

Winter 2021 Newsletter

As with so much of life, the COVID-19 pandemic has impacted our [Mothering & Albinism](#) project. However, 2020 created space for further data analysis, continued theoretical work on human rights and religion, creation of knowledge mobilization materials, and preparation for virtual fieldwork in South Africa (which is now underway!).

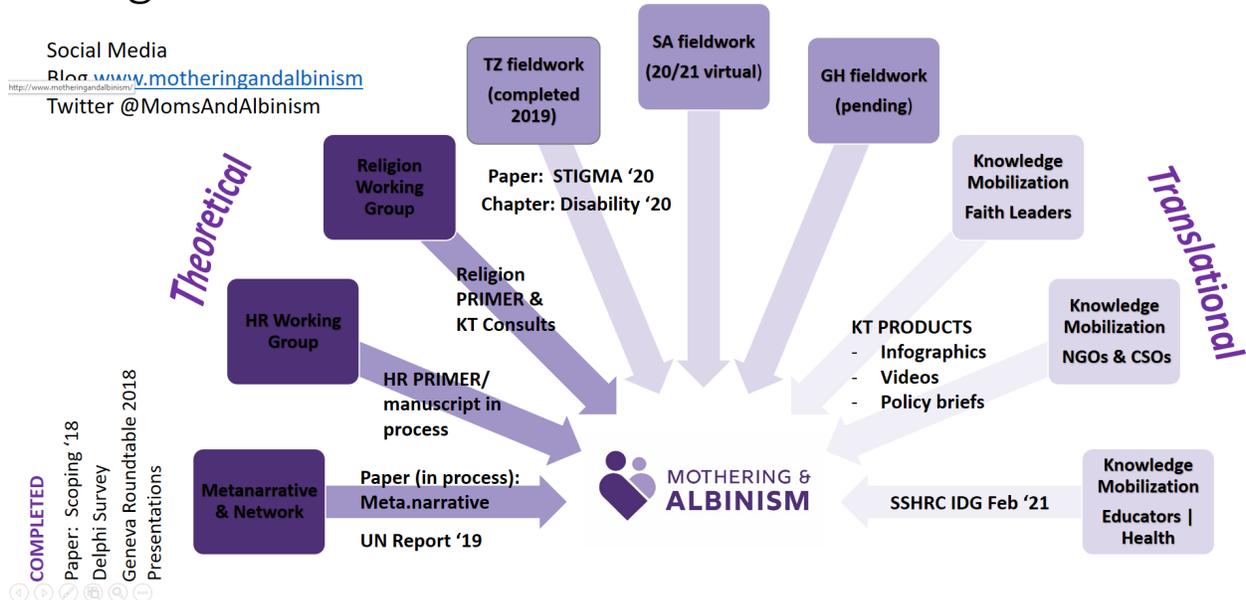
Updates on Albinism and Human Rights

IK Ero's tenure as mandate holder on the enjoyment of human rights by persons with albinism is coming to a close this year (2015 to 2021). She submitted her [final report](#) to the UN Human Rights Council in December for the 46th session of the Human Rights Council on February 22 to March 19, 2021. In this report she outlines the "achievements, accomplishments, challenges and the way forward" (p. 1). IK has made a tremendous global impact during these 2 terms, bringing much attention to human rights for persons with albinism, all with incredible grace, wisdom, and good humour.



Follow the work of IK's Mandate [here](#) .

Program Visualization

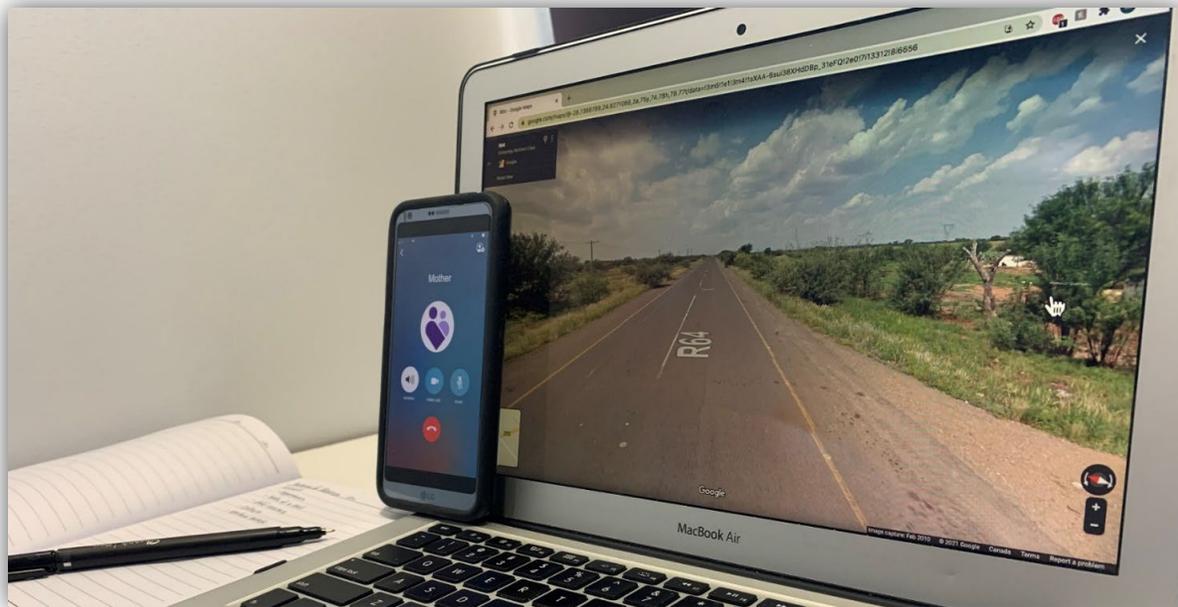


Funding: Social Sciences and Humanities Research Council (#435-2019-1120) 2019-2023)

Fieldwork: Northern Cape, South Africa

Fieldwork is well underway thanks to Mpho Tjope, Founder & Director of Albinism Advocacy for Access and the Northern Cape Community Research Coordinator for our project. Tshego Keitsemore has joined Mpho as Cultural Liaison, herself a mother of a child with albinism. Most interviews have been via WhatsApp, though we have navigated other options where needed. In one instance a participant did not have a smart phone so Mpho was able to call her on his cell phone, place the call on speaker phone, and join a Zoom meeting with the interviewer. We are finding ways to be get creative and work on our adaptability! To foster rapport, we have implemented a process of a brief introductory video call with the participant and Mpho, followed by an interview in subsequent days. We have taken to street view of Google Maps, to tour towns and countryside in South Africa to gain a sense of the context of the participants. Mpho had told us about the distances between towns, and we've been able to experience this virtually with mile after mile of perfectly straight roads across dry fields. And we exchange stories of snow

falling in Vancouver, British Columbia and finding ways to stay cool in the blistering heat of Kimberley, Northern Cape!



We meet with the South Africa team in mid-March to plan when and how to begin the next fieldwork locations (Guateng with Nomasonto Mazibuko (Albinism Society of South Africa) and KwaZulu-Natal with Dr. Maxwell Thabethe (National Albinism Society). Our aim is to have this phase of virtual fieldwork complete in early Summer 2021. We are still anticipating travel to South Africa for some in-person fieldwork; of course this is COVID-19 dependent (as is much of life right now!).

Social Media

Please see (and share) our project blog for our January commentary on Tending to Human Research Ethics. Next up will be a series on research during the global pandemic. www.motheringandalbinism.com



Project Team	
<p>Sheryl Reimer-Kirkham (CA) Barb Astle (CA) IK Ero (CA) Lori Beaman (CA) Bonny Ibhawoh (CA) Elvis Imafidon (NI/UK) Jennifer Kromberg (SA) Innocentia Migijima-Konopi (SA) Nomasonto Mazibuko (SA) Perpetua Senkora (TZ) Sonya Sharma (UK) Wisdom Tettey (CA) Boateng Wiafe (GH)</p>	<p style="text-align: center;"><u>South Africa</u> <u>Research Collaborators</u></p> <p style="text-align: center;">Mpho Tjope Maxwell Thabethe Shirley Mogale Maretha de Waal</p> <p style="text-align: center;"><u>Project Staff</u> Emma Strobell (CA) Meghann Buyco (CA)</p>

Project Publications

Ero, I., Reimer-Kirkham, S., Astle, B., Strobell, E., & Buyco, M. (in press). Women human rights defenders: A case of activism of mothers of children with albinism in Tanzania. In M.Rioux and R.Addlakha (eds.) *Handbook of critical disability studies in a globalizing world*. Springer.

Reimer-Kirkham, S., Astle, B., Ero, I., Imafidon, E., & Strobell, E. (2020). The disproportionate impact of health-related stigma and associated worldviews on the security and wellbeing of mothers affected by albinism. *Journal of Foundation of Science*. <https://doi.org/10.1007/s10699-020-09701-0>

Reimer-Kirkham, S., Astle, B., Ero, I., Panchuk, K., & Dixon, D. (2019). Albinism, spiritual and cultural practices, and implications for health, healthcare, and human rights: a scoping review. *Disability & Society*, 34(5), 747-774.

Report of the Independent Expert on the enjoyment of human rights by persons with albinism on the round table on human rights and albinism: Seeking consensus and priorities on advocacy and research.
A/HRC/40/62/Add.2 URL: <https://undocs.org/en/A/HRC/40/62/Add.2>