Eliminating Discrimination and Enhancing Equality: A Case for Inclusive Basic Education Rights of Children with Albinism in Africa

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Abstract

Background: Various international treaties have acknowledged the rights of children to education; however, for millions of children, this right is just a dream, especially with a vulnerable group of children with physical challenges and other disabilities. Reports by the UN gives an estimate of a significantly large number of children who are yet to take advantage of good quality education. This article examines the plight of children with albinism who suffer discrimination both at the special and regular schools largely because the nature of their disability is not physical. Children with albinism have their right to education and in education limited by the difficulty to understand their impairment both at school and at home leading to entrenched discrimination and inequality, which ultimately erodes their human dignity. Methodology: This article adopts the desk research argues that the proper application of the concept of inclusive basic education of children with albinism will help eliminate discrimination and enhance equality of education of children with albinism. Conclusion: The article concludes that the existing legal framework abound, but proper implementation of article 24 of the Convention on the Rights of Persons with Disabilities will enhance the desired equality.

Keywords: Albinism, children, inclusive education, persons with disabilities, right

INTRODUCTION

It has been well established by various international treaties^[1] that children are holders of rights, among which is the right to education. Yet, for millions of children, this right is just an aspiration, especially with a vulnerable group of children with disabilities.

Reports have shown that a certain percentage of the world population has some form of disability. A very high percentage of persons with disabilities live in isolated and low-income communities in developing countries. Some 62 million children in elementary schools have a disability, and an extremely large population of children with disabilities have not completed primary school education. Furthermore, an insignificant number of children with disabilities in developing countries are in school. [3]

The United Nations estimates that >100 million children are out of school and that many millions more receive poor

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and inadequate education delivered by untrained teachers in overcrowded, unhealthy, and ill-equipped classrooms.^[4] It is unfeasible to estimate the number of children with disabilities who miss out on education because, in many places, they are hidden away and invisible.^[5]

Not long ago, there has been a significant migration from special education toward inclusive education globally, including both low-income and income-rich countries. Ancient history reveals that disabled learners were integrated into mainstream schools alongside their nondisabled peers, and often this integration was physical in nature where the necessary accommodations

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were not made to enable their participation. ^[6] Polat and Kisanji state further that, the amalgamation took many forms ranging from intermittent attendance of disabled students from isolated distinctive schools to conventional schools to full placement in mainstream school and occasional withdrawal from mainstream classes by placing them in "distinct classes" and separated group activities at times outside of mainstream class and school.

Among the members of the African communities who are often marginalized in terms of basic education are children with albinism attributed to a lack of understanding of their circumstances. The lack of color in their hair, skin, and eyes makes people with this genetic condition strikingly contrasting from other people. They are highly endangered in that their pale skin makes them vulnerable to skin damage, they are visually impaired, which is often not recognized or acknowledged, and they suffer social exclusion and rejection. [7]

As a child with albinism approaches the school age, the parents are confronted with the challenge of the education decision of the child. Some parents bother that their child would be isolated from conventional classroom peers, and this could translate to not having a successful social integration. In addition to this is the fear of being deprived of the necessary assistance from the support group when absorbed/integrated into a conventional classroom.^[8] Other parents have concerns about being stigmatized where the children are given visual aid support, unknown to these parents; this assistance promotes the child's independence.^[9] Furthermore, African parents shy away from sending their children with albinism to school. This is due to the erroneous belief that children with albinism are slow cannot compete successfully with their peers and therefore, cannot prosper in life.^[10]

Both at home and in the learning environment, young persons with albinism also seem to continue to experience problems caused by their physical appearance. [11] Lund, in his article, states that their skin color seems to make their lives difficult because most of them are ridiculed. The teachers are not exempted from this behavior of ridiculing the children. The beliefs make these vulnerable children grow up stigmatized; hence, they feel less inferior to their peers. This is worsened by their impeded progress at school due to poor vision, social adaptation, and inappropriate physical environment.

It takes only a trained eye to observe the challenges faced by these children, and hence, the regular teachers often may not realize that the child is struggling with challenges. [12] Ashely states that It is quite obvious that regular teachers struggle with teaching these children neither are their parents equipped with the right skills to provide professional support to assist these educators. Gaigher *et al.* I posity that children with albinism attend special schools for persons with disabilities because of their poor sight in some states, and this had exposed them to further discrimination and hostilities from the children with visible disabilities; this often results in assaults and these vulnerable children suffer the most.

Their Nigerian counterparts, on the other hand, have to attend mainstream schools without any form of preference to their condition or any form of additional facilities to make teaching and learning easier for these children with albinism. In most cases, they are met with social rejection, and no student wants to neither interact with them nor sit close to them.

In all, these negative attitudes of social rejection lead to a number of children with albinism to drop out from school and for those that are forced to go to school by their parents without the required moral support for self-confidence; they pay little or no attention in school and rarely contribute to the academic discussions in school. These vulnerable children cannot be said to equally derive educational benefits as much as a student who does not have disabilities. This paper seeks to establish albinism as a form of disability that should be construed as such within the framework of the Convention on the Rights of Persons with Disabilities. The article will focus on Nigeria and South Africa and examine the country's position on the education of children with disabilities with a view of advocating for inclusive formal training of this vulnerable group while tasking the appropriate institutions on the need to structure educational facilities to accommodate students with albinism.

COUNTRY POSITION ON BASIC EDUCATION

Several countries in Africa, Nigeria inclusive has, in principle, adopted several international protocols^[13] that seek to promote and guarantee access to education, the challenges faced by disabled children cannot be overlooked. Evidence abounds emphasizing the challenges of these children in situating themselves within conventional schools.^[14]

The first National Policy on Education in Nigeria was in 1977, and it has constantly strategized at improving and accommodating vulnerable children with special needs through several activities. Ajuwon states further that this situation is obvious in view of the rise in attendance of these vulnerable students in secondary and other tertiary institutions and the education of specially trained educators in specially designated schools.

Organizations have also made considerable support for children with this form of challenge, and this argument to favor them has gradually been on the increase. This no doubt has been quite successful, but inappropriately trained personnel employed to work with these vulnerable ones have also formed a wall to achieve the desired success. In addition to these problems, Ajuwon identifies the fact that. Leadership issues within the organizations established to protect the vulnerable, inadequate teaching materials have diminished the desired output desired in this special learning sector.

To this effect, appropriate regulatory bodies, as created under the Nigerian constitutions passed the Universal Basic Education Act in 2004. The responsibility of this Act is to support the state toward achieving a continuous 9-year fundamental education for the pretertiary levels of education throughout the country. [15] However with the right to education being a directive principle under chapter II of the Nigerian Constitution of the Federal Republic of Nigeria, [16] as amended, and not a fundamentally entrenched right, this raises questions as to the authenticity of the government's motive.

In South Africa, after many years of the biased educational system, there were calls to probe and institute new strategies and legislation in education, beginning with South Africa's awareness constitution and the development of the Human Rights Commission. As such, section 29 (1) of the South African Constitution^[17] mandates for the right of all learners to basic education, including adult and further education. Furthermore, section 3 of the South African Schools Act^[18] legislates for compulsory education for learners from the 1st day of school of the year when the learner reaches 7 years until the last day of school of the year when the learner reaches 15 years or the 9th grade, whichever occurs first.

The White Paper on Education and Training in a Democratic South Africa^[19] introduced initiatives such as the National Qualification Framework model which according to Lomofsky *et al.* was designed to shape South Africa's education and training system for the future, which would encompass all learners, including those with special needs; the Culture of Teaching, Learning, and Services which seeks to restore respect for diversity and culture of teaching; the Outcomes-Based Curriculum which was designed to respond to diverse learner needs and has been declared a national policy in South Africa; the New Language Policy which includes recognition of 12 official languages, including Sign Language.

These policies are products of the White Paper on Education and Training, the subsequent Report of the National Commission on Special Needs in Education and Training, and the National Committee for Education Support Services. [20] The quest for equal education in South Africa gave rise to White Paper 6.[21]

In as much as South Africa has been able to identify the need for inclusive education and formulated policies in this regard, implementation of these policies is a real challenge, and Lmofsky *et al.* posit that massive poverty had been identified as a central challenge to the implementation of these policies.

CONSTRUING ALBINISM AS A DISABILITY

Existing pieces of literature on albinism in Africa focuses more on the discrimination against persons with albinism and the medical problems associated with the condition. Despite an impressive human rights catalog for all persons in Nigeria, the problem is the exact position of the rights of people with albinism in Nigeria. At present, there is no definite theory to agree with the fact that albinism, in Africa, is a disability. This research sets out to investigate the exact position of the rights of people with albinism under the constitutional dispensation? And are they, or should they be categorized as people with

disabilities? This investigation is done in a comparative manner to South Africa.

Presently while it can be argued that persons with albinism in Nigeria are currently not grouped under the special education framework, interrogating the extent to which specific support is provided for them within the education framework is important. Although it can be argued that the revised National Policy on Education^[23] in Nigeria explicitly recognizes that children and youth with special needs shall be provided with inclusive education services, there is still the need to place children with albinism under the category of disabled children for them to truly benefit from this policy with the commitment to equalizing educational opportunities for all children, irrespective of their physical, sensory, mental, psychological or emotional disabilities.

In the light of this challenge, a National Committee on albinism was recently inaugurated by the Nigerian government, and the committee reiterates its commitment to integrate albinos into the society and come up with a national policy on albinism. This still brings us back to the question of the social and legal status of persons with albinism and a call for constitutional recognition of persons with this condition as persons with a form of disability.

Albinism refers to a group of inherited genetic conditions; it is passed from parents to their children. The word "albinism" or "albino" is derived from the Latin word *Albus*, meaning white. Balthazar Tellez, a historian and missionary, coined the term albino around 1660. Ntinda used the word to describe tribe members with this condition that he saw on the West African coast. Oculocutaneous albinism is a rare, genetically inherited condition resulting in a significant reduction or absence of pigmentation in the hair, skin, and eyes at birth.

Both parents must carry an albinism gene to have a child with albinism, and this follows that parents may have normal pigmentations but still carry the gene. [24] If a person has one gene for normal pigmentation and one gene for albinism, he/she will have enough genetic information to make normal pigment. The albinism gene is recessive and does not result in albinism unless a person has two copies of the genes for albinism and no copy of the gene that makes normal pigment. [25]

Just like the sickle cell anemia, there is a one in four chance at each pregnancy that the child will be born with albinism. This type of inheritance is called autosomal recessive inheritance. [26] However, Oliver states further that due to the lack of medical tests to determine the gene in the parent, there is no way to know prior to the delivery of the baby if the child will have albinism.

Albinism, as a condition, is more common among persons of colour and almost unknown among Asians. [27] McNeil steas further in his work that in parts of Nigeria, 1 out of 1100 has albinism; in parts of South Africa, the incidence is in 1 out of 1800, and the Tanzania Albino Society claims that 2% of the population in Tanzania has albinism.

Oldest records of albinism are found in Rome and Germany. The first observers of albinism are widely known as Aulus Gellius and Plinius Secundus, the Elder. However, Archibald Garrod was the first to consider albino as a sickness. He carried out research on it in 1908 and observed that people affected with albinism had very fair hair and skin.^[28]

To Alley, albinos acquire the disease which is transferred from the genes of their parents. The genes of an albino lack the normal amount of melanin. Sometimes albinism causes hair to change into a red and deep yellow. The eye of a person having albino can be brown, reddish, or blue. They cannot directly stare at the sky, and sometimes it can get even worse.

Albinism can be seen as a form of disability; medical, social, or legal, depending on the conceptualization of disability. Disability is a complex phenomenon with no static state. It can be conceptualized in many ways, including at the level of the body, the person, or the society. [29] Nitinda argues that disability is a global phenomenon and does not only happen to a minority of the population. As a result, what is regarded as a disability depends to a greater extent on individual, societal, cultural, and medical perceptions of what is normal, and this depends very much on the point of comparison. Persons with disabilities have been said to comprise of those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.^[30]

Medically, persons with albinism possess a visual impairment that can be arguably construed as a nonvisible disability. The level of visual acuity varies among people with albinism according to the amount of ocular pigmentation present and the level of macular development. People with oculocutaneous albinism exhibit less pigmentation than people with ocular albinism and tend to have lower acuity levels.^[31]

In addition, people with albinism may possess other eye problems other than visual impairment. People with this condition have an unusual pattern for sending nerve signals from the eye to the brain, and this prevents the eyes from working well together and causes reduced depth perception. A pictorial analysis of the pattern for nerve signals of a person with albinism and a person without albinism is illustrated in Figure 1.

People with albinism also experiences a condition referred to as strabismus, which is a muscle imbalance within the eyes, causing the person to squint and also to use each eye separately rather than together. Ntinda states further that people with albinism do not have a binocular vision, which is the ability to use both eyes at the same time. However, most people with this condition adapt, and so there is not a sense of double vision.

Other eye problems include nystagmus^[34] and photophobia, which can be described as the sensitivity to light. Oetting *et al.* believe that, to this extent, albinos who suffer a sensory impairment are considered as persons with disabilities^[35] within the medical framework.

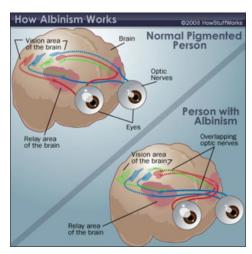


Figure 1: The nerves that connect the retina to the brain of a person without albinism and a person with albinism by $^{[33]}$

Another argument that can be canvassed to prove that albinism is a form of medical disability is the condition of their skin, which lacks pigmentation and makes persons with this condition prone to cancer.

Gaigher states that albinism, when viewed from a sociological rather than a medical perspective, reflects the social disability associated with the condition. The social problems being experienced by persons with albinism stem primarily not from their physical differences, but from the way others respond to those differences and from the social and physical environments, they have to cope with.

Wan-Kee-Cheung is of the position that persons with albinism worldwide and especially in Africa, experience the negative repercussions of an unconventional physical appearance as well as a visual disability. McNiel states that n different parts of Africa, people with albinism are shunned and even murdered as they are feared to be products of witchcraft. Children with albinism are at high risk of abandonment, discrimination and exclusion as a result of the appearance of their skin, and due to disability factors such as impaired eyesight and high susceptibility to skin cancer and other health risks associated with albinism. ^[36] This can be said to be one of the reasons why people hold misconceptions about people living with albinism.

A study once revealed the attitude of normal pigment skinned students towards students with albinism to include the fact that students with albinism should be avoided because they have a disease and that "they are here as a result of evil spirits or wrongdoing," "they or their parents are being punished by God." [37]

Ntinda posits that albinism is surrounded by many beliefs and superstitions ranging from being a curse to being a product of daytime sexual intercourse, to being a product of bewitchmen and a punishment from God. In some other parts of Africa, people with albinism are killed for their parts to be used in making fetish potions that the witchdoctors allegedly advise their clients to drink to obtain wealth.

Furthermore, in some parts of Africa like Malawi, albinism is believed by some to be a very contagious disease. If you eat, sit, sleep next to, drink from the same cup, or any other physical contact with a person with albinism you will also become a person with albinism or you will smell like them or have a child with albinism.^[38]

In some countries, persons with albinism are considered to simply vanish. In other countries, they are referred to as apes and a source of money. They are seen as sorcerers, devils, or persons suffering from a curse, and in some communities, it is believed that contact with them will bring bad luck, sickness, or death.^[39]

In Tanzania, miners use the bones of persons with albinism as amulets or bury them where they are drilling for gold^[36] for luck and protection while fishers weave the hair of persons with albinism into their nets to improve their catches. All these beliefs expose persons with albinism to violent physical attacks, mutilation, and social rejection. This is another justification to class persons with albinism as persons that have a disability.

From the legal point of view, it was edumbrated in the Human Rights Report that the superstitions, erroneous beliefs, and myths put the security and lives of persons with albinism at constant risk. Other frequent myths that threaten the life and physical integrity of persons with albinism include: that sexual intercourse with a woman or a girl with albinism can cure HIV/AIDS; that the sacrifice of persons with albinism can appease "the god of the mountain" when a volcano starts to erupt; or that pulling out the hair of a person with albinism brings good luck. The effect of these beliefs on persons with albinism is constant violent attacks on them, such as ritual attacks, trafficking in persons and sale of children, infanticide, and abandonment of children.

In the OHCHR report,^[40] over 200 cases of ritual attacks against persons with albinism in 15 countries between 2000 and 2013 were recorded. This is not to say that all the cases of ritual attacks were reported. It was reported that cases of ritual killings were always on the rise shortly before and during elections such that persons with albinism are at greater risk during this period.

The killing, attacks, mutilation, trafficking, and exclusion of persons with albinism violates their right to life, dignity, security, freedom from discrimination, to mention a few, as enshrined in the constitutions of most countries and in most international Human Rights Instruments.

The attacks on persons with albinism seem to be on the rise due to the high demand for the body parts of persons with albinism which appears to be sustained by the high prices that some are willing to pay to obtain them. In its resolution 23/13, the Human Rights Council expressed concern about the impunity associated with attacks against persons with albinism; access by persons with albinism to justice, remedies and redress are extremely limited in that persons with albinism face significant

difficulties in having their cases brought to justice for the following reasons: The fear of further attacks, reprisals or further stigmatization; difficulties in finding witnesses owing to the seclusion they face within their community and frequently, the involvement of family and community members in the hostilities; the ignorance of legal rights; poverty; the inadequate capacity of the judicial system to address such cases; the lack of legal aid and adequate legal representation; and the lack of knowledge of or confidence in the law enforcement agencies and the judiciary.

In all, nonrecognition and constant infraction of the rights of persons with albinism makes it pertinent to call for a specific international protocol to classify persons with albinism as persons with disability and be accommodated within the disability framework in Africa and globally.

INCLUSIVE EDUCATION

Ploate states further that it is estimated that there is a considerable large number of disabled people in the world, 50 million of whom are children, 80% of whom live in low-income countries with little or no access to services. Some 62 million children of primary school age have a disability, and 186 million children with disabilities have not completed primary school education. Furthermore, fewer than 2% of children with disabilities in developing countries are in school.^[41] This raises important questions regarding quality education and inclusion in Africa.

The landmark decision in *Brown v. Board of Education*⁽⁴²⁾ identified the preferential nature of racial separation in schools, and it was noted that the success of a child might be compromised with the denial of the opportunity for education. The result was that many nations adopted the special needs education system, and 50 years later, the educational division of many children with disabilities in special schools remains a normal occurrence.^[43] Thus, we are faced with the consequences of special schools, which include a short-term consequence of the child with a disability being hidden in remote cattle posts and the long-term effect of the child being denied the opportunity of formal education such that disability deteriorates to inability.^[44]

The past 30 years have witnessed international debates, particularly in developing countries, on inclusive education. That is the education of students with disabilities and nondisabled students in the same school and class. [45] Inclusive education is based on a value system that recognizes and celebrates diversity arising from gender, nationality, race, the language of origin, social background, level of education, achievement, or disability. [46] Thus, it has been argued further by Lomofsky that inclusion in this sense goes beyond just mainstreaming but extends to a moral issue of human rights and values as embodied in the Salamanca Statement, [47] which sees inclusion as a part of the creation of an inclusive society.

Thus, inclusion in this context connotes the extraction of the material, ideological, political, and economic barriers that

legitimate and reproduce inequality and discrimination in the lives of disabled people.^[48] As such, Byrne posists that there is a need to identify barriers within the school's environment, teaching and learning strategies, and attitudes that prevent the full participation of children with disabilities will also be required.

Supporters of inclusive education have argued that inclusive education is the most effective means of making war against biased attitudes, creating welcoming communities, building an all-inclusive society, and achieving uniform educational chances for all.^[49]

Thus, with the advocacy for inclusive education, children with disabilities gain satisfaction from learning in a conventional classroom, while their peers without challenges gain from being exposed to children with various characteristics, skills, and personality.

Proponents against inclusive schools such as Fakolade have argued that these learning institutions will not adequately meet the needs of the disabled. They base their position on the fact that disabled children stand to benefit more from specialized schools rather than in inclusive schools.

At the 59th session of the National Council on Education in Nigeria, one of the key areas which the Minister for Education harped on was the Albinism Education Policy. The Minister said that Nigeria had a large population of prevalence rates in the world. Children in this category are the most vulnerable of all, with ignorance on the part of some parents preventing them from going to school. The Minister further stated that the Federal Ministry of Education identified the need to integrate children with albinism into the school system, and the National Policy on Albinism and Execution Direction was approved.

BASIC EDUCATION OF CHILDREN WITH ALBINISM

In connection with the basic education of children with albinism, South Africa has few special schools that provide individualized educational programs for children with disabilities, Lund and Gaiher are of the position that the majority of these children are learners with oculocutaneous albinism. Since these schools were mainly designed for learners with poor eyesight, the rooms are adequately furnished with necessaries to aid their vision. Rooms are furnished with movable blackboards, which can be moved around to the best position suitable for the learner at any time. During lessons, these learners are free to move about and even permitted to walk up to the board to read for a clearer vision. These standards assist a great deal in the reduction of extreme sensitivity to light and enhance good vision. For students that choose to attend these special schools, they still have to cope with discrimination, hostility, and rejection from both the teachers and their peers.

Furthermore, by the South African Schools Act 2006, learners with disabilities have been properly accommodated in South African schools. By virtue of the inclusive education,

prospective learners with challengers have the legal freedom to attend any school irrespective of color, religion, or their physical condition. Consequently, most learners with oculocutaneous albinism have been bestowed with the freedom to select and attend any school they desire.

Lund posits that the challenge of poor vision has the possibility of restricting the amount of time and the speed with which they read and write such children spend studying. Investigation revealed that though a learner with oculocutaneous albinism was good in all subjects, she could not study beyond an hour at a stretch because of her poor vision. It takes only a sympathetic teacher to allow a student with albinism to stand up during classes to move closer to the board for a better view or to reduce the effect of sunlight on the vision of the student.

Thus it is not sufficient to make laws on inclusive education for people with this condition, but there is the need to go further in ensuring that the mainstream schools are equipped with the facilities and teachers to make learning easy in the mainstream schools.

In Nigeria, although each State government have different schemes for special education of students with disabilities, there are no expressly stated provision in the Universal Basic Education policy to accommodate students with challenges in learning in the conventional schools. [50] Akyeampong states further that though, by section 10 of the National Policy on Education 2004, the Federal government undertakes to make available special education programs for the gifted and talented people; provide all necessary facilities that would ensure easy access to education; the education of children with special needs shall be free at all levels; the government at all tiers shall fund this program within their areas of jurisdiction; the government further pledges that architectural designs of school designs should not in any way create any obstacle for handicapped persons.

This policy would have addressed the major problems of education of children with disabilities only if it could have been actualized, but in practice, this is just a matter of policy that is not effective in terms of implementation as there are a limited number of schools that cater for the primary education of children with disability and even where they do exist, there is the problem of accessibility.

Realizing the importance of dispelling the myths of albinism within African societies, several organizations for albinism have been developed in Africa and have focused on educating communities about the facts of albinism. Such organizations include the Albino Association of Zimbabwe, Albino Association of Malawi, Albino Foundation of Nigeria, Albinism Society of South Africa, etc.

Conclusion

Since awareness on the rights of persons with albinism is on the rise; undoubtedly, the Nigerian and South African governments had put enough policies in place to make sure and guarantee the welfare and rights of persons with albinism. However, this is a far outcry from reality as persons with albinism are still not adequately protected and suffer from various forms of abuses and. In terms of basic education of persons with albinism, while the South African government had made an effort in having special schools for persons with albinism in some parts of the country, the reality of catering for these children in a regular school remains problematic as the facilities to enhance their performance had not been provided in most mainstream schools. In Nigeria, while the children with albinism are accommodated within the mainstream schools, the teachers are not well instructed on the special needs of these children to accommodate their defects, thereby putting them in a vulnerable position and not giving them a fair chance at a healthy competition with their counterparts.

Thus, both the Nigerian and South African governments have to focus on ways to attain effective policy implementation that could boost the status of inclusive education in various countries. If what we are truly advocating is African Renaissance-African solutions to African problems, then it is important for the African Union to recognize and enlarge the scope of persons living with albinism as vulnerable hence, the need to be protected.

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