaf and Hard of Hearing) 5. Dwarfism 12. Muscular Dystrophy 19. Autism Spectrum Disorders 6. Intellectual 13. Victims of Acid Attack 20 Chronic Neurological Disabilities Conditions 7. Mental Illness 14. Parkinson's disease 21. Disabilities Multiple including Deaf-**Blindness**

Table 2 - Disabilities as Per RPwD Act, 2016.

These disabilities are newly added because authorities identified that people with these diseases face social stigma, discrimination, health-related issues, etc. Therefore, they need special protection from the State to live life without violating their human rights.

Only adding these disabilities in RPwD Act will not solve the issue and will not achieve the purpose of the Convention. We need to check whether it is adequate to save their human rights? Or is it fulfilling the intent? And if not, we need to update or amend it from time to time. For that, first, we will discuss the objectives of the Convention and RPwD Act.

3.2 Objectives of Convention and RPwD Act:

- a) Respect the dignity, freedom to choose, and their independence;
- b) A person with a disability cannot be discriminated;
- c) To promote equal participation in society;
- d) Accept disabled people as part of society with human dignity.
- e) To provide an equal chance;
- f) Easy Access;
- g) There should be gender equality
- h) To focus on disabled children's rights

4. Laws on Hemophilia and Need to Reform

4.1 Hemophilia: Newly Added in the Disability Act:

Throughout countries, disabled people have been maltreated and facing stigma almost in every society. Disable people are grossly neglected and the most backward section of society. Disable people are considered the weakest of the weak and the poorest of the poor. They have been economically, educationally and socially backwards. Disabled people are not considered part of society; they are also socially discriminated against, with little physical access available. Society treats disabled people differently.



While discussing the people with disabilities, they are considered the weakest or weak. hemophilia disease, one of the types of disability and added recently in RPwD Act. Hemophilia is the rarest bleeding disorder compared to other disabilities. Its medication is very costly, and the numbers of patients are very low in India; there are several reasons behind it, like no proper diagnosis system available no awareness among the people about hemophilia. Therefore numbers of patients are very low, and it is one of the reasons people with hemophilia are highly neglected.

Hemophilia is covere under this Act, but it cannot be generalised how different it is, and it needs special protection compared to other disabilities. We can take the example of their health, Hemophilia is a non-curable disorder it needs to take regular medication. There is no proper health care available to them. Even upper-middle-class people cannot afford medication, and those medicines are only available at some places. Therefore, whether provisions of this Act are appropriate to them or not? Let us first discuss Sec. 25 of RPwD Act; after analysing this section, we can conclude on the applicability of this section relating to health.

4.2 RPwD Act, 2016:

4.2.1 Healthcare¹⁵

i) "The appropriate government and the local authorities shall take necessary measures for the person with disabilities to provide";

"Free healthcare in the vicinity, especially in rural area subject of such family income, maybe notified, barrier-free access in all part of Government and private hospital and other healthcare institution and centers, priority in attention and treatment."

ii) "The appropriate government and the local authorities shall take measures and make schemes or programs to promote healthcare and prevent the occurrence of disabilities and for the said propose shall."

"Undertake or cause to be undertaking survey, investigation, and research concerning the cause of occurrence of disabilities, Promote various methods for preventing disabilities, Screen all the children at least once in a year for the purpose of identifying at-risk cases, Provide facilities for training to the staff at the primary healthcare centers, Sponsor or cause to be sponsored awareness campaigns and disseminate or cause to be disseminated information for general hygiene, health, and sanitation, Take measure for pre-natal and post-natal care of mother and child, Educate the public through the pre-school, school, primary health centers, village level worker, and Anganwadi workers, Create awareness amongst the masses through television, radio, and other mass media on the causes of disabilities and the preventive measure to be adopted, Healthcare during the time of natural disaster and other situation of risk, Essential medical facilities for life-saving emergency treatment and procedures, Sexual and reproductive Healthcare especially for women with disabilities."

As par Sec. 25 of this Act is one of the examples where it will not be an element in the case of hemophilia. Clause-I of this section says that the Government has to give Healthcare free of cost, easy access to all hospitals, preference in attendance and treatment. But in reality, there is no treatment available for hemophilia in most government hospitals and not even in private hospitals, so there is no question about free treatment or free health care.

As per Clause-II, if this section says that, surveys, investigation, and research relating to the cause of occurrence of disabilities, promotion of different methods to prevent disabilities, give facilities to train primary health care workers and staff, pre and post-natal care of child and mother. Essential medical facilities and life-saving treatment should be available during natural disasters and emergencies. While discussing hemophilia, there no measures would be taken for the prevention of disability or preventing hemophilia, hemophilia considered as a genetic disorder so that the Government can frame containing policies for it. There are no medical facilities for life-saving emergency treatment. Several hemophilia patients are dying in emergencies due to the unavailability of treatment. Many suffer from excessive bleeding and pain and become victim of physical disability. After analysing this section, the researcher concludes that there is a lack of implementation of this

-

¹⁵ Persons with Disability Act 1995 Section 25



section in hemophilia disease. This section can apply to hemophilia patients to get proper treatment and medication.

The further researcher will discuss section 26 of the RPwD Act, 2016. Section 26 relates to insurance schemes; after analysing this section, we know whether insurance schemes framed under this section apply to hemophiliac patients.

4.2.2 Insurance schemes':16

"The appropriate Government shall, by notification, make insurance schemes for their employees with disabilities".

"The previously genetic disorder was not covered under the Health Insurance Policies and was mentioned in India's Insurance Regulatory and Development Authority. On 19th March 2018, issued in pursuance to the judgment of the Hon'ble High Court of Delhi dated 26th February 2018, directed IRDAI to relook at the exclusionary clauses in the *insurance contracts and ensure that insurance companies do not reject claims based on the exclusions relating to genetic disorders*. On 27th August 2018, Hon'ble Supreme Court of India, while hearing Special Leave Petition has, granted a stay on the operation of the said judgment of the Hon'ble High Court of Delhi to the extent of the conclusions and reliefs granted under (i) to in the said judgment unit further orders."¹⁷

"Because of the above stay granted by the Hon'ble Supreme Court of India on 19th, March 2018, stands abated until further orders. However, the claim settlement in respect of all extant policies shall be as per the terms and conditions of the policy contracts as approved by the Authority in accordance with the applicable regulatory framework. After these orders of The Supreme Court of India, India's Insurance Regulatory and Development Authority modify its regulations and convey modify rules to all life, General, and health Insurers on 5th September 2018 through a notification." Then genetic disorder can be covered under health insurance, but still, the problem is not resolved because now, as per the new rules/regulations of IRDA, the clause of genetic has been removed. Still, no company has formed or offered a new policy after that. If any company offers a new policy, they have to consider this a pre-existing disease and a waiting period of, say, 48 months max can be kept. After putting this pre-existing disorder, the company denies giving the policy. Every company has a right to decide whether to give or not to give policy. One can fight with the company only after they deny the claim. Still, they refuse policy to people with a genetic disorder (hemophilia), so no question arises to fight for the claim.

Recently the Government has introduced 'Swavlamban Health Insurance Scheme' 18, especially for disabled people. They have covered all disabilities, as per the Rights of Person with Disability Act, 2016. If we check that policy, Sum insured of Rs. Two lacs a family floater for a period of twelve months, although it will cover up to Rs 2,00,000/- that is not sufficient in case of hemophilia because the cost of medicines is too high. So we can say this policy is not appropriate for hemophilia. So we can say that there are various insurance schemes available to people with disability, but unfortunately, those schemes are not helpful for people with hemophilia.

The researcher will discuss section 34 of the RPwD Act, 2016, the most crucial section for claiming reservation policies for people with disabilities.

4.2.3 Hemophilia is not covered under benchmark disability:

Rights of Persons with Disabilities (RPWD) Act 2016', 'the disability has been defined based on an evolving and dynamic concept, the types of disabilities have been increased from existing Seven to Twenty-One which will be helpful for the empowerment of person with a disability.'

¹⁶ Persons with Disability Act 1995 Section 26

Gauri Shankar v. Union of India, AIR 1995 SC 55 at 58 : (1994), 6 SCC 349. (P.g no. 879-880 of Indian Constitutional Law- M.P Jain 7th Edition 2014, Publication of Lexis Nexis.) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6482682/

¹⁸ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6657542/



Still, this Act needs to improve because some of the disabilities added in this Act are not included under the benchmark category. Therefore they are not getting equal rights as other people with a disability get. So we can say that there are discriminations among the equals,

Specially bleeding disorders, which include Hemophilia, Thalassemia, and Sickle Cell disease

4.2.3.1 RPWD Act, 2016¹⁹

(1) "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, one per cent. Under clauses (a), each shall be reserved for persons with benchmark disabilities under clauses (a). (b) & (c) and one per cent. For persons with benchmark disabilities under clauses (d) & (e), namely:"

| Name of Disability | Name of Disability | |
|---|---|--|
| a) 'Blindness and low vision.' | d) 'Autism', 'intellectual disability', | |
| | 'specific learning disability', and 'mental | |
| | illness'.' | |
| b) 'Deaf and hard of hearing.' | e) 'Multiple disabilities from amongst persons under clauses (a) to (d) including deaf-blindness in the posts identified for each disability' | |
| c) 'Locomotor disability' including 'cerebral palsy', 'leprosy cured', 'dwarfism', 'acid attack victims' and 'muscular dystrophy' | | |

Table 3 - Disabilities Covered under benchmark disabilities.

"Provided that the reservation in promotion shall be in accordance with such instructions as are issued by the appropriate Government from time to time: Provided further that the appropriate Government, in consultation with the Chief Commissioner or the State Commissioner, as the case may be, may, having regard to the type of work carried out in any Government establishment, by notification and subject to such conditions, if any, as may be specified in such notifications exempt any Government establishment from the provisions of this section."

This section provides special protection (Reservation) to disable people in Government Jobs, but the only for the benchmarked disabilities which are mentioned from clause a to d. none of the clauses covered Hemophilia, therefore the Hemophiliac persons cannot claim reservations in Government Jobs, so even though Hemophilia covered under this Act. Rights of people with Hemophilia violated. There are many other aspects where this Act does not focus on blood disorder, like education, financial support, rehabilitation scheme, etc. There is no such specific mechanism for saving the rights of people with Hemophilia. The word hemophilia is mentioned only in the last part of this Act, saying that Hemophilia is caused by disability.

Researchers observed that many hemophiliacs, even qualified for the post, in government jobs; still, they were rejected, saying that people with Hemophilia are not fit for any post. They cannot do any kind of post job. Hemophilia is not covered under benchmark disability. Then the question arises why "Hemophilia' is added under the disability Act? Why can people with Hemophilia not claim their rights like other people with disability?

The principle of equality of law thus means not that the same rule should apply to everyone. Still, that law should deal equally with all in one class: that there should be equal treatment under similar circumstances, which means that equal should be treated equally.

This Act has included Twenty-One disabilities then all disabilities should be treated equally. After analysing all these aspects, there should be some rules suitable for specific disabilities. There is a

-

¹⁹ Persons with Disability Act 1995 Section 34



violation of 'Article 14 of the Indian Constitution. The researcher found that there is a need to amend the present Act, as per the requirement of the disability, to achieve objectives of this Act and for saving the rights of people with Hemophilia.

5. Recommendations:

- a) Need to amend present Act for saving rights of people with Hemophilia
- b) Need to add specific provisions relating to health, education, employment, and other aspects with respect to blood disorders.
- c) It should be covered under benchmark disability.
- d) Need to apply preventive measures specifically for the genetic disorder like "Hemophilia
- e) Need to focus on blood disorders.

6. Conclusion:

Hemophilia is a bleeding disorder that we need to control. Therefore the Government has included it in the "The Rights of Person with Disabilities Act, 2016". But provisions of this Act are not adequate to save "Rights of People with Hemophilia", as the researcher discussed section 25. 26, and 34 of this Act in this article and explained how it does not apply to Hemophiliacs. Therefore, there is a gross violation of the human rights of Hemophiliacs, and the researcher concludes that there is a need to amend this Act to protect the rights of people with Hemophilia and other people who are suffering from other blood disorders.

Acknowledgement

The authors wish to acknowledge Symbiosis Law School for providing the library facilities.

Conflict of Interest: There is no conflict of interest among the authors.

Funding: Self-funded

Ethical approval: Not applicable

References

- [1] Anuradha Mohit, Meera Pillai & Pratiti Rungta. (2006), Rights of the Disable. National Human Rights Comission. p.g (10-11). Retrieved from nhrc.nic.in/sites/default/files/DisabledRights.pdf
- [2] Centres for Disease Control and Prevention. What is Hemophilia? Retrieved from www.cdc.gov/ncbddd/hemophilia/facts.html
- [3] Convention on the Rights of Persons with Disabilities (CRPD), 2008
- [4] Gauri Shankar v. Union of India, AIR 1995 SC 55 at 58: (1994), 6 SCC 349. (P.g no. 879-880 of Indian Constitutional Law- M.P Jain 7th Edition 2014, Publication of Lexis Nexis.) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6482682/
- [5] Insurance Regulatory and Development Authority of India. (2018), Blood Disorder. Retrieved from www.irdai.gov.in/ADMINCMS/cms/Circulars_Layout.aspx?page=PageNo3588&flag=1
- [6] Joseph Wilson James, Chethan Basavarajappa Thanapal Sivakumar, Ruma Banerjee, and Jagadisha Thirthalli.(2019), Swavlamban Health Insurance scheme for persons with disabilities: An experiential account. Indian J Psychiatry Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6657542/#:~:text=The%20Swavlamban%20Health%20Insura nce%20Scheme%20was%20the%20first%20government%2Dsubsidized,insurance%20for%20PwD%20in%20India.&text=Currently%2C%20mental%20retardation%2C%20cerebral%20palsy,Ayushman%20Bharat%3A%20PM%2DJAY www.irdai.gov.in/ADMINCMS/cms/Circulars_Layout.aspx?page=PageNo3588&flag=1
- [7] M.P Jain. (2014), Indian Constitutional Law. (7th ed) Lexis Nexis.)
- [8] Ministry: Social Justice and Welfare. The Right of Persons with Disabilities Bill, 2014
- Persons with Disabilities (Equal Opportunities, protection of Rights and Full Participation), Act 1995
- [9] Prashant Srivastava and Pradeep Kumar. (2015), Disability, Its Issues and Challenges: Psychosocial and Legal Aspects in Indian Scenario. Delhi Psychiatry Journal Vol. 18 No. 1, Retrieved from www.researchgate.net/profile/Pradeep_Kumar142/publication/277139451_Disability_Its_Issues_and_Challe nges_Psychosocial_and_Legal_Aspects_in_Indian_Scenario/links/5c3a192892851c22a36fa110/Disability-Its-Issues-and-Challenges-Psychosocial-and-Legal-Aspects-in-Indian-Scenario.pdf;Retrieved from www.prsindia.org/billtrack/the-right-of-persons-with-disabilities-bill-2014-3122



- [10] Suresh Bada Math, Guru S. Gowada and others. (2019), The Rights of Persons with Disability Act, 2016: Challenges and opportunities. Indian J Psychiatry. Retrieved from www.indianjpsychiatry.org/temp/IndianJPsychiatry61108094894073_133540
- [11] The Persons with Disabilities Act of 1995. (2016), Retrieved from yourstory.com/2016/05/disabilities-act-simplified#:~:text=The%20government%20of%20India%20has,force%20on%20February%207%2C%201996
- [12] The Rights of Persons with Disability Act, 2016.
- [13] Uma Jadhav, Kanchan Mukherjee, Anil Lalwani, (2014) Ethical issues in the care of persons living with haemophilia in India. Indian J Med Ethics Retrieved from https://ijme.in/articles/ethical-issues-in-the-care-of-persons-living-with-haemophiliain-india/?galley=html
- [14] World Hemophilia Federation- Introduction to hemophilia, Retrieved from elearning.wfh.org/elearning-centres/introduction-to-hemophilia/#what_is_hemophilia

Books and Journals articles

- [1] Indian Constitutional Law- M.P Jain 7th Edition 2014, Publication of Lexis Nexis.
- [2] V.N.Shukla's Constitution of India- Twelfth Edition 2016, Publication of Eastern Book Company.
- [3] Mason and McCall Smith's Law and Medical Ethics- J.K. Mason and G.T.Laurie , 7 th Edition 2006, Publication Oxford University Press.
- [4] Rajendra Pratap Gupta, Health Care Reforms in India: Making up for the lost decades, Publication: Elsevier, Reed Elsevier India Pvt. Ltd. Year 2016..)