



2020
ANNUAL REPORT
EPILEPSY SUPPORT ASSOCIATION UGANDA (ESAU)



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FORWARD FROM EXECUTIVE DIRECTOR

Epilepsy over the years has been misunderstood in various degrees across the globe. Most of the Information circulated in our communities is not right. This only leaves people with epilepsy more discriminated, marginalized and stigmatized.

The year 2020 started well only to deteriorate into a pandemic that has left the world not the same and may never be the same again. The Covid 19 scourge did not leave persons with epilepsy the same neither.

Many that were running small income generating activities ended up in hopeless situations since the government and Ministry of health announced a total lock down and observance of the Standard Operating Procedures (SOPS). Access to health services and medication was stifled by the shutdown of public and private transport coupled with mental health departments in major referral hospitals being turned into Covid 19 management centres. PWE moved long distances to access these services amidst hunger and poverty.

With the support from the MOH, ESAU was able to acquire movement stickers such that a person with epilepsy does not continue suffering during the lock down.

ESAU was able to support up to 500 PWEs with cash handouts for them to get basic needs for their survival. Partnerships with 5 Not for Profit, faith based health centers were established so as to have readily available anti-epileptic drugs. Covid 19 related Radio programs (Talk Shows, spot messages and Drama skits) were aired for a PWE to keep informed all over the country.

ESAU will remain grateful to persons with epilepsy, their parents and volunteers who kept positive in the event of the pandemic. We shall remain indebted to our donors who made our work easier in the year 2020. The Disabled People's Organisation of Denmark, The Agha Khan Foundation, Disability Rights Fund, Light For the World and the International Bureau of Epilepsy. We shall not forget all the employees of ESAU for the dedication and hard work exhibited during and after the lockdown to serve a person with epilepsy in the country.

Sarah Nekesa
Executive Director

1.0 INTRODUCTION

Epilepsy Support Association Uganda (ESAU) is the only, indigenous NGO that brings together people with epilepsy, their families to work towards eliminating the social stigma attached to epilepsy, create an environment where epilepsy is better understood among communities in Uganda and the diaspora; so people with epilepsy can reach their full potential and enjoy equal rights. The association exists to empower people with epilepsy use the challenge of epilepsy as an opportunity, come out of the shadows, and contribute to development processes in their respective communities while also supporting them to lobby development partners and their local and central governments improve service delivery to persons with epilepsy.

The association is democratically governed by the members who elect a local executive committee at sub-county and district levels. Each district branch sends two delegates to a national assembly that elects a national board. At the helm of the association is the board which is the policy making organ of the association.

1.1 ESAU VISION, MISSION, VALUES AND PRINCIPLES

VISION STATEMENT

An inclusive Ugandan society where families affected by epilepsy have equal opportunities and live to their full potential

ORGANIZATION MISSION

ESAU exists to mobilize, organize, support, skill, care, and advocate for the rights of people with epilepsy to live a dignified life

ESAU CORE VALUES

People	We believe that the strength of ESAU lies in the strength of its members and empowered persons with Epilepsy
Equality	In pursuing our mandate, we treat everyone with fairness, without stigmatization or discrimination and we strive to create an institution and a society where there is no form of unequal relations
Accountability	We hold ourselves accountable to go to the highest level of ethical behavior and responsibility in our actions, while minding integrity in our performance
Commitment	All our work is primarily focused on improving the quality of life of people with epilepsy
Compassion	We are passionate about improving the quality of lives of persons with disability
Empathy	As an association of people with epilepsy we know best what it means and feels to have epilepsy. We will use our experience to support one another emotionally to lead positive and independent lives
Transparency	We shall ensure that our operations and activities are open to society and our stakeholders at all times
Cooperation	We work collaboratively with epilepsy related organizations, professionals, government, public sector and communities

1.2. BACKGROUND TO THE ANNUAL REPORT

2020 started well but saw most countries in the world suffer one of the most deadly pandemics - The COVID- 19 pandemic. Nevertheless the association kept afloat and ESAU ran a number of projects with support of numerous donors. These funders included Danish Epilepsy Association (DEA) through Disabled People's Organization of Denmark, The Disability Rights Fund, The Aga Khan Foundation, Light for the World, Uganda National Action on Physical Disability (UNAPID), and The International Bureau for Epilepsy

The main themes addressed under these funding's included; Awareness Raising, Advocacy, Organizational Development, Monitoring, Networking, Fundraising & Resource Mobilization. All projects funded were in line with the Association's mission, vision, objectives and strategic plan.

2.0 ESAU ACTIVITIES CARRIED OUT IN 2020

2.1 AWARENESS RAISING

2.1.1 Demystifying epilepsy.

The organization exists to demystify epilepsy among rural communities in Uganda, partners, central and local governments so as to ensure that the needs of people with epilepsy are understood and incorporated in development processes as well as in the budgets and programs of various partners and institutions.

Most of ESAU projects are anchored on the strategic objective of the association- Improve knowledge about epilepsy among people with epilepsy, their families and communities by 2023.

With support from her main funder, The Disabled People's Organization of Denmark, in a project code named "*Sustainability, Visibility and Democracy*" - under a major theme to ensure visibility for the association a lot of activities were planned for and implemented. They included: partnerships with media, printing information and educational materials, participation in national, international events to raise the profile of the association among her partners, partnering with schools through E-clubs.

A. Supporting awareness raising in schools through E-Clubs establishment

In making the above a reality, the association partnered with 6 schools to establish Epilepsy Clubs. The main objective of these clubs was to create awareness about epilepsy within and out of the school environment in order to create a conducive environment in schools for people with epilepsy. Activities held to realize this included:

- 12 teachers were trained in epilepsy care, its management, establishment and running of school epilepsy clubs, reporting among many others.

- The teachers were then tasked with the responsibility of establishing the E-clubs, recruiting E-club members and rolling out the awareness raising programs in their schools.
- The teachers recruited a total of 210 epilepsy club members, sensitized the school administration about epilepsy, and sensitized the teaching and non-teaching staff about epilepsy and the E-club objectives and activities.

B. Production and distribution of information and educational materials

- 200 Christmas cards, 100 calendars and 40 diaries produced and distributed to ESAU partners. These calendars had messages on epilepsy care and its management, pictures and snapshots of ESAU activities in the years. They were distributed to donors' partners and uplifted the organizational profile.

These branding materials produced supported the visibility function for the organization among key central government ministries, partners in health, education as well as donors. This was a new phenomenon that supported the marketing function for the organization.

C. Media conferences

The association was privileged to hold 1 main media conference with journalists during celebrations to mark international day for epilepsy. This press conference brought together 4 national TV journalists, other activities to mark this day included:

- ESAU was hosted on Nation Media Television for a free talk show and communities in Uganda were provided with insights into what epilepsy was, causes, types, management as well as the plight faced by people with epilepsy and how communities in Uganda can better support people with epilepsy live to their full potential.

- Over 15 radio and print journalists provided with epilepsy facts. The association received over 50 calls in to the secretariat within this period with clients from all over Uganda being supported in the care and counselling function.

ESAU approximately reached over 2500 people with accurate epilepsy information based on the coverage of the Television and radio stations.

D. Participation in international and national events

ESAU participated in the celebrations to mark the international day for people with disabilities in Kampala held at Sheraton Gardens. The association participated in the world AIDS day celebrations in the country. ESAU showcased her work to over 20 partners in health, education and line central government ministries.

Other International events the association participated in were the patient's solidarity day which were marked with talk shows on plights of people with epilepsy. How these can be harnessed while also supporting the awareness raising function.

The association held 2 talk shows on capital FM a national radio in Uganda with a clientele of over 4000 people. Extracts of these talk shows were aired to 7 other local radios affiliated to the national radio.

E. Partnership meetings

The association staff participated in over 20 partnership meetings with disabled partners, partners in health, education and line government ministries of health, education, gender among others. In these meetings the association showcased her work, the service delivery challenges of people with epilepsy and how best partners and line government ministries can reduce the burden felt by people with epilepsy

F. Website and social media updates

Infinity graphics re- contracted to host the domain for ESAU website in the reporting year, Nexus graphics supported the redesign function for the website.

ESAU was also helped in the redesign function for the website by the an IT consultant from the Danish Epilepsy Association- ESAU administrative assistant held 3 day long sessions with the Danish IT consultant on best methods to improve the website.

The website has greatly improved with new content updated each day by the ESAU administrator.

The association has a Facebook and twitter account with over 120 followers. The association activities and messages are regularly shared on these platforms and this has supported the visibility function for the association tremendously. 22 clients with epilepsy and 3 international partners have gotten into contact with the association through these social media accounts.

The Ushahidi Platform as a means to regularly communicate with ESAU membership:

With support from the Aga Khan Foundation, ESAU was able to engage a prepaid communication platform- The Ushahidi platform to support the association regularly communicate with her membership through SMS messages. ESAU was able through this platform to get her membership views on service delivery during the COVID -19 pandemic, send season's greetings to her membership, get regular updates on health service delivery to clients during COVID -19 and as a result engage with governments to improve service delivery to people with epilepsy.

Radio talk shows and Spot messages:

- 2 radio talk shows held with City FM, Jinja and Gomba FM respectively. 600 spot messages run on the two radios for a period of a month with epilepsy and COVID-19 relevant information. This was with the support of Disability Right's fund.
- 600 Radio spot messages were also ran by radio Amani in the districts of Moyo and Adjumani
- ESAU reached out to her membership with COVID-19 Information in the four districts of Moyo Adjumani, Jinja and Gomba while also reaching to communities with accurate facts on epilepsy. 20 call in were made during these talk shows. The association was able to also provide epilepsy relevant information to 12 media personalities on these radios.

With support from Disabled People's Organization of Denmark, ESAU engaged 7 local and 2 national radio stations to air epilepsy relevant information to communities in the whole of the country. These radio messages led to approximately 32 call-ins to the secretariat for counselling from the communities.

2.2 Advocacy and lobbying

ESAU was awarded a grant from the Disability Rights Fund in 2019 for a period of one year.

The overall objective of this grant was to support the advocacy and lobbying function to improve health service delivery at local government level in 2 districts of Gomba and Jinja.

Intermediate objectives of the grant included:

- To mobilize People With Epilepsy into psycho- socio support groups so as to better advocate for themselves.

- To empower PWEs & their leaders to advocate for themselves
- To lobby duty bearers and decision makers better understand PWEs so they include them in programming & budgeting processes at district levels.

Progress on grant activities:

- 8 groups of people with epilepsy mobilized in the 2 districts. They meet regularly, discuss issues affecting them as people with epilepsy in terms of service delivery. Mobilise new membership to their groups, sensitize communities on epilepsy care and its management, and lobby their district local governments to improve service delivery to them.
- 28 PWE leaders acquired skills in epilepsy care and its management, mobilising new clients to the association, group dynamics and its management, identifying health service challenges in their districts and lobbying for better service delivery. They acquired skills in partnerships and networking among others. A component of sustainability for their community based organizations was added. Currently all groups are strategically lobbying their district local governments for better service delivery.
- ESAU was able to get more funding for the Jinja group from Light for the World. 100 PWEs from the 4 subcounties were supported with cashouts during COVID-19 to improve their basic needs and support their families
- 2 inception meetings held with duty bearers to identify challenges of service delivery, work with the duty bearers to forge a way forward to these challenges. 2 whatsapp groups were formed for each district to regularly share information with health workers and get their views on service delivery. ESAU used the opportunity to

demystify epilepsy among the duty bearers and lay out the project goals, objectives and expectations from the duty bearers

- 4 quarterly meetings held with district health teams in the 2 districts. The duty bearers and ESAU were able to classify the challenges to service delivery and paved way forward for this.

Community mobilization meetings. 5 sensitization meetings held with communities in the 2 districts. The main objectives of these community mobilization meetings were to reach out to communities with accurate epilepsy information, lobby the district local government's community staff and communities to better understand people living with epilepsy and provide support systems in the community for their welfare. This was partly realized
ESAU held 2 quarterly meetings with duty bearers/service providers in the 2 districts. It was agreed in these meetings that horizontal borrowing of medication be authorized by the district health teams where there were drug outages at health centre threes and fours and excess medication at lower health units.

Observation and lessons learnt

- It was realized that most people have a lot of misconceptions and lack facts about epilepsy in our society. The audience's opinions would seem to show that epilepsy is some kind of a curse or traditional illness.
- Continuous engagement of duty bearers , communities and partners improves their knowledge base on epilepsy and the gaps in service provision and with time improves their attitude to PWEs

- Grassroots advocacy cannot be done alone, it has to be combined with national level advocacy because some decisions have to be made at national level to improve service delivery
- Advocacy and lobbying is a long term process that involves continuous engagement of the main players at national level while also at district level while also taking consideration of the government calendar in this process. With persistence this process is possible.
- Health workers now more supportive to PWEs at health centres and understand their plight much more.

2.3 Organizational Development

With support from the Disabled People’s Organization of Denmark, ESAU focused on sustainability theme whose main objective was to ensure that the capacities of key members in the organization were built in a sustainable way. This function was supported by Disability Rights Fund, Uganda National Action on Physical Disability among other players. Activities carried out under this thematic area included:

a) *Recruitment of ESAU accountant.*

ESAU in December 2019 recruited a fully qualified accountant with experience of over 12 years in financial accounting. This position fell vacant when the previous accountant took on strategic leadership of the organization. The finances of the organization are more secure now, control and oversight of the organization's finances are being observed.

Staff training & BOD training in fundraising & website upload and design

2 staff, the Executive Director, and the Head of Programs underwent a one week training course in fundraising resource mobilisation in Arusha. The main objective was to support

the strategic fundraising role for the organization. This has been achieved as through this training the association was able to add 4 new donors to her fundraising basket. ESAU membership have been further supported to mobilise more resources for their community based organizations. This will be reported upon under fundraising.

1 staff, the administrative assistant was mentored and coached in website management and regular upload of activities and items on the organizational website and social media accounts. As per activities held by the organization, this information is uploaded on a weekly basis depending on the activities held. This has greatly improved the organization's visibility international and nationally.

Mentioned the Commissioner, Mental health in the Ministry of Health, Dr Hasifa Lukwata in one of the partnership meetings:

“I would like to commend ESAU for being active and carrying out business as usual for the organisation during the lockdown. I have been following their activities on their website, social media platforms, they fulfilled the function of providing alternative medication to PWEs during the lockdown, and this is quite commendable”

b) Training regional TOTs

The association trained 80 regional TOTs in advocacy and lobbying, epilepsy care and its management, group’s dynamics and fundraising and partnership development. This was done throughout her regions. These trainings were held by respective district community based officers and psychiatric nurses.

Through these trainings, ESAU was able to support her groups get contacts of their respective Community Development Officers, 20 branches got promises of support towards fundraising from their respective community development officers. 5 branches so far have been supported to apply for funding to their community services departments.

The capacity of community development officers that supported the trainings was built in epilepsy care and management. Many were not aware that epilepsy was a disability. They pledged their support to groups of PWEs and committed towards lobbying their fellow community development officers to support PWEs and better understand their plight while carrying out their work.

c) Training of health workers

With support from The Aga Khan Foundation, 14 health workers from 5 not-for-profit health units in the 2 districts of Moyo and Adjumani were trained in epilepsy care and its management, management of drug banks in 2 separate trainings. These trainings were held by District clinical officers and in-charges of the mental health units in the respective districts.

So far 2 mentoring and coaching sessions have been held with the trained health workers to ensure that they continue providing quality care to people with epilepsy in Moyo and Adjumani districts.

Said the Psychiatric nursing officer, Moyo District, Sr. Letiyo Rose Betty:

“Ever since I trained the health workers from the respective Not -for -Profit health units, I have not gotten any complaints from the clients about the quality of care they provide to them. I am constantly in touch with these clinical officers when they have challenges in diagnosis to support the proper diagnosis function in epilepsy care in their respective health units. Am happy with their ability to provide quality epilepsy care”

Mentioned the psychiatric clinical officer, Fr. Bilibao Health Centre, 3, Metu, Mr. Badru Andama.

“I had a challenge in diagnosis of epilepsy among adolescent girls, being able to differentiate between epilepsy and hysteria. I also had a challenge managing status epilepticus, I did not know it was a medical emergency that needed referral to the main Hosipital. This training has opened my knowledge base in epilepsy diagnosis. I am grateful to ESAU for this”.

d) 4 Regional meetings held for women

ESAU has established 4 regional women wings in Western, Central, and North Eastern and Northern Uganda. The association held the first ever meeting with specifically women to bring out their specific challenges and work with them to counter these challenges/ Issues.

72 women were trained in epilepsy care and its management, epilepsy specific issues for women with epilepsy, group dynamics, leadership and financial resilience. These trainings were held by gender officer from the districts where the trainings were held.

All women that attended the trainings were grateful for the opportunity this provided for them to share their experiences, learn specific issues about their epilepsy and share their experiences with other women and learn from their expertise.

2.4 Monitoring and support Supervision

2.4.1. National BOD meetings

ESAU has held 2 board meetings during the implementing period. The BOD met to approve work plans, discuss programs to be implemented for the association. The BOD was updated on fundraising progress made by the association director and staff. The Board was quite appreciative of information provided to them. They too appreciated the positive developments at the secretariat.

2.4.2. Financial Monitoring by BOD

Each month, the BOD chairperson /Treasurer monitor the finances for the association. This has helped to keep the project on course and supported early implementation of activities for the project.

2.4.3. Monitoring visits to West Nile: These have been held with support from the Aga Khan foundation. These visits were held in the districts of Arua, Moyo and Adjumani. The main objective of these visits was to check progress on activities implemented in the COVID-19 response project that involved alternative drug distribution to 5 health centers and provision of cash outs to members in 2 districts of Adjumani and Moyo, identify gaps in implementation and harness these gaps and ensure smooth project implementation.

Through the monitoring visits, gaps identified in uptake of medication in the 5 health centers included: low attendance of PWEs to epilepsy clinics due to fear of COVID-19 scourge, challenges of retention of patient books by Moyo Hospital hence affecting medication uptake in Moyo mission and Metu mission health center threes. Other gaps identified included poor mobilization of clients to health centers by ESAU membership.

Outputs realized through the monitoring visits included a 30% increase in epilepsy medication uptake at health centers through target setting for ESAU leaders in mobilization of clients to attend clinics. Involvement of village health teams in mobilization of clients to uptake medication. The association further engaged with the in charge of the psychiatric health unit, Moyo Hospital, Sr. Letiyo Rose and client clinic attendance books were released to the 2 not-for-profit health centers and improve attendance to epilepsy clinics.

In addition to the above there was marked improvement in collaboration between not-for-profit health units and the main hospitals.

2.4.4: Support Supervision: 2 support supervision visits held by the in-charges of the mental health units from Adjumani and Moyo hospitals. Mentoring and coaching and support supervision provided to clinical officers to the not or profit Health centers.

ESAU held follow up meetings with her membership in Arua. ESAU's activities in Arua included re-mobilization of her membership and partners in Arua District. ESAU membership re-committed themselves to the association, pledged to work with the association, fill up in the secretariat with their membership database- so far 3/7 sub county branches in Arua have sent in their membership information, committed to collaborating with their duty bearers, service providers and respective district local government to register their groups as community based organizations.

2.5 Networking

2.5.1. Membership to International, National bodies and Corporate.

Internationally ESAU is a member to the International Bureau for Epilepsy, International League against Epilepsy, and International Alliance for patients Organizations, Epilepsy Alliance Africa where the Executive Director is a vice president and shall continue expanding her membership in the coming years. In the year 2020, membership was paid to International Alliance of Patients Organizations, Uganda Alliance of Patients Organizations and International Bureau for Epilepsy and Epilepsy Alliance Africa.

Nationally, ESAU is a full member of National Union of Disabled Persons in Uganda, National Union of Women with Disabilities in Uganda, Uganda Alliance of Patients Organizations.

ESAU works closely with most Disabled Peoples Organizations; the association provides accurate information on epilepsy to the membership of these disabled peoples organizations, attends partnership meetings supported by these organizations. In these meetings the association staff showcases organizational activities, lobby for the inclusion and mainstreaming of epilepsy in the programming and budgeting of the respective organizations.

2.5.2: Partnership meetings: This year ESAU staff have attended 24 partnership meetings hosted by different partners in health, education, disability among others and showcased epilepsy, sensitized partners about epilepsy, supported partners in development of their strategic plans, development of position paper among others.

2.5.3. International Celebrations: The association participated in the international Disability Day celebrations. This year's International Disability Day celebrations started with a disability symposium that took place on 2.12.2020 at Imperial Royale Hotel. At this meeting, major stakeholders in central government ministries, Representatives of the District Unions, partners and donors were present. The achievements of the disability movement, gaps were identified and promises to rectify gaps by various concerned parties were agreed upon.

On the 3.12.2020, the main celebrations of the disability day were held at Sheraton Hotel, Kampala with a dialogue meeting. Present in the meeting were partners in health, education, livelihoods, representatives of disabled peoples organizations, donors, line ministry of health, education, gender representatives, representatives from equal opportunities commission, National Council for Disability among many other partners.

Different position papers, researches on disability were presented to show case progress and gaps for the year in the disability movement. Major achievements realized by the disability movement included:

- representation of PWDs on the national COVID -19 taskforce,
- representation of PWDs on the all district COVID-19 taskforce,
- Ability of at least 6 disabled people's organization to raise funds for their membership during the COVID -19 lockdown to cater for the basic needs, health services of their membership.

Main challenges realized were that not all PWDs were able to access government support in their districts and nationally, many failed to access their medications and other services due to morbidity and government budget constraint issues.

Other International day celebrations attended by the association staff included; World AIDS day Celebrations and participation in media campaigns to commemorate the International Patients Alliance Day- ESAU sensitized communities in Uganda about epilepsy, management of epilepsy, gaps in care realized during the COVID -19 lockdown and strategies to combat these gaps on 2 national and 5 local radios. The association reached approximately 4miliion Ugandans with this information. 33 calls to the association secretariat were made to the secretariat after the media campaigns run for 2 weeks.

2.5.4. Partnership with Network of Public Interest Lawyers (NEPTIL): In partnership with NEPTIL and Mental Health Uganda, ESAU was privileged to have a legal officer placed in their organization for a period of 6 months. The main objective of this placement was to interest recently qualified lawyers in disability litigation, understanding the disability movement and supporting the disability movement in any legal challenges they had. Three legal officers were placed in the three marginalized disability organizations of ESAU, Mental Health and Uganda Parents of Children with Intellectual Disabilities.

With support from the Aga Khan Foundation, ESAU was able to host the lawyer for another one month to provide legal support services to her paralegals spearheading the gender based violence case management. Ms. Mbabazi held mentoring and coaching sessions for the paralegals, supporting them to better understand case management and follow up processes for these cases at village, clan and family protection unit in police with evidence as a basis

for their cases. ESAU hopes to retain this lawyer given the availability of funds to sustain this position.

2.6 Fundraising and Resource mobilization

2020 began with a strong focus on fundraising, identifying and engaging new donors to partner with as an association. This is under thematic focus area; Building partnerships to fundraise for sustainability of ESAU programs in ESAU strategic plan 2019- 2023. ESAU's main project "Sustainability, Visibility and Development" main focus area is built on the foundation of sustainability for the branches and the secretariat and activities under this theme were deliberately targeted at resource mobilization right from the grassroots to the top of the organization. Main activities carried out under this theme include:

2.7.1. Map, update and build relationships with donors:

ESAU developed her donor database, the main focus here was to identify probable donors to collaborate with, identify their main thematic areas, get their contacts and engage them. The output here is that ESAU mapped donors she intends to engage, started engaging a few of them as will be reported.

2.7.2: Hire fundraising mentor.

The association contracted a fundraising mentor to provide staff and BOD with short training in fundraising and resource mobilization strategies for a period of three days. ESAU staff were taken through the basic concepts of fundraising, fundraising strategies for the

organization, methods of fundraising using the website and organizational social media handles among others. 5 ESAU staff got skills in fundraising and resource mobilization.

2.7.3 Mobilize resources for the organization.

ESAU through the able leadership of the Executive Director has been able to mobilize resources for the organization from various donors:

ESAU engaged the Aga Khan Foundation and got two grants that were renewed:

2.7.3.1.The COVID -19 responses grant; This grant was awarded to the organization for a period of 5 months to a tune of UGX 113,230,000 with the main objective to provide alternative anti- epilepsy medication to PWEs in 2 districts of Adjumani and Moyo in partnership with 5 not-for-profit health units. ESAU reached 550 PWEs with alternative medication, in the categories of Carbamazepine, phenytoin, phenobabitone, folic acid and sodium valproate supplied to PWEs.

The second objective of the grant was to provide cash outs support to PWEs so as to provide for their basic needs and support their sanitation and hygiene components (soap, sanitizers & masks) during the pandemic to enable them access medication at the health centres while also keeping ministry of health standard operating procedures. 280 PWEs accessed cash outs three times in a row during the project period.

The Agha khan foundation also provided funds for institutional strengthening for ESAU. ESAU was supported to clean up her data base together with remobilisation of her non active branches

All 116 PWEs from Moyo district purchased local chicken each as a start-up individual income generating activity. PWEs agreed to this on their own accord and many state that this will form a basis for their savings and eventual support supplication for their welfare in the future

The grant served to reach out to communities, most especially people with epilepsy with information about epilepsy, COVID-19, standard operating procedures of Ministry of health and information on where alternative medication for people with epilepsy could be accessed in the two districts. 420 spot messages run on radio Amani for a period of one month communicating this information.

Outcomes

- People with epilepsy received accurate epilepsy information, understood the standard operating procedures while accessing their medication and got information on where they could access alternative epilepsy medication.
- 450 PWEs accessed alternative medication while there were challenges in medicines supplies during the pandemic. Their adherence levels improved and they were able to participate in their daily activities while also contributing to community development processes.
- A second phase of this grant was awarded to the tune of UGX 33,930,000 with the main objective to address gaps in the previous project to run for a period of 2 months, its currently ongoing.
- Improved collaboration between health workers in government hospitals and health workers at not-for-profit health units.

2.7.3.2. Advancing Gender Equality Project

The association was awarded a grant by the Aga Khan foundation to the tune of UGX 69,500,000 for 5 months with the main objective to identify cases of sexual gender based violence while also skilling paralegals in sexual gender based violence case management, financial resilience, understanding application processes of government development programs for community based organizations. The project area of operation is the districts of Moyo and Adjumani.

Outputs:

- 20 Trainers of trainers skilled and have information on sexual gender based violence case management
- The TOTs have trained 463 community members on sexual gender violence case management, financial resilience, government development programs and epilepsy management in the sub counties of Metu, Lefori and Moyo T/C in Moyo and Ciforo, Dzaipi, Pakele, Ofua, Adjumani town council and Adropi sub counties in Adjumani district.
- 2 women wings established in Moyo & Adjumani. Women with epilepsy for the first time ever are deliberating over issues affecting them, recording them and working to improve their wellbeing.
- 61 sexual gender based violence cases reported by the paralegals. Main categories of cases reported by the paralegals are family neglect, domestic violence, sexual harassment and rape. Most of the cases identified have been mediated with family members and local council one chairpersons with

reconciliation being emphasized. 3 cases were handled with the family protection unit in police.

- The project was extended up till January and reallocations made to suit the project extension.

2.7.3.2. Pig rearing project in Gomba district

ESAU was awarded a 2 time grant from Uganda National Action on Physical Disability. The grant was to the tune of UGX 7,000,000.

Main objective of the grant was to skill PWEs in Piggery rearing, provide them with pigs to supplement their income. The second grant was to support the function of learning and documentation of best practices from various projects implemented by partners

Outputs:

- 20 PWEs skilled in piggery rearing in Gomba district
- 20 PWEs access pigs for a revolving piggery project
- Improved collaboration between ESAU members and district community services & Veterinary department staff
- Improved welfare and dignity of PWEs in Gomba District

2.7.3.3: Making epilepsy a priority among grassroots communities in Uganda.

ESAU received a one year grant from the International Bureau for Epilepsy to the tune of UGX 40,370,000. The main objective of this grant was to engage with local government in two districts to ensure adequate and regular medication access for PWEs. Activities carried out include: Inception meetings held with 24 duty bearers in the districts of Gomba and Jinja. Challenges of anti-epilepsy supply chains in the two districts identified documented and to be followed up.

2.7.3.4. COVID-19 Response grant -LFW

The association was awarded a COVID-19 response grant for people with epilepsy in Jinja in the four sub counties of Butagaya, Bugembe, Buwenge and Mafubira by Light for the World.

The grant award was UGX 9,996,400.



Figure 1 Beneficiaries of cashouts in Buwenge & Mafubira

Outcomes

- 100 PWEs accessed cash out support from light for the world
- 15 women and girls with epilepsy supported in soap making and start up soap making components. The women and girls were able to make up to 100 litres of soap and sell to support their families.

3.0 ACHIEVEMENTS

- ESAU managed to develop 8 National Project proposals and submitted all of them. Three were granted, three still waiting for response while two were not funded.
- Successfully conducted a National Advocacy Epilepsy Conference that brought to light the plight of PWE.
- Developed a 5 year strategic plan.
- Increased membership to the association. More people have joined the association as a result of increased awareness raising compared to last year (2019)
- 28 Counseling and guidance services were provided as a result, parents and clients were happy due to reduced negative attitudes in their communities
- 6 district branches were supported by the secretariat to develop and submit applications for their respective branches for funding.
- ESAU continued supporting 8 faith based health centers to run community drug banks and this enabled PWE to access regular and cheap epilepsy medications.

4.0 CHALLENGES

- Limited and un timely disbursement of medicine (AEDs) at health centers as well as long distances travelled by some of the Persons with epilepsy still poses a challenge to the association especially as the numbers are increasing.
- ESAU still has to mobilize funds to fully implement her activities throughout her districts of operation. With the creation of new districts, there have been more branches formed. However, some of these branches are not facilitated and there

are no sufficient funds to cover such areas.

5.0 FUTURE PLANS FOR THE ASSOCIATION

- fundraising plans are in place for this year's fundraising efforts and start a cultivation drive for supporters of ESAU
- Engage new donors and write more grant proposals to international and bi-lateral donors.
- ESAU plans to continue mobilising persons with epilepsy and sensitising communities so as to increase membership to the association.
- Continued awareness raising, among district officials in the districts of operation, civil society leaders on issues concerning epilepsy.
- Continued advocacy and lobbying at national, district and sub county level.
- Improving fundraising strategies and thereby make ESAU's activities more sustainable; proposals for funding as one of the alternative funding resources as well as from membership.

6.0 Conclusion

ESAU finds 2020 a fairly successful year though constrained by the COVID-19 pandemic. The organization staff pledge to continue fundraising and engaging new donors while also cultivating the old donors.

APPENDICIES

Board of Directors

Karutokye Henry	Chairperson-	Rubanda
Kiwanuka Musisi	Vice Chairperson	Luweero
Namugenyi Goreth	Treasurer-	Masaka
Nassuna Shakira	Secretary	Luweero
Otim Robinson	Publicity Secretary-	Oyam
Okidong Richard	Committee Member	Bushenyi
Acoet Margret	Board Member-	Katakwi
Atuhaire Lydia	Reserve	Bushenyi
Atim Joan	Reserve	Soroti

ESAU Staff

Sarah Nekesa	Executive Director
Kenneth Bikala	Accountant
Engole Justine	Head of Programs
Mbabazi Stella	Legal Officer
January Ishimwe	Project Officer
Tumuhaise Beatrice	Administrative Assistant
Reagan Kaka	Logistics officer/Driver

Support staff

1. Muhereza Darius
