BREAKING THE SILENCE ABOUT DWARFISM: FACTS AND MYTHS

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About the Little People of Uganda (LPU)

LPU is a self-help organisation providing and sharing information and support for people with dwarfism and their families. The organisation aims to help reduce the distress and disadvantages of people with dwarfism by trying to:

- Reduce social barriers
- Improve their quality of life
- Enhance the role little people in society
- Lessen the fear and distress of families when a child with dwarfism is born
- Provide friendship, mutual support and encouragement for individuals and their families
- Develop an awareness of diversity and promote equality within the society where little people live.
- The organisation represents little people and their families and acts as an advocate on their behalf.

Facts and Myths about Dwarfism

What is dwarfism?

Dwarfism is a condition where the affected person will not or has not reached 4’10’ in adult height. A dwarf is a person who is of short stature. Of course some people are shorter due to their environment, or perhaps their families are just generally shorter in height i.e. not through a medical condition. Little People of America (LPA) defines dwarfism as a medical or genetic condition that usually results in an adult height of 4 feet 10 inches or shorter, among both men and women, although in some cases a person with a dwarfing condition may be slightly taller than that. The average height of an adult with dwarfism is 4 feet but typical heights range from 2 feet 8 inches to 4 feet 8 inches.
Dwarfism isn’t:

• an intellectual disability. A person who has dwarfism is typically of normal intelligence.
• a disease that requires a “cure.” Most people with the condition can live long, fulfilling lives.
• a reason to assume someone is incapable. Little people go to school, go to work, marry, and raise children, just like their average-size peers.
What causes dwarfism?

There are over 200 conditions that can cause dwarfism, each with its own distinct features, symptoms and causes. Most of these conditions have genetic and mutational causes and the typical characteristic all these forms of dwarfism have in common is a significantly short adult height compared to the average. Other conditions are caused by genes inherited from one or both parents. Skeletal dysplasias (abnormal bone development) are the most common cause of dwarfism. These conditions affect bone and cartilage growth and typically result in disproportionate short stature. Dwarfism has other causes, including metabolic or hormonal disorders in infancy or childhood. Chromosomal abnormalities, pituitary gland disorders (which influence growth and metabolism), absorptive problems (when the body can’t absorb nutrients adequately), and kidney disease can all lead to short stature if a child fails to grow at a normal rate. Most skeletal dysplasias are caused by a Spondyloepipheseal genetic mutation in the egg or sperm cells prior to conception.
Common types of dwarfism

The most common form of dwarfism is achondroplasia. Other more common forms are Diastrophic Dysplasia, and Sponyloepipheseal dysplasia (SED – all types). Less common types are hypochondroplasia, pseudoachondroplasia, Cartilage Hair Hypoplasia (CHH), Osteogenesis Imperfecta (Brittle bone disease) and many more. Types of dwarfism are usually divided into “short limb” types eg. achondroplasia, and “short trunk” types eg SED. Short limb dwarfism generally means the person has an average size body (trunk) but shorter arms and legs. Conversely, the short trunk dwarfisms generally have a shorter body and average size arms and legs. However, those types caused by pituitary gland problems, or metabolic problems are often proportional – just like average height people, only smaller all over.

The most frequently diagnosed cause of short stature is achondroplasia, a genetic disorder that results in disproportionately short arms and legs. The average height of adults with achondroplasia is 4’0”. Other relatively common genetic conditions that result in disproportionate short stature include spondyloepiphyseal dysplasia congenita (SEDs), diastrophic dysplasia, pseudoachondroplasia, hypochondroplasia, and osteogenesis imperfecta (OI). OI is characterized by fragile bones that fracture easily.

Proportionate dwarfism -- short-stature conditions that result in the arms, legs, trunk, and head being in the same proportion (relative size to one another) as in an average-size person -- is often the result of a hormonal deficiency, and may be treated medically, resulting in an average or near average height. There are not such treatments available for people with disproportionate short stature. Although achondroplasia accounts for perhaps 80% of all cases of dwarfism, there are over 200 diagnosed types, and there are some individuals with dwarfism who never receive a definitive diagnosis and/or have a condition that is unique to themselves or their family.
What is the medical diagnosis of a person with dwarfism?
Orthopedic complications are not unusual in people with disproportionate dwarfism such as achondroplasia and diastrophic dysplasia, and sometimes surgery is required. A common problem, especially in adults, is spinal stenosis -- a condition in which the opening in the spinal column is too small to accommodate the spinal cord. People with this condition suffer from numbness and/or pain. Many will require surgeries or other medical interventions to address complications and maximize mobility.

Who is to blame for a child born with dwarfism?
No-one is to blame for a child born with dwarfism. Often, a gene just mutates and causes a dwarf child. In fact approximately 80% of people with achondroplasia are the first ones in their family with it. It results from spontaneous mutation and can happen in any pregnancy and males and females are at equal risk. Generally, when average-size parents have a child with short stature due to a spontaneous mutation, it is rare to have a second child who is also of short stature. However, if parents have some form of dwarfism themselves, the odds are much greater that their children will have it as well.

Can average-size people become parents of children with dwarfism?
Yes, for example approximately 80% of people with achondroplasia are the first ones in their family with it. Many forms of dwarfism are usually the result of a spontaneous mutation in a single rogue gene in either a sperm or egg cell from average-size parents during conception. It is not known why this occurs, but it may happen in any pregnancy.

Can dwarfism be cured?
No, dwarfism cannot be cured. It can be managed and adaptations made to help those affected. Most little people are capable of living very average productive lives, doing a variety of jobs, and living about the same average lifespan of average height people if necessary adjustments and adaptations are done. Some little people require surgeries to relieve pain caused by their dwarfism type, others need hormone replacements.
Are little people (dwarfs) intelligent?
In most forms of dwarfism, intelligence is completely normal. It is not unusual to find little people in developed countries engaged in all kinds of professions from medicine to engineering and teaching among others. However, this requires high level of acceptance and awareness on the part of little people and the society at large. In Uganda, majority of little people are exploited in circus/entertainment and other non professional jobs.

How many little people are in Uganda?
Despite the fact that dwarfism affects all tribes, races, men and women alike, a census has never been carried out in Uganda to ascertain how many they are. And this impedes necessary planning for incorporation of the needs of the little people in government programmes. However, LPU estimates that there are approximately 5,000 people affected with dwarfism in Uganda.

Are little people disabled?
Opinions vary within the disability community about whether or not this term applies to little people. However, certainly many little people could be considered
disabled as a result of conditions, mainly orthopedic, related to their type of dwarfism. In addition, problems of accessibility exist even for healthy little people just like it does with other disabilities. Consider for example, the simple fact that most achondroplastic adults cannot reach an automated teller machine or office reception desks. Also it’s important to note that little people have disabilities that cut across different disability groups e.g. spinal injuries, heard of hearing, immobility, loss of grip among other constraints. In fact in many countries including USA and UK dwarfism is a recognized condition under the Disabilities Acts.

What are the biggest challenges facing little people in Uganda?

Acceptance:
Little people have challenges getting accepted and integrated even within the families they come from. Because of the stigma and stereotypes associated with dwarfism, parents especially fathers and paternal relatives shun children affected with dwarfism. This discrimination extends to society and communities where little people live. Stigma and discriminations affects self perception and self worth of little people, which consequently impacts on their ability to exploit their full potential.

Lack of knowledge and information:
There is generally scanty knowledge about dwarfism, its causes, complications, challenges, capabilities of people affected with dwarfism and how society needs to respond to little people. This lack of knowledge has given room for speculation and superstition about dwarfism in Uganda, which has put little people in a quagmire of discrimination.

Lack of medical expertise:
Although dwarfism comes with numerous complications, most of which are medical, we do not have specialists for example in skeletal dysplasia who can help parents and adult little people. This gap coupled with limited information has exposed especially children affected with dwarfism to dwarfism related
complications, which further impair their wellbeing. Also adult little people face similar challenges looking for specialized medical personnel in the country.

What is the acceptable way of referring to people with dwarfism?
Some people are happy to be called dwarfs, or little people. Some prefer “short statured”. However, “midget” “miniature” are no longer an acceptable terms and are considered offensive. But most of all, little people like to be called by their names!

Are little people the same as pygmies and Batwa?
Not the same, but similar. Batwa, and other pygmy groups like Mbuti, Baka and Aka are proportionate and smaller than average height people. They do not have bone dysplasias, or collagen defects. Although it is not really known why they are smaller, it is assumed that they are smaller because of their environment and lifestyle, not a medical problem.

Can little people be productive in other professions rather than entertainment and comedy?
Absolutely!!! There are many, many little people from all around the world with all sorts of different jobs! Teachers, nurses, geneticists, therapists, brick layers, lawyers etc.

Can little people participate in sports activities?
Sports and activities are good exercise for all people and little people are no exception. However, because of orthopedic problems certain sports like gymnastics and rough contact sports aren’t recommended due to bone and joint issues. Some little people need to be careful of their neck areas too, to avoid permanent damage to their spinal canals. Most often, all people know and learn their limits to avoid getting hurt.
Can little people couples become parents? Of children with dwarfism? Of average-size children?
Yes! It depends on the inheritance pattern of the particular type of dwarfism the little person has. Little people can most certainly get married and have children. Some children may also be little, and some children can be average height.

Medical complications associated with dwarfism.
Short stature is the one quality all people with dwarfism have in common. After that, each of the many conditions that cause dwarfism has its own set of characteristics and possible complications. For example, some babies with achondroplasia may experience hydrocephalus (excess fluid around the brain). They may also have a greater risk of developing apnea — a temporary stop in breathing during sleep — because of abnormally small or misshapen airways or, more likely, because of airway obstruction by the adenoids or the tonsils. Occasionally, a part of the brain or spinal cord is compressed.

Public perceptions
Dwarfism is a medical condition that is not fully understood by the public at large. In fact dwarfs or little people are most times made fun of and portrayed in an unflattering way in the entertainment world. There is a long history of people with dwarfism being treated as spectacles for entertainment. And the portrayal of people with dwarfism in modern movies and entertainment often resorts to stereotypes. However, the reality is that little people have the ability to accomplish just as much as or more than an average size person if especially environmental barriers that impede them are minimized.

People of average height often hold misconceptions about people with dwarfism. Many wrongly believe that people with dwarfism have limited intellectual abilities or personality disorders. Judging maturity by height rather than age, some people may treat adult people with dwarfism as children. Because dwarfism is relatively uncommon, children may feel isolated from their peers. However, being of short stature is only one of the characteristics that make a little person who he or she is. If you are the parent or loved one of a little person, you know
How can the government and the general society respond to little people?

Most importantly, it is best to treat any little person as you would treat any average height person. However, it’s important to remember the little person may need stools or some other aids to help with everyday life. For example in an office, a little person needs an adjustable chair with a foot rest, lumbar support and reduced depth of seat.

Little people are productive members of society.

Although they face challenges, most of which are environmental (as with people with other disabilities), they value the opportunity to contribute a unique perspective to the diversity of our society.

Therefore, the government can respond to the needs and challenges of little people through positive policy formulation and change in education (encouraging reasonable accommodation for little people in schools), health care (through provision of specialised health care in referral hospitals), employment (encouraging employers to provide conducive working environments for little people), education and awareness programmes (sensitizing parents and the general public about dwarfism and society needs to respond to them) to address the challenges facing little people. Including little people as a special category under the disability census will help ascertain the numbers and distribution of little people in Uganda and this will help government to plan for them appropriately.
Members of the LPU attending a Conference organised by Little People Uganda.

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