



MOTHERING & ALBINISM

Newsletter: FALL 2021

With over a year of navigating how to continue this research project in the middle of a global pandemic, we bring this newsletter with hope for what lies ahead.

Announcements

Welcome to the next United Nations Independent Expert on the enjoyment of human rights by persons with albinism:

Muluka-Anne Miti-Drummond

Muluka-Anne Miti-Drummond was appointed as the second Independent Expert on the enjoyment of human rights by persons with albinism in August 2021. Muluka is a lawyer from Zambia and currently resides in the United Kingdom. She has multiple years of experience working with albinism and human rights through research, consultations, campaigns, and advocacy. Among her contributions are the [manual](#) for the National Human Rights Institution of Amnesty International, and participation in the creation of the [International and Regional Standards for the Protection and Promotion of the Human Rights for Persons with Albinism](#).

She is committed to ensuring the inclusion and participation of persons with albinism. We look forward to supporting her mandate!

Follow the work of Muluka and the UN Mandate [here](#)

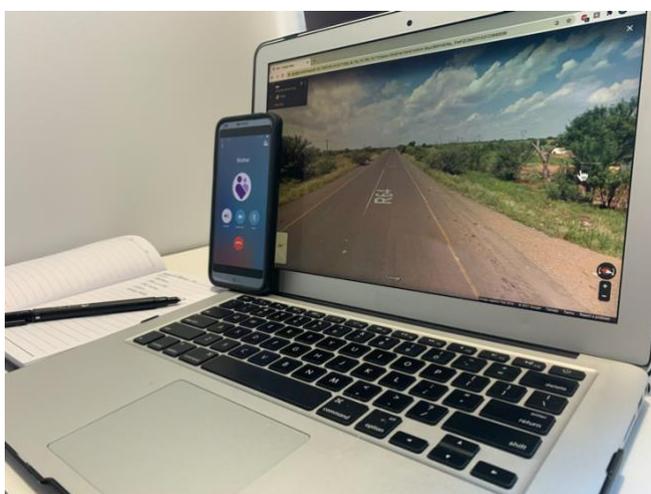


Current Security Situation of Persons with Albinism: Highlight on Malawi

We are disheartened by the recent report of attacks against persons with albinism in Malawi in August and September this year. Ian Muhamba, a 20-year-old man with albinism was reported missing and was found a few days later buried in a grave with several of his body parts removed. Not long after this report, the grave of James Nyama, a deceased person with albinism, was found to have been exhumed and unknown individuals made away with his bones. As of this time, authorities are conducting investigations and have yet to release information of possible suspects. The [United Nations](#) called for urgent actions to ensure the rights of persons with albinism and to implement the [National Action Plan on Persons with Albinism](#).

Fieldwork

Virtual fieldwork is paused in the Northern Cape and Gauteng provinces of South Africa. To date, we have interviewed a total of 13 participants in South Africa: 8 mothers impacted by albinism and 5 key stakeholders. We have developed Trauma-Informed Guidelines for Virtual Interviewing and continue to adjust our methods as needed during the pandemic. We hope to be back in the field when it is safe and feasible for all involved.



The South Africa team (Innocentia Migijima-Konopi, Jennifer Kromberg, Nomasanto Mazibuko, Maxwell Thabethe, Mpho Tjope, Dianah Msipa, Maretha De Waal, and Shirley Mogale with Sheryl Reimer-Kirkham, Barbara Astle, I.K. Ero, Emma Strobell, and Meghann Buyco) has been meeting to discuss the logistics of fieldwork during the pandemic, to explore the application of decolonizing methodologies, and to begin data analysis of South African data. Our conversation has been very rich, in surfacing how decolonizing methodologies are applied in contextual ways in South Africa and Canada. The project is also benefiting from contextualization in relation to existing South African policies. At the July 2021 Team Meeting, Maretha de Waal presented her research and experience developing curricula and training programs related to gender and disability. She presented the United Nations Development Programme's (UNDP) [Gender Results Effectiveness Scale](#), which guides gender response evaluation of policies and programs. Further, she presented the South African government's approach of '[gender budgeting](#)' where gender, youth, and disabilities are tagged in budget lines for planning and implementation. The work of the Mothering & Albinism Project, Maretha suggested, can utilize this effectiveness scale which the South African government also employs as a framework.

The intent of conducting research in 3 countries was, among other reasons, to share **Best Practices** between countries. We are seeing how national differences in government policies and services, as well as the histories of Tanzania and South Africa are resulting in varied lived realities for mothers impacted by albinism.

Knowledge Translation Initiatives

Given the disruptions to fieldwork, the project has focused more on knowledge translation and community engagement.

In June 2020, some members of the project team gathered into two working groups to

draft what we referred to as primers, so we would be operating from a place of relative shared understanding going forward. One group formed around a human rights and albinism primer, and a second group around religion, albinism, and human rights.

The first group has been working on a manuscript that is ready for submission. The manuscript is entitled “Shifting Wrongs to Rights: Lessons in Human Rights from the Situation of Mothers Impacted by Albinism in Africa” (Ibhawoh, Reimer-Kirkham, Ero, Mgijima-Konopi, Beaman, Senkora, Astle, Strobell, Imafidon), for submission to the *Journal of Human Rights Practice*.

The work of the second group has resulted in a knowledge translation project as a first step, bringing together faith leaders in Tanzania (described below).

Knowledge Translation in Tanzania: Plans for a Faith Leaders’ Summit

In partnership with Perpetua Senkoro (Knowledge Translation Facilitator, TZ), Kondo Seif (Knowledge Translation Facilitator, TZ), Reverend Cannon Thomas Godda (Interreligious Council for Peace Tanzania), Marco Methuselah (St. Paul’s Theological Seminary, Mwanza, TZ), and Upendo wa Mamas (TZ), we are planning an interreligious Faith Leaders’ Summit (hybrid/virtual). The focus is on bringing together faith leaders from diverse backgrounds to consider strategies that best protect and promote the rights of mothers impacted by albinism around Tanzania. Discussion topics will include the experiences of mothers impacted by albinism, responses by faith communities, and teachings from sacred texts and traditions that provide grounding for advocacy by faith communities. This summit will provide an important platform for the mobilization of the project research findings regarding mothering and albinism. We also hope that the summit will foster an ongoing sustainable network of faith leaders’ advocacy for persons with albinism.

African Disability Rights Yearbook Manuscript

Helene Combrinck, member of the editorial board for the [African Disability Rights Yearbook](#), published by the Centre for Human Rights, University of Pretoria, invited us to submit a commentary for their 2021 edition. The focus of the commentary is to provide recommendations for disability rights, drawing from our mothering and albinism research project in Tanzania and South Africa. In the commentary, we make a case for a human rights approach for mothers impacted by albinism, on account of discrimination, harmful practices, stigma and lack of access to services, and gender inequality. The Convention on the Rights of Persons with Disability, ratified by both Tanzania and South Africa, can provide protection for mothers impacted by albinism. Our study underscores the importance of immediate ratification and implementation of the Africa Disability Protocol, which recognizes harmful practices as human rights violations indefensible by culture or tradition.

Poster for Canadian Conference on Global Health

Members of the research team from South Africa and Canada will be presenting (virtually) an e-poster on November 24 to 26, 2021 at the [Canadian Conference on Global Health](#) for the Canadian Association of Global Health (CAGH). The focus of our presentation is on applying a decolonizing lens to a South Africa-Canada intersectoral partnership during the global pandemic, with illustration from our mothering and albinism project.

University of Toronto Graduate Seminar

Wisdom Tettey extended an invitation to join him to present in a graduate seminar at the University of Toronto on November 4, 2021. This is for an interdisciplinary graduate course on “Development, Policy, and Power.” We will be discussing the influence of human rights

conceptualizations and intersecting social structures on policy and exploring directions of the United Nations (drawing from IK's reports) on advocacy and policy to address the welfare and security of persons with albinism.

Team Updates



We celebrate Ikponwosa (I.K.) Ero for a successful mandate as the first Independent Expert on the enjoyment of human rights by persons with albinism! Her work has heightened global awareness to albinism and resulted in numerous initiatives to protect and promote the rights of persons with albinism. Please visit the blog where we honour her [here](#).



Innocentia Migijima-Konopi has left her position as Manager of the Disability Rights Unit at the Centre for Human Rights, University of Pretoria, and has started a fellowship with Atlantic Fellow for Health Equity South Africa (AFHESA) at Tekanoalong and is pursuing her PhD!



We welcome Dianah Msipa, the Acting Manager: Disability Rights Unit at the Centre for Human Rights, University of Pretoria!

Blog www.mothingandalbinism.com

Project Team

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