

ERT Interview with Mumbi Ngugi, Managing Trustee of the Albinism Foundation of East Africa

1. Can you explain a little about your personal experiences of discrimination?

I cannot talk with certainty about discrimination in the sense that is recognised by the law.

In the area of education, I think the greatest problem was the failure to recognise – and therefore make reasonable accommodation for – my visual limitation, which typically accompanies the condition of albinism. I think that the way our system deals with visual challenges for children with albinism is in itself discriminatory. The state places children with albinism in schools for the blind, forcing on them the study of Braille and, from my experience, one is better off not attending such an institution.

In the area of employment, I suspect, but again I cannot say with certainty, that I was discriminated against. Despite good qualifications, I had great difficulty securing employment. Of the many jobs I was interviewed for after I left university and before deciding to go into private legal practice, I was successful in only one. In legal practice, I have had occasion to wonder whether certain negative treatment that I have encountered in the courts and in dealing with government officers has been caused or influenced by perceptions of my condition and therefore of my abilities, but again it's hard to tell. I think the social challenges are the greatest problem – the name calling, the staring, the

superstitions and the misconceptions. These tend to inform how potential employers perceive one and judge one's ability.

2. Would you say your experiences are typical of people with albinism in Kenya or are they more or less severe than the discrimination suffered by others?

I think my experiences of discrimination are less severe than the experiences most people with albinism have had. The circumstances in which I grew up, the schools I went to and my professional training all helped to make my life and experience less difficult than it would otherwise have been. The fact that I am also in a profession where I have been able to fit in despite my condition has made a big difference. I think that those with albinism who have been able to get a good education, professional training and employment, probably experience less discrimination and mistreatment than others because of the environment in which they operate.

3. What would you say are the biggest challenges facing people with albinism in Kenya? What are the most common forms of discrimination which people living with albinism face?

While the condition itself presents considerable challenges – poor vision does tend to limit one's capacity and the photo-sensitivity poses major health risks if one has to work in the sun – the biggest challenge is the so-

cial isolation and exclusion that people with albinism face.

Albinism is a condition that is little understood in most of our communities. People believe that one is either bewitched, has supernatural powers (beliefs that people with albinism do not die remain common) or that

a child with albinism is the result of infidelity on the part of the mother. People fear that albinism is contagious, so there are those who will recoil from contact with a person with albinism. Such fears and misconceptions, of course, translate into discrimination in access to education and employment in particular.

Due to the misconception that all people with albinism are blind, most children with albinism, probably about 90%, are educated in schools for the blind. In these schools they are required to learn in Braille, but because they can see, albeit not as well as people without visual impairments, they tend to perform worse in school than even their blind schoolmates. This means that their access to tertiary education is limited, and without professional qualifications, access to employment is correspondingly limited.

Negative perceptions of albinism further limit access to employment. While no employer will tell you directly that the reason you did not get a job was because of your genetic condition, you are left with the very strong impression that that is precisely the reason why.

4. What made you decide to begin working on the protection of people with albinism? Was there a single event which acted as a catalyst or was it something that you had always wanted to do?

From my experience as a child growing up with albinism, I have always felt that it was necessary to express the feelings and concerns of people with albinism, to ensure that the challenges I faced as a child in school – the eye problems and inability to see the board, the sun burn, the insults from strangers – did not continue to affect young people with albinism.



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However, I think what really made me want to work on the issues was the continued negative portrayal of albinism in the media. The cases were always of miserable, hopeless situations of people with albinism living on the fringes of society, sunburnt and prone to cancer, with poor vision, no education and no employment. I always felt that presenting albinism from a different perspective was critical, both for the people, especially children with albinism themselves, but also for their parents and for society in general. Full participation in society by people with albinism was going to be impossible for as long as the condition was viewed with these kinds of misconceptions and contempt. In addition, from talking with my own mother, I came to realise that the way albinism was viewed by society imposed an extremely heavy burden on women – even if not abandoned by their spouses as I came to find out later was often the case – the treatment they received made life extremely difficult for them.

5. Can you explain a little about the Albinism Foundation of East Africa and how the organisation operates?

We started the Albinism Foundation of East Africa (AFEA) in 2008 with a view to raising awareness about the challenges facing people with albinism in the region. While we are based in Kenya, our thinking is that the challenges that people in Kenya face are similar to those faced throughout the region, and it would be more effective in the long term to work on programmes that bring change in the entire region.

The Trustees of AFEA include people with albinism, parents of children with albinism, and friends from diverse sectors interested in addressing the challenges faced by people with albinism. Due to lack of resources, we have been operating a skeleton secretariat,

with two core staff, volunteers and contacts in various areas in Kenya.

6. What are your current advocacy priorities and how does the organisation go about achieving these aims in a difficult environment?

Our operations have centred mainly on public education and awareness on albinism, directed at persons with albinism themselves, their parents and society in general. The purpose of the awareness campaigns is to demystify the condition and begin to reduce the social isolation and exclusion that people with albinism face. We have also engaged policy makers in the areas of health and education to encourage them to put in place policies to improve access to education and health care for persons with albinism. This has required carrying out education campaigns in public institutions such as schools and hospitals, and when possible, holding public forums such as open days to sensitise the public about albinism. We have also been seeking engagement with critical government ministries such as the ministries of Health, Education, Youth, Gender and Children Services and Internal Security.

We hold quarterly meetings for people with albinism and the parents of children with albinism, where people can meet and discuss the challenges they face. The aim is to create a support group, while older people with albinism mentor and encourage the youth and children with albinism.

7. What are the biggest challenges you face as an organisation?

Resource mobilisation has proved to be the biggest challenge, particularly because there is very limited understanding of albinism. Getting funding organisations to understand

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that people with albinism face insuperable challenges that greatly limit their enjoyment of fundamental human rights has been very difficult. The challenge has been to locate issues of albinism within the human rights discourse in Kenya. While issues related to access to education, health care, employment and social acceptance of people with albinism are clearly human rights issues, most organisations do not see albinism as a special need that merits attention. In addition, the fact that people with albinism form a minority means that provision for their material needs – such as sun screen – are seen as unsustainable and that few organisations have been willing to give us a hearing.

Most organisations – wrongly, I think – don't see albinism as falling within the issues that they focus on. Indeed, issues pertaining to

albinism are a novelty – until the killings of people with albinism in Tanzania hit the media in 2007, there was very little interest or concern about people with albinism.

8. What level of support or cooperation does the organisation get from a) human rights organisations; and b) other organisations working on the protection of discriminated groups, such as women's organisations?

We do get some limited support from human rights, women's rights and disability rights organisations such as the Federation of Women Lawyers, Urgent Action Fund, Ford Foundation, Kenya National Commission on Human Rights, Kenya Society for the Blind and the African Braille Centre. Such support is limited in most cases to participation

in our activities such as open days or consultative forums on the human rights issues directly affecting persons with albinism. As yet, no organisation has incorporated violations of the rights of persons with albinism in any of their projects, in the way that the Kenya Human Rights Commission has taken on LGBT or reproductive health rights issues. This, again, could be because of the limited understanding and appreciation of the challenges that those with albinism face, and it emphasises the need for AFEA to articulate the issues.

9. What single change to Kenyan law or government policy do you think would have the biggest impact on the lives of people with albinism? Why?

Currently, government policy and practice place people with albinism within the category of those with visual disabilities. This means that their peculiar visual challenges – low vision, but not low enough to require Braille, yet not good enough to fall within the “normal” category – are not addressed. It also means that their other health challenges – photo-sensitivity which can lead to skin cancer – and the social stigma that they are exposed to, are never addressed. Consequently, there are no statistics on the numbers and situation of those born with albinism, and so no policies to address their peculiar needs. Policy changes that recognise persons with albinism as a group with special needs, inclusion in laws such as the Persons with Disability Act and prohibition of discrimination on the basis of genetic inheritance could have a major impact on persons with albinism as it would place them on the radar of the law. Currently, persons with albinism are invisible.

10. Kenya is nearing the end of a constitutional review process and a draft constitution will be the subject of a referendum in early August. Article 27 (the right to non-discrimination) in the draft Constitution does not explicitly prohibit discrimination on grounds of albinism or genetic inheritance, which you favour. However, as the list is non-exhaustive it provides the opportunity for legal challenge on these grounds through the courts. Do you think this will present an opportunity to extend protection for people with albinism?

The anti discrimination provisions in the proposed constitution probably present the best opportunity ever for us to extend protection to those with genetic differences such as albinism and to address the challenges that people with albinism face. We could, for example, lodge legal challenges against education and examination rules that fail to make reasonable accommodation for children with albinism and require them to learn in Braille. The recognition of the right to health in the constitution gives us an opportunity to challenge government failure to provide skin protection for persons with albinism and skin care for those who have developed skin cancer.

11. People with albinism face very severe danger in neighbouring Tanzania because of superstitious beliefs held by some groups there. Do you foresee any risk of these kinds of belief transferring to Kenya?

Initially, I was very apprehensive that the killings would spread here, for many of the misconceptions and superstitions about albinism held by Tanzanians are common here also. However, I am encouraged that, at least

to my knowledge, only one killing of a Kenyan with albinism has occurred in the two years since the killings in Tanzania began to be reported. That killing involved a kidnapping from a border village in Kenya and the

murder took place across the border in Tanzania. I am hopeful therefore that though we have similar superstitions in Kenya, they will not translate into the kinds of killings that have taken place in Tanzania and Burundi.

Interviewer on behalf of ERT: Jim Fitzgerald

This interview was conducted in July 2010 during the run-up to the referendum on Kenya's new Constitution.