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Rajrupa Basu & Saptaparni Raha

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# **THE HUMAN RIGHTS OF PERSONS SUFFERING FROM ALBINISM: A DISCUSSION ON LAW & POLICY FRAMEWORK**

Rajrupa Basu<sup>1</sup> & Saptaparni Raha<sup>2</sup>

## **INTRODUCTION**

Albinism is the Latin terminology, that originates from the word 'Albus' which means white. It is a rare genetic disorder that happens by the complete or partial absence of melanin pigmentation of skin, hair, and eyes. It happens due to a defect of tyrosinase. Albinos are sometimes having eye problems and their skin conditions sometimes lead to skin cancer. Countries like America, China, Japan, and Africa are common for albinism. They are facing exploitation due to their skin colour. In India, about 100,000 to 200,000 are suffering from albinism. Many people in India are not aware of this disease, so people often misunderstood it as Leucoderma or an unknown disease. They face social and family discrimination for their different appearance<sup>3</sup>.

However, in order to discuss the disease albinism in particular and the fate of the sufferers, that how their human rights are infringed, it is pertinent to discuss the relevant laws and policy frameworks across the globe and in India.

## **ALBINISM IN INTERNATIONAL LEGAL INSTRUMENTS**

It is recognized by the Universal Declaration of Human Rights in Article 2 that all person shall enjoy their rights without being subjected to any discrimination.

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<sup>1</sup> LL.M Candidate and Advocate, High Court at Calcutta.

<sup>2</sup> Law Student, LLM Aspirant.

<sup>3</sup> Albinism in India: A Situation Analysis (2019), submitted by White Paper Research & Analysis Pvt. Ltd. May 19, 2022. Page No. 3 & 4.

Articles 23 and 25 of this instrument said that all people shall have just and favourable conditions of work and they should have a standard of living with adequate health and wellbeing for themselves and their families.

Article 55 of the Banjul Charter as the optional protocol of the convention on the rights of persons with disability mandates the commission to receive communications other than those of states.

Article 3 of the African Court of Human Rights mandates that receiving individual communications and deciding on possible violations of albinism can be a prime focus under the convention on the rights of persons with disabilities to protect their Rights like Equality (Art.5), Life (Art.10), Liberty and Security (Art.14) and freedom from torture (Art.15)<sup>4</sup>.

### **ALBINISM: WHETHER A DISABILITY UNDER THE INDIAN LEGAL FRAMEWORK OR NOT?**

India being a signatory to the United Nations' Convention on Rights of Persons with Disabilities<sup>5</sup> enacted and implemented The Rights of Persons with Disabilities Act, 2016<sup>6</sup>. The said statute empowers persons with disabilities and promotes the rights of persons with disabilities in India. However, the said statute has no specific provisions relating to the rights of the albinos (person affected by Albinism). Albinism is a rare genetic condition where the skin contains no or less melanin which results in whitened skin and hair colour and low vision. However, people infected with albinism face certain social stigma and prejudices. If we see Pullan Family from North Delhi are addressed as "*Angrez*" for fair skin due to albinism. This family belongs from South India but they

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<sup>4</sup> Demystifying Albinism: An analysis of Legal, Social and Cultural practices in the Lake Victoria Region (2011-2012), Giorgio Caviglia, May 20, 2022. Page No. 22-27.

<sup>5</sup> Convention on the Rights of Persons with Disabilities, 2008 ("CRPD").

<sup>6</sup> The Rights of Persons with Disabilities Act, 2016 ("RPWD").

moved to Delhi for better acceptance. Pullan boys were fond of cricket but no one wants to take them in their team. They are living tough life<sup>7</sup>.

The Society seem to believe that the albinos have a certain superpower which they tend to use for evil purposes. They are reportedly facing problems in education, workplace and employment<sup>8</sup>. Government of India in 2016 included albinism under the rights of persons with disabilities Act. As mentioned earlier, India has no specific statutes on the empowerment of the albinos. However, there are general provisions relating to human rights. Also, the Constitution of India, 1950 contains some provisions such as Article 14 (Right to Equality) & Article 21 (Right to Life and Personal Liberty)<sup>9</sup>.

Further, in India an NGO named Jan Vikas Samiti provides support to albinos to ensure safety, health, education and non-discrimination by educating common mass, and also provides an appropriate recommendation to the government so that they can extend their support<sup>10</sup>.

## **SUGGESTIONS & RECOMMENDATIONS**

As it is very evident that India promotes unity in diversity. It has many cultures, customs traditions, rules and so on. And in many rural parts of India albinos are being stigmatized, they are being humiliated and put down and ever not allowed to lead a life with dignity as propounded by the Constitution framers by and through Article 21, that is to say, right to life & personal liberty. The authors shall suggest the appropriate authority to include the rights of persons with albinism in The Rights of Persons with Disabilities Act, 2016 by way of amendment

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<sup>7</sup> A Delhi family feels singled out for their skin: Arun Sharma.

<sup>8</sup> Supra 1.

<sup>9</sup> Constitution of India, 1950.

<sup>10</sup> How One Man and His Team are Helping Albinos come out of their shell and fight discrimination: Neeti Vijaykumar.

of the said statute. It can also be done like enacting and implementing a different statute on the subject in order to curb this form of social evil.

## **CONCLUSION**

National Human Rights Commission is responsible to protect the human rights of people and address the violation so that the commission can take some measures to prevent such violations. But till date they have not recognized the albinism, Commission should recognize them as soon as possible. However, so far as Albinism is concerned, it needs social and mass awareness and despite that no changes can be to the sufferer's life in particular and the society in general.