



## CHESHIRE HOMES SOCIETY OF ZAMBIA

### TERMS OF REFERENCE FOR THE BASELINE STUDY ON THE PROJECT - OUT OF THE SHADOWS FOR GOOD: AN END TO THE MURDER, MUTILATION AND EXCLUSION OF CHILDREN AND ADULTS WITH ALBINISM IN ZAMBIA.

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#### a. Introduction

Cheshire Homes Society of Zambia (CHSZ), along with the Africa Albinism Network (AAN) and other local partners, is implementing the project “Out of the Shadows for Good: Ending the murder, mutilation, and exclusion of Children and Adults with albinism in Zambia” funded by the Dutch Postcode Lottery through Liliane Foundation (LF). The project will be implemented in 4 provinces of Zambia which are Muchinga, Northern, Luapula and Eastern provinces.

Albinism is a rare genetic condition marked by reduced or absent melanin, leading to little or no pigmentation in the eyes, hair, and skin. Globally, individuals with albinism face significant challenges, such as limited access to healthcare, education, and enduring severe discrimination, including abduction, trafficking, and murder for ritual purposes. In Zambia, the difficulties experienced by people with albinism (PWA) vary in form and intensity across regions.

A [UNICEF Situation Analysis on the rights of persons with disabilities in Zambia](#) highlights albinism as a lesser-known disability and under-represented among disability groups.

#### b. Background to the Albinism project “Out of the shadows for good.”

The albinism project will run for 3 years (June 2024 – May 2027) and is aimed at improving the quality of life of all children and adults with albinism in Zambia in the project areas through access to health care, education and safety.

The project will be working on national, provincial and community levels to drive change and improve access to justice for the persons with albinism. It will focus on direct support to persons with albinism and lobby and advocacy to improve access to services provision among the service providers which will be contributing to achieving the sustainable development goals as the project responds to human rights violations, including inadequate access to health services and related barriers. Key strategies of the project include advocacy, learning, and sharing innovations to protect the rights of persons with albinism. In addition, strengthening organizations of persons with albinism, organizations of persons with disabilities, civil society organizations, and social movements. All of these are crucial to achieving the project’s objectives.

[The CRPD report of March 2024 of the Zambia government](#) highlights minimal legal or policy measures to protect PWA from skin cancer, stigma, harmful practices, bullying, and hate crimes.

To be able to provide this and have a baseline understanding of the situation, we seek the services of the consultant to carry out the study in the four provinces of Zambia (Muchinga, Northern, Luapula and Eastern provinces).

**c. Overall objective of the project**

The overall objective is aimed at improving the quality of life of all children and adults with albinism in Zambia in the project areas through access to health care, education and safety.

The specific objectives of this baseline study are:

- 1) To establish a solid baseline regarding the education situation of children(persons) with albinism
  - Attention should be paid to understanding attitudes and barriers that surround access to education and what can be done to improve access.
- 2) To establish a baseline regarding the current levels of access to and provision of skin cancer screening and treatment for persons with albinism
  - The consultant will look into how access to skin screening and availability of services in the provinces and treatment options. Sunscreen provision and access to should also be considered. Availability of trained personal and referral systems.
- 3) To identify capacity gaps and practical competencies needed for various stakeholders especially the organizations of persons with albinism including the justice system to support lobby and advocacy.
- 4) To establish the security issues that surround persons with albinism, access to justice and how this can be improved.
  - Particular attention should be paid to the Justice system of handling cases of PWAs, community security concerns and family perceptions around the security of PWAs.
- 5) To find out what National policies or legislations are available for PWAs in the judicial system and all-round access to human rights with particular attention to access to education, health and social services.

**d. Rationale for carrying out study**

Based on the background given, it is necessary to conduct a baseline study which will inform the project operation and take into consideration the mapping of stakeholders and knowledge gaps in each of the 4 provinces. The study will also help to identify areas that may need more focus among organisations of persons with albinism (capacity building). It should also be able to give a strong baseline situation on access to justice, education and health services for persons with albinism and systems in place with care to look at some of the imbedded community beliefs (attitudes) that may need intervention from the implementing partners and the stakeholders. Therefore, we anticipate that the report will guide on the availability of access to services and channels, identify barriers, legislation/policies available and or recommended.

CHSZ therefore seeks the services of a consultant who is well versed on disability issues to conduct the study.

**e. Deliverables**

- Full status report

**f. Report expectation**

- Inception Report to include proposed detailed methodology, assessment tools (qualitative and/or quantitative), detailed assessment schedule and responsibility of team members.

- A briefing session with CHSZ and partners at the end of the field phase to provide initial findings, to clarify any questions.
- Final report according to CHSZ requirements in English: It will present the analysis of the key deliverables mentioned in the TOR. While the main part should present the results in a very concise form, details can be placed in the appendix.
- A final detailed report (hard and soft copy max 30 pages) which includes executive summary, should be submitted to CHSZ within the agreed timeframe. The 1-2-page summary shall be drafted so that it can be used as a stand-alone document for further distribution to stakeholders. The final report will be the last deliverable and it must be satisfactory to LF, CHSZ and AAN.
- The successful candidate will be given access to the project log frame.

**g. Duration and Phasing**

The assessment is expected to last a maximum of 21 days over a period of 1 month as follows:

- 2 days development of assessment methodology and tools
- 14 days baseline assessment in all project site (Muchinga, Northern, Luapula and Eastern provinces)
- 5 days draft report ready

**h. Ethical Considerations**

The baseline study should adhere to the Research Ethics Standards of Zambia

**i. Submissions of Proposals:**

Interested consultants are invited to submit a concise proposal by 30<sup>th</sup> September 2024 to the following [cheshirezambiajobs@yahoo.com](mailto:cheshirezambiajobs@yahoo.com)

The proposal should highlight the following:

- Understanding of the TOR and the questions to be answered
- Details of the proposed methodology
- Schedule of evaluation activities
- Proposed budget
- CV/s of lead consultant(s).

**j. Consultancy Fee and Payment Terms**

The consultant will be paid depending on experience and agreed modalities with CHSZ. CHSZ will deduct tax (10%) if the consultant does not have a tax clearance certificate. The payment schedule will be discussed and agreed upon with the successful consultant. The consultant will be offered a fixed-price contract to include all the activities and deliverables listed above. CHSZ shall pay the consultant in the following stages: 40% as a commitment fee – to commence the data collection process 60% on submission of the final report