

Tactics to Secure the Right to Education for Children Living with Albinism in Kenya

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Introduction

Discrimination or treating people unfairly because of prejudice can make the lives of young people with disabilities very difficult. This is the case of children living with albinism in Kenya, where the physical or social effects of this condition mean they are generally classed as having a disability.¹ Despite having the same hopes and ambitions as non-disabled persons, they encounter barriers that make it much harder for them to succeed and enjoy their human rights. Persons living with albinism experience significant discrimination in areas such as education, health, gender and equality. The types of discrimination they face can be linked to attitudes, the environment, local laws or cultural practices.

Albinism refers to a group of conditions, arising from inherited altered genes, generally affecting pigmentation of the eyes, skin or hair, and involving visual impairment.² The conditions develop when the body does not make the required amount of the pigment, melanin.³ The low levels of melanin can also lead to other serious health problems, such as skin cancer from prolonged exposure to sunlight.⁴

Children Living With Albinism in Kenya

Lack of societal tolerance and acceptability of children with albinism has increasingly exposed them to exclusion and discrimination since they remain unrecognised and unacknowledged in Kenya. People tend to treat them with curiosity and disdain because of the difference in the colour of their white skin. They are regarded with contempt with brands of 'Mzungu', 'Pesa', and 'albino' and have to go through numerous hardships to gain recognition. All of the issues that

affect children and young people in Kenya, such as access to education, employment, health care and social services, also affect children with albinism, but in a far more complex way. Attitudes and discrimination linked to albinism make it much more difficult for them to go to school, to find work or to participate in local activities. In many communities, both rural and urban, the environment is immensely challenging with physical and communication barriers that make it hard for them to participate in social life. From negative perceptions, abuse, abandonment, and derogatory language used in reference to them, persons with albinism are also severely hindered from active participation in development processes. Policy makers rarely give attention to issues affecting persons with albinism, and neither do they involve them in policy formulation or decision-making, much less to matters which greatly affect or influence their lives.

Particular Difficulties Faced in the Enjoyment of the Right to Education

In Kenya, access to quality education by children living with albinism is hampered by various factors, including:

- Lack of proper facilities in schools to accommodate the visual problems of children with albinism. Most are forced to study in Braille in schools for the blind, yet it is medically proven that persons with albinism are not blind.⁵
- Lack of provision by Kenya Government of large print material during national examinations.⁶
- High dropout rate among children with albinism due to lack of information on the part of teachers and parents on how to deal with the visual and skin problems associated with

albinism. Further, for most persons with albinism and parents of children with albinism in Kenya, sun screen is an unaffordable luxury. Classified as a luxury item targeted at the expatriate or tourist population, its cost is prohibitive.⁷

- Lack of access to quality education in the 'normal schools' due to lack of facilities to cope with their visual challenges.⁸

The majority of persons with albinism are poorly educated and in most cases unemployed, and fall within the 40 per cent of the Kenyan population living below the poverty line.

The Relevant Legal Framework

Lack of legal recognition and provision for persons with albinism is manifested in the existing lacunae in various provisions of law in Kenya whose analysis present clear need for law reform to protect their rights as well as consider the prospects presented by the Constitution of Kenya, 2010. Persons with albinism, like every other Kenyan, have the right to education, and the Government is duty-bound to ensure their access to education, free access by all children to primary education, access to affordable secondary education, equal access to education for women and girls, inclusion of (ethnic, linguistic, religious, cultural) minorities, and proximity for easy access to school. In particular, Article 53(1)(b) of the Kenyan Constitution 2010 provides that '[e]very child has the right...to free and compulsory basic education'. This guarantee also exists in various international human rights treaties to which Kenya is a party, including Article 13 of the International Covenant on Economic, Social and Cultural Rights, Article 17(1) of the African Charter on Human and Peoples'

Rights, and Article 11 of the African Charter on the Rights and Welfare of the Child.

They are also guaranteed the right to access information held by the government or by an individual, and which is required for the exercise or protection of a right or fundamental freedom.

It is also possible to frame this issue within the context of protection for persons with disabilities as albinism affects several organs including the eyes and skin. Accordingly, albinism should qualify as a disability under the law. In this regard, the Kenyan Constitution recognises that '[a] person with any disability is entitled...to access educational institutions and facilities for persons with disabilities that are integrated into society to the extent compatible with the interests of the person'.⁹

Aside from the direct protection the Bill of Rights affords to persons with disabilities in relation to education, there are also other constitutional provisions designed to promote the well-being of persons with disabilities. For example, Article 56(b) provides that the 'State shall put in place affirmative action programmes designed to ensure that minorities and marginalised groups...are provided special opportunities in educational and economic fields'. Such provisions echo efforts made at the international level to address the issue of albinism. For example, the Convention on the Rights of Persons with Disabilities provides, *inter alia*, that disabled persons are entitled to 'full and effective participation and inclusion in society'¹⁰ and that 'States Parties shall ensure an inclusive education system at all levels'.¹¹

Under the Constitution's Bill of Rights, the government has an affirmative duty to protect every person's fundamental rights and freedoms. When the government fails to discharge its constitutional duties, individuals may take legal action to secure their rights.¹² These

constitutional protections apply equally to persons with disabilities.¹³

Complementary Tactics to Ensure the Right to Education

However, it is clear that legislation to address the right to education of persons with albinism alone will not ensure that the rights of Kenyans living with albinism will be respected fully. Indeed, laws for their protection already exist, as set out above. What is necessary is that the laws be executed in an effective manner. Moreover, beyond executing the law, the Kenyan government and non-profit organisations must go about transforming people's beliefs about persons with albinism. Although legal measures certainly have a role to play in ensuring that these persons access adequate education facilities, it is impossible to change the Government's perceptions about albinism exclusively via the legal process. There is a lack of political will to effect change to the existing legislation. Policy makers rarely give attention to issues affecting persons with albinism, neither do they involve them in policy formulation or decision-making much less to matters which greatly affects or influence their lives.

Kituo Cha Sheria is a non-governmental, human rights organisation with the core mandate of enhancing access to justice to the poor and marginalised community members in Kenya. Apart from litigating on human rights issues, the organisation employs advocacy strategies to ensure that pro-poor and pro-marginalised laws and policies are adopted and enacted. The civil process in Kenya demands exhaustion of all other means before litigation. The organisation's effort in lobbying the Government of Kenya to commit itself to providing people with albinism with their rights and services was successful in the past year. The Government, after a Parliamentary Budget Committee Hearing, and after presentations made by Kituo Cha Sheria, allocated KES 100,000,000 to albinism in the current 2011/2012 supplementary budget. The money was placed within

the Ministry of Gender and Children's Affairs and was to be spent within four months. As a result of the lobbying, Kituo Cha Sheria was invited to participate in a newly formed taskforce and a subsequent meeting proposed the funds be used for the following projects: purchase of sun screen lotion; awareness creation on the sun screen program; a baseline survey and census; and a pilot project on the local production of sun screen lotion.

Conclusion

From the foregoing, lessons can be drawn that advocacy for human rights and the rights of persons with albinism can be used as an effective tool in fighting for their rights. By addressing the problem via the dual approaches of law enforcement and lobbying for better policies at the cabinet and parliamentary level, one might be confident that Kenyans with albinism will eventually enjoy the full rights that fellow citizens enjoy. The Government has the greatest duty to ensure that persons with albinism and, indeed, all disabled persons have equal access to education and participation in economic activity. To this end, both the Government and non-governmental organisations must take affirmative action to change the cultural acceptance of discrimination against persons with albinism.

To date, public education programmes to raise awareness for persons with albinism are rare and there has been no general health campaign targeting people with albinism. The result has been low quality of life and life expectation due to lack of adequate information and health care interventions.

Other options for ensuring that the rights of persons with albinism are adequately addressed would include extensive training to judges and government officials, both to educate about human rights more generally and to familiarise them with the issues faced by persons with albinism.

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initiatives.¹⁰ To cater for access to education for orphans, the State kicked off the Cash Transfer Programmes that seek to ensure that orphans can still access their right to education.

However, although some positive strides have been noted on the part of the State in its quest to ensure FPE, the same has been marred by graft and mismanagement¹¹ with development partners threatening to withdraw and/or suspend funding the FPE programme. In addition, the delayed remittances of the FPE grant, forcing school managements to impose levies,¹² has resulted in some children not being able to access primary education simply because they cannot afford it.

Conclusion and Strategy

EACHRights therefore seeks to undertake litigation around the fact that whereas primary education is supposed to be free, there are a lot of hidden costs levied by some schools which parents and guardians have to pay for. For those parents and guardians that cannot afford to pay these levies, they have been forced to withdraw their children from school. On the other hand, for those able to pay for a better education, they opt to move their children to private schools, which generally perform better than public schools.

EACHRights has identified non-fee barriers as a hindrance to equal access to free and compulsory education for children in Kenya, particularly from urban slums. Considering the complexities of proving that the State is failing to meet its obligations to realise universal primary education, it shall first undertake a baseline survey in collaboration with INTERIGHTS to establish the current extent to which these barriers hinder equal access to free and compulsory basic education in Kenya, focusing on the urban slum. The findings of this survey will then be used to develop a case on the right to education in Kenya with a view to enhancing the jurisprudence on the right to free and compulsory basic

education for children from vulnerable and marginalised groups in Kenya. The survey will assist in consolidating evidence showing that the State is failing to regulate public schools to ensure that the poorest are able to access education in line with the State's human rights obligations. At this point, it will be necessary also to consider alliances and networks with other civil society organisations to ensure that there is a bigger advocacy strategy around access to universal primary education by children in slums.

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¹ Minister for Education Hon. Mutula Kilonzo, during the National Launch of the Sanitary Towels Programme at KIE on 8 May 2012, available on <<http://www.education.go.ke/ShowPage.aspx?department=&id=1168>> (accessed on 1 November 2012).

² *Ibid.*

³ DARAJA: Civic Initiatives Forum (2007) *Falling Short: The Right to Free Primary Education*, available at <<https://www.concern.net/sites/www.concern.net/files/resource/2009/04/3584-kenya-fallingshort-theright-to-free-primary-education.pdf>> (accessed on 1 November 2012).

⁴ Community Initiative Action Group – Kenya (CIAG-K) (May 2010) *The Hidden Costs of Kenya's Free Primary Education: The Case of Kisumu Municipality* available at <http://ciagkenya.org/index.php?option=com_docman&task=cat_view&gid=3&Itemid=8> (accessed on 1 February 2013).

⁵ Ministry of Education (February 2012) *Task Force on the Re-Alignment of the Education Sector to the Constitution of Kenya 2010: Towards a Globally Competitive Quality Education For Sustainable Development* Report of the Task Force, p.20, accessible at <http://www.vision2030.go.ke/cms/vds/Task_Force_Final_Report_Feb_20123.pdf>.

⁶ *Ibid.*, p.128.

⁷ Available at <http://eachrights.or.ke/pdf/2012/EACH_Rights_Perception_Survey_Report.pdf>.

⁸ Participant from Jericho FGD.

⁹ Government of Kenya (January 2012) *Education Sector: Medium Term Expenditure Framework 2012/13-2014/15*, p.29.

¹⁰ /C.12/KEN/1, Implementation of the International Covenant on Economic, Social and Cultural Rights: periodic reports submitted by States parties under articles 16 and 17 of the Covenant: Kenya (see <<http://www.unhcr.org/cgi-bin/texis/vtx/refworld/rwmain?docid=47343c2e>>).

¹¹ *Supra* note 5.

¹² *Ibid.*

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The international community could and should provide the Kenyan legal sector and other government actors with such training. Among the most obvious, transforming a culture is much more difficult than enacting and executing laws. Laws are nothing more than words on paper if they are neither enforced nor followed. Ultimately, the aim of lobbying for the right of persons with albinism to access education is to one day see them rise to decision-making bodies like Parliament and Cabinet, where they would effectively represent their kin.

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¹ Albinism is likely to be classified as a disability, which Article 26 of the Constitution of Kenya, 2010 defines as including 'any physical, sensory, mental, psychological or other impairment, condition or illness that has, or is perceived by significant sectors of the community to have, a substantial or long-term effect on an individual's ability to carry out ordinary day-to-day activities'.

² NOAH (National Organization for Albinism and Hypopigmentation), 'What is Albinism?' fact sheet, at <http://www.albinism.org/publications/what_is_albinism.html>.

³ *Ibid.*

⁴ *Ibid.*

⁵ Interview with Mumbi Ngugi, Managing Trustee of the Albinism Foundation of East Africa (2010) *The Equal Rights Review*, Vol. Five, p.81, <<http://www.equalrightstrust.org/ertdocumentbank/Mumbi.pdf>>.

⁶ Angote, G. N. and Nyandieka, A., *A Handbook on Constitutional and Legal Rights of Persons with Albinism*, Albinism Foundation of East Africa, December 2012, p.13.

⁷ For example, sun screen with a high sun protection factor (SPF) of 30-50 retails at between KES 1500 to 2000 (approximately GBP 10-15).

⁸ Interview with Mumbi Ngugi, Managing Trustee of the Albinism Foundation of East Africa (2010) *The Equal Rights Review*, Vol. Five, pp.80-81, <<http://www.equalrightstrust.org/ertdocumentbank/Mumbi.pdf>>.

⁹ Constitution of Kenya, 2010, Article 54(1)(b).

¹⁰ Article 3.

¹¹ Article 24.

¹² Constitution of Kenya, 2010, Article 22(1).

¹³ Article 27 sets out a non-discrimination guarantee, including specifically on the ground of disability.