

Change Story – Capacity Development with Albinism Umbrella

First Things First: How Internal Governance Can Create Sustainable Change for an Organisation

Background

Ensuring that the lives and dignity of People with Albinism are protected, that they are able to realize their full potential and to support their livelihood – these are the goals that Albinism Umbrella (AU) is striving to achieve. Since 2020, AU has been partnering with the GIZ Governance and Civil Society Programme (GCSP). Together the two embarked on a journey of strengthening organizational capacities.

Context

Persons with Albinism face multiple and intersecting forms of discrimination: Erroneous beliefs, misconceptions and witch-craft related superstitions put their security and lives at constant risk. Persons with Albinism are subjected to discrimination and violence, including murder and physical attacks, as well as banishment and torture. They often face health challenges such as vision impairment and increased risk of skin cancer. A spatial mapping that was conducted by AU in the Northern, Central and Western Regions of Uganda in 2021 showed that an average of 80% of the Persons with Albinism in the three regions have sight impediments and are not able to read without glasses. However, in the Central Region only 30.2% and in the West only 20.2% of the interviewed have ever gone for an eye checkup.

Both, the constant stigmatization and the health problems, often make it difficult for Persons with Albinism to exercise their right to education. About 59% of the interviewees in the North and 52% in the West indicated that either they or their children with Albinism had been discriminated at school. The lack of education often leads to unemployment and poor living conditions consigning many Persons with Albinism to poverty. Persons with Albinism therefore require specific measures for their protection and the promotion of their rights.



Persons with Albinism marching in Lira on the International Albinism Awareness Day 2022.
©AU/EG Bhaki

The Organization

AU was established in 2015 and fully registered as a non-governmental organisation (NGO) in 2017. As an umbrella organisation with 10 community-based member organizations and

over 400 individual members, AU is committed to create a joint voice for all Persons with Albinism in Uganda to empower them with knowledge on their human rights, advocacy and livelihood skills. AU raises awareness amongst Persons with Albinism, their parents, caretakers and the communities where they live. In 2019, AU launched its first strategic plan (2019-2023) and thereby became aware that the organisation needed to strengthen its institutional capacities to achieve its objectives and to live up to its full potential.

The start of the journey

“This project with GCSP has built a foundation for AU to ride on and has created an impact for as long as AU will exist.” (Olive Namutebi, Executive Director AU)

At the beginning of 2020, AU initiated a partnership with GIZ GCSP. The Organizational Capacity Assessment that AU conducted with GCSP support showed gaps related to AU’s internal governance system and management which in the long run would hinder the organisation in its growth. AU members had not held an annual general meeting (AGM) to elect a board of directors that strategically leads the organisation. In addition, there was no tailor-made constitution in place to outline the purpose, structure and responsibilities of the organization and its members. Furthermore, several policy documents were missing which are crucial for the internal management of the organisation. AU also did not have an adequate accounting system to keep up with the transparency and accountability standards required by donors. Limitations like these can ultimately create obstacles for an organization: An interim board of directors staying long term lacks the official mandate to steer and represent the organization. Opportunities for partnerships and resource mobilization are also limited:

Partner organizations and donors often require a constitution, a fully mandated board and a transparent accounting system as basic criteria.

Strengthening organizational capacities

Collaboratively, the team, consisting of AU and GCSP staff, developed a results-oriented concept that depicted the necessary actions required to strengthen the organization’s capacities.

Despite the limitations during the Covid-19 pandemic, AU staff and interim board members with the support of two GCSP advisors drafted a constitution in a consultative process that exactly fits the organisation's needs. With financial assistance from GCSP, AU held an AGM in November 2020 during which the constitution was presented and approved. The members officially elected the board of directors. These were crucial steps for the organization: members were able to express their view and increase the sense of ownership within the organisation - ultimately creating the foundation to enhance organizational performance and attract new partners.



Newly elected AU board of directors at the first AGM in 2020. ©AU/ Okiria

With the new board of directors in place, AU and GCSP continued working on internal policies and documents. The elected board members started into their term by developing a tailor-made *Board Manual* to guide the work of the board and orient new board members in

the future. AU board and staff members in a joint effort edited an *Anti-corruption Policy* as well as an *Accounting and Financial Manual*. With support from a consultant who accompanied several partner organizations of GCSP in similar processes, AU also developed a *Human Resource Manual*. A GIZ data security specialist trained AU staff on data protection and data management and supported the team in formulating a *Data Protection Policy* for the organisation. While it is helpful for organizations to have these documents to clarify internal procedures and set internal standards, they are also often preconditions for network and donor organizations to maintain close connections.

AU staff and board members also participated in trainings in different areas of organizational development conducted by a training institute that GCSP partnered with to provide capacity development. Thereby, the team members were able to improve their knowledge on internal governance, leadership, resource mobilization or financial management among others. In addition, GCSP supported AU with a suitable accounting system that corresponds to the growing tasks of the organisation. The software was installed by an expert team that also trained staff. AU has since been able to comply with financial reporting guidelines and act as an accountable organization. Also, adequate IT equipment was procured for staff to work more efficiently. GCSP provided AU with board room equipment like furniture and a projector. Furthermore, a tent was purchased that was used for the workshops and trainings that GCSP provided and has since been used for diverse project activities of AU, saving on meeting costs.

What kind of change was created?

When conducting the organisational capacity assessment in 2020 with support of GCSP, the results pointed out that AU - besides the gaps

in the internal governance systems - required higher visibility and stronger partnerships. They also identified a need to strengthen their capacity to mobilize resources. Instead of trying to address all the challenges at the same time, AU prioritized internal issues and got their house in order. The Executive Director, Olive Namutebi, states today that improving the internal governance system interestingly also had a positive effect on the other issues: Within the last two years, AU has evolved from a small initiative driven by the founders to a fully membership-based organization set out to achieve its goal of protecting Persons with Albinism and their rights. Olive Namutebi can proudly say that AU has become a resource center for others. *“When the topic of Albinism comes up, even in government, AU is the central contact. Through all the trainings and exchange platforms we have grown, so that we can also pass knowledge to others now.”*



Olive Namutebi with the Minister for Disability Affairs at the launch of the National Action Plan on Albinism in 2022. ©AU/ EG Bhaki

AU has improved its organizational ownership: Staff and board members do not only know and understand the organisation’s crucial documents but developed them themselves. The support to the internal governance system, the first AGM and the board has laid a foundation for the organisation, says Nicole Phiona, the AU Administration Officer, while appreciating the participatory approach GCSP is

using. *“The policies came from ourselves and showed us how to protect our people and treat data sensitively. The trainings really helped us to identify our gaps and prioritize the needs of our target group.”* This stabilizes the organisation and enables it to work soundly as a platform for all Persons with Albinism. Olive Namutebi confirms that the sound internal governance system has helped AU in strengthening partnerships. Meanwhile, AU has also become a full member of the National Union of Disabled Persons of Uganda (NUDIPU) after proving that they have the required governance framework in place. This increased AU’s visibility in the sector.

Thanks to the accounting system, AU complies with financial reporting guidelines and acts as a fully accountable organisation. The organisation’s Finance Officer, Henry Mujuni, emphasized *“Through the trainings, I learned a lot in terms of financial management and resource mobilization in the field of working with NGOs. And now we pass it on to organizations that come along.”*

“We have been audited twice since collaborating with GCSP. Having all these systems in place has made the audits a lot easier – we have our house in order. Also, when we write proposals - we have everything available: the audited books, the accountabilities, all the documents required.”

(Henry Mujuni, Finance Officer at AU)

In July AU celebrated its 5th anniversary with a lot of success stories to share. Their recently finalized spatial mapping for Persons with Albinism in Central, Northern and Western Region provides sound information to crucial actors that is used to improve the livelihood of Persons with Albinism in Uganda. The celebration of the International Albinism Awareness Day in June underlined the constructive relationship of AU with the government and other stakeholders.



Participants of the AU Annual General Meeting 2021. ©AU/ Okiria

GCSP appreciates the commitment and passion shown during the implementation of the mutual cooperation and congratulates the AU team on the progress made by not only being part and origin of the different interventions but putting them directly into practice. This has led to a remarkable outcome and has the potential to benefit stakeholders way beyond the AU office.

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