

# Inclusive Education for Children with Albinism: Unleashing the Prime Enabler

Shina Moses Owoeye

Department of Psychological and Sociological Studies, Ebonyi State University, Abakaliki.

John Emaimo

Department of Social Work, Federal College of Dental Technology and Therapy, Enugu.

Oluwakemi Ottun-Emaimo

Department of Psychological and Sociological Studies, Ebonyi State University, Abakaliki.

Samuel Olutokunbo Adekalu

Chartered Institute of Social Work Practitioners of Nigeria (C-ISOWN)

Corresponding Author Email: shinaowoeye@gmail.com

To Link this Article: <http://dx.doi.org/10.6007/IJARPED/v12-i1/16483>

DOI:10.6007/IJARPED/v12-i1/16483

*Published Online:* 13 March 2023

## Abstract

Early childhood education is critical in building civil, enlightened and developed society. It is therefore important to pay attention to issues that appears as impediment to realization of early inclusive childhood education. Studies have revealed several violence, discrimination and shocking social exclusion inside and outside of school for children with albinism. In fact, social workers, student counsellors, caregivers, teachers and educators have raised issues about schools in Africa, especially in Nigeria; is ill-equipped phase to accommodate children with albinism in classroom engagement when compare with schools in Asia and western settings. This article explored comparison of research and identified relevant prime enablers to promote all-inclusive approach that will aid learning for children with albinism in schools and homes aimed to encourage government and relevant stakeholders to take full advantage of various options at their disposal. This article identified seven potential prime enablers relevant to the subject matter: need for teacher of visually impaired, provision of functional visual assessment, engagement of optometrist, conducive classroom setting, training of parents and guardians, need for physical and health education, and political will or social support. This article concludes by addressing tasks to complement quality inclusive education and school experience to fulfil the needs of children with albinism. Further, it serves as a knowledge data bank to enable concerned social workers, caregivers, parents, teachers, agencies, stakeholders and researchers to use as inputs in providing a meaningful inclusive education experience for children with albinism.

**Keywords:** Inclusive Education, Albinism, Children with Albinism, Schools

**Introduction**

Children with albinism can be found in all parts of the world and have been reported to face several community-based violence, social discrimination, cultural shock and social exclusion inside and outside of the learning environment (Franklin et al., 2018; Astle et al., 2019). Admittedly, educators, teachers and counsellors have been reported to raise concerns about discrimination at the institutional level, evidence to these claimed are reveal by non-provision of learning materials to support children with albinism with visual impairment in school (Nebre 2018; Human Rights Watch, 2019), this complement the claimed from individual perceptions of teachers and educators that avoid children with albinism based on the belief that persons with albinism has a contagious condition (Lund, 2005).

Limited research in sub-Saharan Africa reveals prevalence of person with albinism estimated to be around 1 in 2000 to 5000 (Roelen and Sabates-Wheeler, 2012; Hong et al., 2006). Statistics on the prevalence of persons with albinism amongst school children in Zimbabwe and South Africa estimates a prevalence rate in the region of 1 in 2000 to 4000 (Lund and Gaigher, 2002). Demographic information from 2011 in Namibia revealed the highest national prevalence reported in Africa to date at 1 in 1755, compared with 1 in 2673 in the 2012 census in Tanzania (Raliavhegwa et al., 2001). In specific, persons with albinism in Nigeria represent a unique portion of the population with an estimated number of over 6 million, acknowledged to be the highest population of persons with albinism in the world (National Policy on Albinism, 2012). This population have been reported to encountered live threaten challenging due to lack of melanin pigment, leading to the change in their skin color, eyes and hair (Taylor et al., 2019).

In short, giving birth to albinos are often considered as misfortune in communities where children with albinism are mostly found in Nigeria. In most case, attempts are made before birth to abort pregnancy confirmed to be albinos as well as to kill at birth or banish children with albinism from the community (Braathen and Ingstad, 2006; Cruz-Inigo et al., 2011; Benyah, 2017; Nebre, 2018; Reimer-Kirkham et al., 2019). In fact, mothers of children with albinism are often answerable for their child's condition, alleged of infidelity with white foreigners, carriers or spirits (Wan, 2003). Consequently, several children with albinism are raised without the support of both parents, creating economic problems and helplessness to afford education or health care for their child (Bucaro, 2010; Franklin et al., 2018).

Unfortunately, the mainstream of schools in Africa, particularly in Nigeria has more to do with educational needs and are less equipped to accommodate children with albinism. However, in spite of the growing number of research about the learning difficulties, social discrimination and violent treatment experiences of children with albinism at various level of the society, precisely, in the educational sectors, there is little research about inclusive education and relevant enabler that will aid learning for children with albinism.

**The Current Research Expectation**

The scenario of children with albinism in learning and social experience while at school is not encouraging. In some schools, children with albinism benefits from special equipment with specialize teachers for teaching and extra curriculum activities among children with albinism, visually impaired and blind children who share the same classroom facilities and joint-teachers engagement (Gaigher et al., 2002). This research aimed to document the unleashing

prime enablers that will aid learning for children with albinism in schools for (teachers/instructors) and in homes for (family/guidance) living with albinism. In this article, inclusive education is referred to students with diverse background, which engage in learning and physical abilities in the same classroom setting to learn side by side. In Nigeria, educational institutions do not operate an inclusive setting; the reason for this include but not limited to; inadequate funding, cultural beliefs, negative perception and teacher's qualification.

The present article explores relevant materials of albinism and inclusive education, in order to introduce teachers and parents who have difficulties in engaging children with albinism on the methods to use that will aid learning. From the position of literature, there are several studies about parents of children with disabilities that neglected the challenges encountered about the absence of learning materials for children with albinism in schools. This article geared to address this gap in literature on albinism. Hence, the article highlights several prime enablers for teachers and educators as well as social workers, counsellors, caregivers and relevant stakeholders to exploits the measure provided to facilitate the learning progress and coping strategies for children with albinism in classroom settings.

### **Literatures Position on Inclusive Education for Albinism**

In brief, the sub-Sahara Africa have several education policies in practice for children and non-children with albinism. These policies often time encourage visually impaired children to attend special schools (Franklin et al., 2018), despite the increasing agitation to subscribed and adopt inclusive education, specifically for children with albinism (Dogbe et al., 2016). Till date, children with albinism are not seen as 'worth educating' in some communities and family's settings (Lynch et al., 2014; Aborisade, 2021) as they are not considered capable to contribute to the socioeconomic advancement of the communities they live.

Citizens right to education is excluded of children with albinism, thus attention needs to be given to ensuring that their needs are met within and outside the learning environment. Research on inclusive education have recognized gender bias in the classroom setting and access to the special support service provided for children with albinism in school (Lynch et al., 2014; Franklin et al., 2018). Other studies revealed how family members escort their children to school and to other areas of the community because of the fear of ritual and kidnapping (Burke et al., 2014; Franklin et al., 2018) while some families report sending their children away to boarding schools, camps or relations in safer areas (Burke et al., 2014). These occurrences call for stakeholders' attention to raised awareness of the need to address the challenges facing person with albinism, including stigma and the lack of access to education (Burke et al., 2014; Aborisade, 2021).

This can sometimes mean only minor adaptations to classroom layouts, such as access to visual aids, but perhaps more fundamentally requires a change in attitudes amongst teaching staff and other pupils. A study at a special school for children with albinism in rural South Africa identified that although the school had access to magnifiers and low vision devices, these were only used in specific lessons such as map reading (Yahalom et al., 2012). In Zimbabwe and parts of Zambia children with albinism attend mainstream schools where inclusion can be challenging. Teachers can fear teaching a child with albinism (Miles, 2011) and a lack of educational materials and correct information about the condition in the local community

inevitably increases the probability of teachers drawing on local myths in their approach to children with albinism (Baker et al., 2010). Access to appropriate educational support, including teachers with the knowledge of how to assist children with albinism has been recognized as important in enhancing the self-esteem of these children, promoting their personal development and growth and creating a sense of belonging (Pooe-Moneymore et al., 2012). The following are relevant facilities (prime enablers) needed for children with albinism (CWA) to participate in all appropriate academic activities:

### **Relevant Prime Enablers to Facilitate Learning for Children with Albinism**

The teachers and parents, need help to enhance learning for children with albinism. But, due to their desire to be seen as capable and 'normal' to take responsibility, they will usually not request openly for help to enable smooth teaching engagement for children with albinism. Nevertheless, the researchers have tried to identify the relevant prime enablers that can help to enhance learning engagement for children with albinism as highlighted below:

- 1. Need for Teacher of Visually Impaired (TVI):** in teaching profession little or no reference is made to teachers of visually impaired, they are most found in special schools not the mainstream schools where children with albinism mostly found considering the fear that most parents of children with albinism faced to send their children to school. Teacher of visually impaired is required to create conducive learning environment for children with albinism. The service of this specialized professional teachers is needed to ensures that right educational aids such as braille texts, supplementary materials, and equipment needed by the visually impaired student are provided in a timely manner for maximum participation in all classroom activities for children with albinism.
- 2. Provision of Functional Visual Assessment (FVA):** there is urgent need for functional visual assessment to facilitate the learning challenges experienced by children with albinism. Though, children with albinism are known to suffer low vision that require need for functional visual assessment. This will assist to measure the level of vision of children with albinism and test the visual performance on routine tasks at different situated point and with different materials in school. For example, the assessment “paints a picture” of how a child uses vision and what visual skills the children with albinism needs, and what can be done to best facilitate learning through the visual sense.
- 3. Engagement of Optometrist:** There is no inclusive educational policy’s consideration for optometrist in the teachers’ recruitment exercise when compare with other sectors in some regions. This have affected children with virtual impairment to access the service of optometrist and ophthalmologist in term of challenges peculiar to children with albinism in school. This set of professionals’ service is required to aid learning engagement of children with albinism, thereby making inclusive teaching effective and accessible for all.
- 4. Conducive classroom setting:** Conducive learning environment matters for children with visual impairment. This required a comprehensive classroom seating arrangement that helps to aid learning process which is not mostly found in conventional school setting. For example, most time children with albinism have issue to read directly from projector screens because of glare, however, to achieve inclusiveness in educational system,

classroom seating arrangement must be inculcated in schools at advantage for children with albinism and others.

5. **Training of parents and guardians:** training of families living with albinism is an important prime enabler that will help children with albinism in term of physical abilities, assessment and evaluation for comprehensive learning process. This assessment from the parents/guardian will pave way for the child to develop teamwork and self-confident among their peers in order to achieve a comprehensive learning atmosphere both at school and home.
6. **Need for physical and health education:** in most time low visual children especially the one with albinism usually get excluded from various physical activities due to their impairment and susceptibility to sunburn. The school personnel are required to include children with albinism into all activities in order to avoid leaving them sitting on the sidelines. "Small ball" games (tennis, badminton, softball, baseball) are difficult for children with albinism because of the size and speed of the balls. However, other games like swimming, aerobics, gymnastics, track, wrestling, horsemanship and skiing are sports which can be enjoyed with minimal adaptations required for children with albinism.
7. **Political will and Social Support:** Children with albinism most time stand out differently in skin, eye and hair and may require emotional support for responding to their classmates. Teachers and families living with children with albinism must help to deal with teasing or other forms of discrimination by encouraging them to share their experiences and feelings at home after school hours. Also, there must be a political will in the part of the government and relevant stakeholder that are saddle with educational responsibilities to implement policy that will aid smooth and effective engagement of teachers, counsellors and parents of children with albinism.

### **Recommendations, Conclusion for Future Research**

This article is part of the ongoing doctoral research of the lead author, in the field of Social Work at the Department of Psychological and Sociological Studies, Ebonyi State University, Abakaliki, Nigeria. Education is acknowledged as one of the bedrocks for any society to experience development. The authors recommend from the above findings, the need for the government and relevant stakeholders to improve on the existing policy on albinism that will incorporate services and learning aids for children with albinism in schools and homes. There is lack of sufficient research to understand the lives of children with albinism, specifically, from the perspectives of educational setting. The limited available research evidence on children with albinism has mainly focused on experience of parent living with albinism. Though, findings indicated children with albinism are often exposed to severe prejudice and violence from family members premised on their perceived disability. This article captured enablers that will aid learning engagement for children with albinism, based on the academic research findings.

Mores so, this article calls for a convincing political will on the part of the government to adequately fund schools to a standard and support teachers in quest for inclusive education for children with albinism in schools. This will provide an ideal environment to promote a comprehensive educational policy implementation for children with albinism. Further,

parents should be trained and well informed about confident required to deal with condition of children with albinism. Educative programs, support groups and workshops focusing on albinism and its management should be designed for an interactive, social learning process. These can become instrumental in creating an informed community willing to address children with albinism in schools, in an objective manner, against the background of existing indigenous knowledge about inclusive education for children with albinism.

From the practical standpoint, the prime enablers introduced in this article can be adapt to different setting, where children with albinism are in a small and large majority. Also, this article can be useful to stand in gap as an eye-opener to academics, social workers, educators, stakeholders governments agencies/non-government organization (NGOs), and the parents in knowing the right strategies to employed towards engaging with children with albinism. In addition, the article will help in reviving early childhood education status in the national and international community, and help teacher of visually impaired (TVI) to acquire practical knowledge and skills necessary for the children with albinism in schools.

In conclusion, the theoretical and practical implication in this article aimed to contribute to the existing knowledge in progressive education and development, inclusive education and school social work practice. This article shed light on the relevant prime enablers such as need for teacher of visually impaired, provision of functional visual assessment, engagement of optometrist, conducive classroom setting, training of parents and guardians, need for physical and health education, and political will or social support which is not mentioned in the literature of progressive education and development, inclusive education and school social work practice with connection to children with albinism in African literatures. Also, this article expanded researchers understanding on the contribution of inclusive education in advancement of social work-related field of study. Though, this conceptual article calls for empirical research to evaluate the use of relevant teaching materials if any exist for children with albinism, to know its effect on the performance of the children.

## References

- Aborisade, R. A. (2021). "Why Always me?": Childhood Experiences of Family Violence and Prejudicial Treatment against People Living with Albinism in Nigeria. *Journal of Family Violence*, 36:1081-1094
- Baker, C., Lund, P., Nyathi, R., and Taylor, J. (2010). The myths surrounding people with albinism in South Africa and Zimbabwe. *Journal of African Cultural Studies*. 2(22),169-81.
- Bucaro, S. (2010). A black market for magical bones: the current plight of east African albinos. *Pub Int Law Rep*. 2:15. Available at: <http://lawecommons.luc.edu/pilr/vol15/iss2/8>
- Burke, J., Kaijage, T. J., and John-Langba J. (2014). Media analysis of albino killings in Tanzania: a social work and human rights perspective. *Ethics and Social Welfare*. 8(2),117-34.
- Franklin, A., Lund, P., Bradbury-Jones, C. and Taylor, J. (2018). *BMC International Health and Human Rights*, 18:2.
- Gaigher, R. J., Lund, P. M., and Makuya, E. (2002). A Sociological Study of Children with Albinism at a Special School in Limpopo Province, *National Library of Medicine, (BMC)*, 25(4), 4-11.
- Hong, E. S., Zeeb, H., and Repacholi, M. H. (2006). Albinism in Africa as a public health issue. *National Library of Medicine, (BMC)Public Health*. 6:1.

- Lund, P. M., and Gaigher, R. A. (2002). Health Intervention Programme for Children with Albinism at a Special School in South Africa. *Health Education Research, (17)*, 365-372.
- Lynch, P., Lund, P., and Massah, B. (2014). Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi. *International Journal of Educational Development, (39)*, 216-224.
- Miles, S. (2011). Exploring understandings of inclusion in schools in Zambia and Tanzania using reflective writing and photography. *International Journal of Inclusive Education, (15)*, 1087-1102.
- National Policy on Albinism. (2012). *National Policy on albinism in Nigeria: Implementation guidelines*. Federal Ministry of Education, Abuja: Retrieved from <https://albinofoundation.org/wp-content/uploads/2017/04/National-Policy-on-Albinism-Implementatio-Guideline.pdf>. Accessed 15 Feb 2023.
- Nebre, M. (2018). Social discrimination against people with albinism. Retrieved From <https://www.csustan.edu/sites/default/files/groups/University%20Honors%20Program/Journalstwo/17nebre.pdf>. Accessed 12 Jan. 2023
- Pooe-Money more, M. B. J., Mavundla, T. R., and Christianson, A. L. (2012). The experience of people with oculocutaneous albinism. *Health SA Gesondheid 17(1)*, 1-8.
- Raliavhegwa, M., Oduntan, A. O., Sheni, D. D. D., and Lund P. M. (2001). Visual performance of children with oculocutaneous albinism in South Africa. *Journal of Medical Genetics, (38)*, 35.
- Reimer-Kirkham, S., Astle, B., Ero, I., Panchuk, K., and Dixon, D. (2019). Albinism, spiritual and cultural practices, and implications for health, healthcare, and human rights: As coping review. *Disability & Society, 34(5)*, 747-774.
- Roelen, K., and Sabates-Wheeler, R. (2012). A child-sensitive approach to social protection: serving practical and strategic needs. *Journal of Poverty and Social Justice, (20)*, 291-306.
- Yahalom, C., Tzur, V., Blumenfeld, A., Greifner, G., Eli, D., Rosenmann, A., Glanzer, S., and Anteby, I. (2012). Refractive profile in oculocutaneous albinism and its correlation with final visual outcome. *Br J Ophthalmol. (96)*, 537-9. doi: 10.1136/bjophthalmol-2011-300072.