



Right of Persons with Disabilities Act 2016 & Dwarfism

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Abstract:

*After India signed and ratified the UNCRPD in 2007, the process of enacting a new legislation in place of the Persons with Disabilities Act, 1995 (PWD Act, 1995) began in 2010 to make it compliant with the UNCRPD. After series of consultation meetings and drafting process, the Rights of PWD Act, 2016 (RPWD Act, 2016) was passed by both the houses of the Parliament. In the RPWD Act, 2016, the list of disabilities has been expanded from 7 to 21 conditions includes i.e. cerebral palsy, **dwarfism**, muscular dystrophy, acid attack victims, hard of hearing, speech and language disability, specific learning disabilities, autism spectrum disorders, chronic neurological disorders such as multiple sclerosis and Parkinson's disease, blood disorders such as haemophilia, thalassemia, and sickle cell anaemia, and multiple disabilities. There are various discrepancies which kills the right of some genuine victims. This paper mainly focuses on only dwarfism and their definition, height, physical problem, needs, provision and revision need in policy.*

Key words: dwarfism, RPWD Act. and stature

Introduction:

People with dwarfism have short stature means under 4' 10" as an adult. They are usually of normal intelligence. Dwarfism most often does happen in families where both parents are of average height. More than 300 different conditions can cause dwarfism. Achondroplasia is the most common type of dwarfism. It is a genetic condition that affects about 1 in 15,000 to 1 in 40,000 people results arms and legs short in comparison to head and trunk, also a larger head and weak muscle tone. Other genetic conditions, kidney disease, and problems with metabolism or hormones can also cause dwarfism. The conditions that cause dwarfism can also cause other health problems. With proper medical care, most people with dwarfism have active lives and live as long as other people.

As per definition of Person with Disability Act, 1995 (PWD Act, 1995) defined disability means (i) Blindness; (ii) Low vision; (iii) Leprosy-cured; (iv) Hearing impairment; (v) Loco motor disability; (vi) Mental retardation; (vii) Mental illness. Rather than above seven criteria there is huge need to include several type and criteria

of disability in old policy. Now the disability has been redefined based on an evolving and dynamic concept. In the Rights of Person with Disability Act, 2016 (RPWD Act, 2016) the term “person with disability” means a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others. In the RPWD Act, 2016, the list of disability has been expanded from 7 to 21 and includes other remains disabilities i.e. cerebral palsy, **dwarfism**, muscular dystrophy, acid attack victims, hard of hearing, speech and language disability, specific learning disabilities, autism spectrum disorders, chronic neurological disorders such as multiple sclerosis and Parkinson’s disease, blood disorders such as haemophilia, thalassemia, and sickle cell anaemia, and multiple disabilities.

“Abled does not mean enabled. Disabled does not mean less abled”- Khang Kijarro Nguyen

Review:

There are mainly five types of disability RPWD Act, 2016 namely- Physical disability, Intellectual disability, mental behaviour, disability cause due to some criteria and multiple disabilities another sixth category may be notified by Government of India later. In four types of physical disabilities one is Locomotor disability and it is also divided in five types- Leprosy cured person, Cerebral palsy, **Dwarfism**, muscular dystrophy and Acid attack victims. In 2005, Srinivasulu formed a group and filed a petition in the Andhra Pradesh High Court seeking special status for dwarfs. The petition demanded free public transport passes, right to education and loans at low interests. The group got a favourable response and these facilities are being provided to the dwarf population in state of Andhra Pradesh and Telangana. A study done by Preetam Nath (2013) on child growth included 2,500 consecutive admissions to Bai Jerbai Wadia Hospital for Children in Bombay, India; 140 (5.6%) were considered to be of short stature (less than the 5th percentile of an Indian standard). *“On 3.7.2015, we had issued the directions on a letter petition sent by the petitioner stating that he is a dwarf with the height of 4’6” and is being discriminated in the employment. He has prayed that dwarfs should be included in the Schedule of the Disabled Persons by the Central Government as well as the State Government for giving reservation in appointments”* High court of judicature for Rajasthan at Jaipur bench, civil writ (PIL) Petition no.8708/2015 date of order: 5/8/2015. *“There is a need for social awareness and public sensitisation. They are laughed at, stereotyped for certain jobs and discriminated against in several spheres- these need to be corrected”* (Javed Abidi, world chair of Disabled People’s International and director of the National Centre for Promotion of Employment for Disabled People, Delhi). Till 2014, dwarfism was not a separate classification in the Act. Even the 2011 Census which listed 6,105,477 people with locomotor disabilities in India, failed to count dwarfs separately.

Objective:

The main objectives of this paper are as follows-

- To discuss information about RPWD Act, 2016.
- To discuss about dwarfism and their height, physical problem and need.
- To discuss about reservation provision for dwarfism.
- To discuss about some revision need in RPWD Act, 2016 regarding dwarfism.

Description:

Dwarfism is a growth disorder in human. It's most common type is called **achondroplasia**. Typically, adults with dwarfism are 4 feet 10 inches or under. Achondroplasia commonly results in-

- larger head and a prominent forehead
- flattened bridge of the nose
- shortened upper arms and legs and a relatively long torso
- shortened hands and fingers

Little People of America (LPA) defines dwarfism as a medical or genetic condition that usually results in an adult height of 4'10" (147 centimetres) or shorter, among both men and women, although in some cases a person with a dwarfing condition may be slightly taller than that. As per RPWD Act, 2016- *“Dwarfism means a medical or genetic condition resulting in an adult height of 4 feet 10 inches (147 centimetres) or less”*.

Table no. 1 Average human height in India & US (wikipedia.org)

Country	Male	Female	Year
India	164.7 cm (5 ft 5 in)	151.9 cm (5 ft 0 in)	2005-2006
United States	175.7 cm (5 ft 9 in)	161.8 cm (5 ft 3 ½ in)	2011–2014

Ministry of Social Justice and Empowerment (MSJE- 2001) suggests- “Recumbent length or longitudinal height below 3rd percentile or less than 2 Standard Deviation from the mean is considered to have short stature” and “Every 1inch vertical height reduction should be valued as 4% permanent physical Impairment”

Table no. 2 showing average height in India (MSJE June, 2001)

Age	Male			Female		
	Mean.	S.D.	-2S.D.	Mean	S.D.	-2S.D.
21year+	64.64 inches	2.40 inches	59.84 inches	60.24 inches	2.24 inches	55.76 inches
	164.18 cms	6.09 cms	151.99 cms	153.00 cms	5.69 cms	141.63 cms

In India the average height of men and women differ approximately 4 inches or 10 cms while in new provision an adult height of 4 feet 10 inches (147 centimetres) or less under the dwarfism. While the average height of women of United States 161.8 cms compare to India 151.9 cms, means approximately 10 cms difference in average height of women of US and India. The same criteria for labelling followed by India like US for men and women dwarfism. So there is huge need to revise minimum height criteria for both the genders in Indian context.

As per RPWD Act, special provisions for persons with benchmark disabilities section, every appropriate Government shall appoint in every Government establishment, not less than four percent of the total number of vacancies. One percent each shall be reserved for persons with benchmark disabilities under clauses (a), (b) and (c) and one percent for persons with benchmark disabilities under clauses (d) and (e), namely- (a) Blindness and low vision (5,032,463 seeing disabled person by Census 2011); (b) Deaf and hard of hearing (5,071,007 hearing disabled person by Census 2011); (c) Locomotor disability (5,436,604 movement disabled by Census 2011) including cerebral palsy, leprosy cured, dwarfism, acid attack victims and muscular dystrophy; (d) Autism, intellectual disability, specific learning disability and mental illness;

(e) Multiple disabilities from amongst persons under clauses (a) to (d) including deaf-blindness in the posts identified for each disability. Since seeing, hearing and locomotor disabilities are more than 50 lakh in each category by Census 2011 while new policy includes cerebral palsy, leprosy cured, dwarfism, acid attack victims and muscular dystrophy in locomotor disability without increasing percentage in reservation till now it is only one percent. So there is very big need to revise and follow reservation provision as per population and types of disabilities that make justice with dwarfism.

Physical problems with Dwarfism:

- reduced muscle tone and delayed motor skill development
- breathing problems
- limited joint flexibility and arthritis
- lower back pain or leg numbness
- curvature of the spine, such as scoliosis
- recurring ear infections and risk of hearing loss
- bowed legs
- crowded teeth

Students with Dwarfism needs:

- extra time getting to classes due to mobility problem
- extra time on tests if manual dexterity is an issue
- miss assignments or class time due to medical appointments
- step stools for bathrooms, water fountains, classrooms, and other areas
- additional accommodations in the classroom and around school
- feel anxious, depressed, or embarrassed by their size
- be at risk for teasing or bullying
- benefit from an individualized education program (IEP)

Teachers should do:

Our classroom can offer a welcoming and productive learning environment by providing adaptive accommodations where necessary. Students with dwarfism should be able to reach everything their classmates can reach. Treat your students with dwarfism according to their age, not their size. Unless the student has a learning disability, educational expectations should not differ from those of other students. Dwarfism students may be limited in the types of exercises and activities that they can do, but it's very important that they participate in safe physical activities to help stay fit. Students with dwarfism may feel embarrassed around other students. Educating yourself and students about dwarfism can decrease bullying and increase self-confidence for students with dwarfism.

Conclusion and Suggestions:

RPWD is a big weapon for various excluded people and victims who have now become a part of legal beneficiaries. Right of Persons with Disabilities Act, 2016 has really opened the unlimited opportunities for the deprived persons to develop themselves and become a part of mainstream. It has also seen that some real victims may be deprived from their right due to ambiguous or dual rules framed in provision. It is

essential issue to collect the comprehensive information from those victims who are not included in this act and put up their real status before the panel. The level of efficiency and deficiency can be checked by the panel of medical practicer before including in RPWD Act. So there is huge need to logically review the RPWD Act and provide minimum height criteria for both the genders. Also need a new guideline with regard to height especially for women. It is also serious concern to follow reservation as per population and types of disabilities so that the real inclusion would possible in future.

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