# Providing life changing support to people with mental health issues in Agago District, northern Uganda

## Endline Study

November 2020

Malachite, Basic Needs UK in Uganda and Network for Africa

Funded by Comic Relief

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## Acronyms

| | |
|---|---|
| ACDO | Assistant Community Development Officer |
| BNUU | Basic Needs UK in Uganda |
| CDO | Community Development Officer |
| CORE-10 | Clinical Outcomes in Routine Evaluation 10 |
| EMHSLU | Essential Medicines Health Supplies List Uganda |
| FGD | Focus group discussion |
| HC | Health Centre |
| HUMC | Health Unit Management Committee |
| HW | Health worker |
| KII | Key informant interview |
| LC1 | Local Council One |
| LRA | Lord’s Resistance Army |
| MLC | Malachite |
| MDE | Mental disorders and epilepsy |
| MH | Mental health |
| mhGAP | Mental Health Gap |
| mhGAP-IG | Mental Health Gap Intervention Guide |
| N4A | Network for Africa |
| PDA | Participatory data analysis |
| PHC | Primary Healthcare |
| PLHA | People Living with HIV/AIDS |
| PMDE | People with mental disorders and epilepsy |
| PMI | People with mental illness |
| PN | Psychiatric Nurse |
| SHG | Self-help group |
| UCG | Uganda Clinical Guidelines |
| VHT | Village Health Team |
| WHO | World Health Organisation |

## Executive Summary

Network for Africa (N4A) and Basic Needs UK in Uganda (BNUU) partnered to deliver a project titled "Providing life changing support to people with mental health issues in Agago, northern Uganda" funded by Comic Relief from 2018-2020. The N4A-BNUU project based its intervention on the World Health Organisation (WHO)'s Mental Health Gap Action Plan (mhGAP), adapting it for both clinical and counselling services for mental health. Its overarching goals were to: increase provision of treatment for mental illness and epilepsy; increase take-up of mental health and epilepsy services; reduce stigma faced by people with mental disorders and/or epilepsy (PMDEs), their families and communities; and support PMDEs and caregivers in advocating for mental health interventions. The project has covered communities in four project areas: Wol, Paimol and Lukole subcounties, and Kalongo Town Council. Each of the project area is home to a health centre (HC) or hospital, which was the location of the project's monthly mental health clinic for that area: Wol HC III, Paimol HC, Lapirin HC III (located in Lukole subcounty) and Dr Ambrosoli Memorial Hospital located in Kalongo Town.

This Endline Study presents an analysis of results achieved by June 2020. The objective of the report was to assess progress of the project's results against the project indicators at Baseline Study, which was conducted in early 2018. The team conducted two surveys for this Endline Study: the Community Members' Survey administered to 135 community members based on their availability to participate in the survey and the Patient Intake Questionnaire administered to 168 patients also based on their availability.

### Main Findings

- **Increased availability of mental health services:** 1,663 clients had received treatment or services from at least one of the project's monthly mental health (MH) clinics at one of the four HCs in the project's four focus areas. In addition to this, 1,413 counselling sessions had been provided to 695 PMDEs and caregivers by one of the project counsellors in their community.
- **Improved communication with people seeking care and their caregivers:** Psychoeducation sessions have meant PMDEs and their caregivers have an improved understanding of the diagnosis, treatment plan and what support the family needed to provide support to the client. Increasing delivery of psychoeducation sessions at home has widened access.
- **Assessment and diagnosis skills:** There has been improvement of knowledge and skills among health workers (HWs) and village health teams (VHTs), with 100% assessed at endline demonstrating appropriate skills to diagnose mental illnesses and deliver basic mental health services.
- **Treatment, counselling and support:** clients reported that most of the barriers to accessing services, such as long waiting hours at the mental health clinics and limited drug supplies, have been overcome during the project. PMDEs and caregivers also report that they appreciate the home visits which allow them and their families more time to discuss strategies to support the patients more effectively. They also report that BNUU's counselling and SHG activities helped reduce isolation that most of them felt as a result of the illness.
- **Mobilising psychosocial support:** 1,174 patients and caregivers were enrolled in 61 self-help groups and others reported that they were more involved in community activities like participating in religious activities, other community groups, and young PMDEs had returned to school.
- **Protection of Human Rights:** HWs, BNUU counsellors and VHTs have been trained on the rights of patients and how their conduct affects or enables PMDEs to exercise these rights. PMDEs and caregivers report improvement in the way they are treated by the community, and health workers.
- **Attention to overall wellbeing:** PMDEs and their caregivers report that BNUU's counselling and SHG activities helped reduce isolation that most of them felt as a result of their illnesses.
- **Greater knowledge and understanding among duty bearers:** HWs and members of VHTs were better able to articulate the definitions of mental health, mental illness and epilepsy. They attributed this to the training, the tools provided to enable them to do their work and the opportunities to put these tools into practice. LC1s' active work with SHGs of PMDEs points to an improved understanding of mental illness including corrected misperceptions and biases.

- **Advocacy:** All self-help groups were trained in human rights and advocacy, and SHGs had conducted 27 human rights monitoring activities. The issues ranged from solving problems around how PMDEs were treated by family, to supporting PMDEs to seek justice for crimes committed against them.
- **Barriers to support:** BNUU has worked to overcome many of the barriers established at Baseline. Long distances to the health centres coupled with limited transport were barriers to many PMDEs, so BNUU increased the number of home visits for PMDEs with children, disabled and elderly persons who did not need medicine or those with children who had stabilised on medication. The limited family support from many caregivers of PMDEs has been addressed through home visits, allowing the counsellors to spend time with the families addressing their concerns, misconceptions and answering any questions. Where many beneficiaries initially forgot their mental health clinic appointment dates, BNUU purchased airtime on community radio to broadcast messages announcing MH clinic days.
- **Community members' behaviour towards PMDEs and their caregivers:** There has been progress towards improving some of the negative perceptions that the community had at baseline. Community members now demonstrate greater understanding of the causes of mental illness and epilepsy, where to seek treatment or help, PMDEs' capacity to work, and report greater involvement of PMDEs in community or social activities. However, a lot more needs to be done to improve community attitudes towards PMDEs' right to work and engage in meaningful activity.

**Progress Against Recommendations Made at Baseline**

- **Mental treatment act/mental health bill:** BNUU is an active member of the district NGO monitoring committee. The new MH act came into law in 2018, but there is slow movement on MH policy at national level.
- **Awareness raising:** Community and caregiver attitudes have changed, and a majority of PMDEs and caregivers who participated in the Endline Study reported that they feel optimistic about their future.
- **Medicines and psychiatric nurses:** BNUU has made efforts to ensure that all medicines are available during the mental health clinics. This was a result of negotiations with the District Health Officer and HCs in other subcounties. After negotiations between BNUU and Dr. Ambrosli Hospital, the psychiatric nurse (PN) was able to support mental health clinics once a week for just over two years until she sadly died earlier this year. There is no PN in Agago District at the moment, only the two volunteer PNs who offer some support to the MH clinics.
- **Training health workers and other duty bearers:** VHTs work with the awareness raising guide and home visit checklist; HWs and Counsellors use the counselling and clinic protocols, diagnostic tools and psychoeducation tools; CDOs were trained using the SHG guide.
- **Duty bearers:** For the most part they now show support to PMDES and their caregivers. However more targeted awareness raising is required for them to support livelihood initiatives of PMDEs that are now being introduced.
- **Capacity building for the Community Development Office:** Community development officers (CDOs) have supported involvement of PMDEs and caregivers in the local government planning and budgeting process, provided guidance for the SHGs on how to register with the local authority, and educated people on the rights of PMDEs as well as helping them to identify referral pathways

The project can be deemed successful. From the endline results, an appropriate mental health (MH) service has been established in Agago District and is well utilised. PMDEs and their caregivers are accessing the monthly mental health clinics and community attitudes towards PMDEs are changing for the better. PMDEs report that they feel better supported. The provision of counselling by BNUU has been particularly successful, with the number of counselling sessions conducted greatly exceeding the initial target per quarter.

# 1 INTRODUCTION

Network for Africa (N4A) and Basic Needs UK in Uganda (BNUU) partnered to deliver a project titled "Providing life changing support to people with mental health issues in Agago, northern Uganda" funded by Comic Relief from 2018-2020. The purpose of the three-year project was to improve mental health services for vulnerable and disadvantaged people in northern Uganda by developing existing health structures. Through training, raising awareness and advocacy, the project would also reduce stigma, increase understanding of mental illness, and empower sufferers so they can take control of their lives. It would provide counselling and mental health support to people suffering from mental health disorders and/or epilepsy (PMDEs) in four project areas of Agago District in northern Uganda (three subcounties plus Kalongo town).

## 1.1 Project background

It has been about 14 years since the end of the Lord's Resistance Army (LRA) war in northern Uganda and communities have tried their best to return to some kind of normal life. Like all districts in northern Uganda, Agago District (formerly a part of Pader District) was directly affected by the war. The district had three large Internally Displaced People's (IDP) camps in Kalongo, Patongo and Adilang sub counties and other smaller ones scattered throughout the district. The LRA war left physical and mental scars on the citizens of northern Uganda and limited government support and poverty have exacerbated mental illness in the districts. Agago District is affected disproportionally because it is a new district that is hard to reach due to a poor road network and limited access to basic amenities.

Many people who live in northern Uganda continue to suffer from psychological distress as a result of adverse experiences during and following the civil war. The N4A-BNUU project based its intervention on the World Health Organisation (WHO)'s Mental Health Gap Action Plan (mhGAP), adapting it for both clinical and counselling services for mental health. The project had four overarching goals. These were:

1. Increased provision of appropriate and adequate treatment for mental illness and epilepsy, as determined by the psychiatric nurse and the WHO mhGAP intervention guide.
2. Increased take-up of appropriate mental health and epilepsy services.
3. Reduced levels of stigma as perceived by PMDE in their families and communities.
4. PMDEs and caregivers are able to advocate for appropriate mental health interventions.

The project has covered communities in four project areas: Wol, Paimol and Lukole subcounties, and Kalongo Town Council. Each of the project area is home to a health centre (HC) or hospital, which was the location of the project's monthly mental health clinic for that area: Wol HC III, Paimol HC, Lapirin HC III (located in Lukole subcounty) and Dr Ambrosoli Memorial Hospital located in Kalongo Town.

This Endline Study presents an analysis of results achieved by June 2020 against the Baseline Study conducted in early 2018 (during the first six months of the project). The report will not provide further contextual information about Agago District or the two organisations as little has changed since the Baseline Study was produced in 2018.

## 1.2 Endline Study limitations

The data for the Endline Study was collected in the month of June 2020, two weeks after the Government of Uganda had eased restrictions on movement due to the COVID-19 pandemic. However, the restrictions on the number of people attending meetings were not lifted and therefore no focus group discussions (FGDs) were conducted. All data was collected using the survey tool and instead of FGDs, key informant interviews (KIIs) were conducted. Participants were selected based on their comfort and willingness to participate in the study during the COVID pandemic. The team made sure that all staff and study participants wore masks during the data collection exercise. Social distancing was also maintained by collecting data at household level to avoid crowding at health centers and community halls.

## 1.3 Methodology

The objective of the report was to assess progress of the project's results against the project indicators at baseline.

The research questions on which the study focused included, but were not limited to, the following:

a) Are the mental health services that are available to people living in the four subcounties of Agago District in compliance with mhGAP and/or the Uganda Clinical Guidelines? (The question includes use of talking therapies).
b) How do duty bearers (Religious Leaders; Traditional Leaders and Healers; Village Health Teams (VHT) etc.) define mental illness? What do they attribute to be the cause of mental illnesses? How can they tell that a person has a mental illness? What interventions are available to treat people with mental illnesses? Who provides these interventions? How can you tell that a person with mental illness has been cured?
c) What issues have people with mental illness and their carer givers living in Agago District advocated for?
d) What do people with mental health problems consider to be the barriers to accessing support and treatment in the project areas? Which of these has the project addressed in order to improve access to mental health services?
e) How does the community behave towards people with mental illnesses/epilepsy and their caregivers? What is the reason given for this behaviour? What structures are available to support people with mental illness in the community? What type of support do these structures provide? How much do community members from the four subcounties (Kalongo town, Wol, Paimol and Lukole) know about mental health and mental illness? How do they define mental illness and epilepsy? What do they attribute to be the cause of mental illness or epilepsy? How can they tell that a person has a mental illness or epilepsy? What proportion of these community members know that mental health problems and epilepsy are not contagious?
f) What are the common beliefs and attitudes held by community members regarding people with mental disorders and/or epilepsy and their ability to contribute to the life of the community?

## 1.4 Data Collection

The staff and MLC teams used the same tools and processes used during the baseline to collect endline data.

The team conducted two surveys: the Community Members' Survey administered to 135 community members based on their availability to participate in the survey and the Patient Intake Questionnaire administered to 168 patients also based on their availability.

The data collectors relied on the Local Council One (LC1) Chairpersons, members of village health teams and chairpersons of SHGs to mobilise study respondents.

## 1.5 Data Analysis

Quantitative data was analysed in Excel, using the sorting and filter functions to compare study variables, as shall be presented in the findings.

Qualitative data was analysed by listening to recorded KIIs, identifying common themes or differing opinions for each category of data collected.

# 2 FINDINGS

## 2.1 Availability of mental health services.

**Research question a)**
*Are the mental health services that are available to people living in the four project beneficiary subcounties of Agago District in compliance with mhGAP and/or the Uganda Clinical Guidelines? (The question will include use of talking therapies).*

At baseline, N4A and BNUU established that mental health services were included in the Uganda minimum health care package in the first National Health Policy. The baseline also established that mental health (MH) personnel are included in the Human Resources Strategy for Health (2004), and the Uganda Clinical Guidelines (UCG) and essential medicines for mental health were also included in the Essential Medicines and Health Supplies List (2010).

However, when the team conducted the Baseline Study in 2018, they concluded that:

1. Mental health services are available in the district but not many people are accessing these services.
2. There is limited skill for diagnosis in the area, which contradicts the UCG and Essential Medicines Health Supplies List Uganda (EMHSLU). These documents assume that basic skills are available to HC IIIs[1], enabling them to provide first level intervention.
3. Drug supply is erratic and, in many cases, the medicines supplied do not meet the standards required for the Essential Medicines kit for HC IIIs and HC IIs.
4. Only Wol HC III provided some kind of mental health education. The other facilities, including the Dr Ambrosoli Memorial Hospital (Kalongo hospital) did not.

**MHGAP Standards**
Mental Health Gap Action Program (mhGAP) was started by the WHO in 2014 with the purpose of bridging the treatment gap for mental health. The programme asserts that general health workers at nursing officer level and above can effectively treat and manage mental health problems within primary health care settings. The programme developed an intervention guide that makes diagnosis for common conditions that may present in Primary Healthcare (PHC) much more effective. The intervention guide provides standards and guidelines for:

1. Communication with people seeking care and their caregivers.
2. General assessment.
3. Treatment, including pharmacological treatment, psychoeducation and psychosocial support.
4. Special provisions for special populations like pregnant and nursing mothers, children and the elderly.
5. Handling psychiatric emergencies.
6. Supervision of General Health Workers (GHWs) providing mental health services in PHC.

Data collected at endline shows promising results. By the time of the endline data collection in June 2020, 1,663 clients had received treatment or services from at least one of the project's monthly mental health clinics at one of the four HCs in the project's four focus areas (Kalongo, Wol, Paimol and Lukole). These services included mental health education (psychoeducation), diagnosis of common mental disorders, pharmacological and counselling treatment. 85% of the PMDEs reported good to excellent general health (the form did not specify physical or mental health). In addition to this, 1,413 counselling sessions[2] had been provided to 695 PMDEs and caregivers by one of the project counsellors in their community.

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[1] The Ugandan Health System has a tiered service and referral structure that starts from Health Center (HC) I (community health) all the way up to a National Referral Hospital. HC II is a basic outpatient post that provides primary health care services to a parish. HC III provides basic primary health care services and includes maternal and child health services (include simple deliveries) and mental health services. Some HC III also run specialised HIV outreach clinics.

[2] This number continues to increase – as of August 2020, 1,844 counselling sessions had been provided. This endline study is based on the data gathered in June.

21 health workers, 6 BNUU counsellors and 201 VHT members were trained at the beginning of the project and they have been responsible for providing these mental health services. The project also adapted mhGAP and designed simplified tools to help with diagnosis, counselling and psychoeducating[3] PMDEs and their caregivers. From interviews with health workers, feedback from clients, data review and observing MH clinics, there has been an improvement in the application of the mhGAP standards as explained below.

### 2.2 Communication with people seeking care and their caregivers.

There are various ways this has improved during the life of the project:

1. The BNUU team adapted the mhGAP tools to create a client psychoeducation plan. The psychoeducation plan made sure that the patients and their caregivers understood the diagnosis, treatment plan and what support the family needed to provide to the client.
2. The team also arranged psychoeducation sessions at home for caregivers with children and the elderly in order to reduce the time they spent at the health centre. This is because children with epilepsy, development and behavioural disorders often struggle with long health centre visits and elderly people with dementia were often confused when removed from their home environment. In as much as no medications were given to children with development and behavioural disorders or the elderly, the psychoeducation sessions and home visits provide a conducive environment and teach caregivers about the different diagnoses and work with them to explore treatment management plans.

### 2.3 Assessment

#### 2.3.1 Clients receiving treatment from mental health clinics

At the beginning of the project, 21 health workers (HWs) and 201 VHTs were trained in mhGAP. From the pre-test training assessments, only 50% of the HWs and 58% of the VHTs had appropriate knowledge and skills to deliver basic mental health services. The improvement of skills is attributed to the two training sessions in mhGAP conducted in year 1 and year 2 of the project period, the design of diagnostic tools from mhGAP's intervention guide (see appendix 2.2) and the BNUU mental health clinic protocol (appendix 2.1). By the time of the Endline Study, 100% of HWs and VHTs demonstrated that they had the appropriate skills to deliver basic mental health services. This is evidenced by the improvement of accurate diagnosis and treatment plans, as well as the rate of improvement of patients (reduction of symptoms and the number of clients on drug holidays), by HWs and the support provided by VHTs to identify and refer patients to the MH clinics, by conducting effective home visits and supporting awareness raising activities in the community.

**Table 1: Disaggregation of clients receiving treatment[4] by sex**

| Sex of clients receiving treatment | Number of patients treated |
|---|---:|
| Male | 686 |
| Female | 977 |
| **Total** | **1,663** |

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[3] Psychoeducation is conducted by the team within communities to increase understanding of signs, symptoms and treatment for mental health conditions.

[4] This refers to the number of clients who have received treatment at one or more of the project's mental health clinics.

**Table 2: Conditions diagnosed[5] in clients receiving treatment**

| # | Diagnosis | Number of patients treated |
|---|---|---:|
| **1** | Epilepsy/Seizure | 960 |
| **2** | Depression | 552 |
| **3** | Psychosis | 70 |
| **4** | Developmental Disorders | 22 |
| **5** | Alcohol Use Disorders | 17 |
| **6** | Dementia | 12 |
| **7** | Depression & Psychosis | 9 |
| **8** | Epilepsy/Seizure & Psychosis | 7 |
| **9** | Developmental Disorders & Epilepsy/Seizure | 6 |
| **10=** | Behavioural Disorders | 5 |
| **10=** | Depression & Epilepsy/Seizure | 5 |
| | (Other) [6] | 28 |
| | **Total** | **1,663** |

### 2.3.2 Clients receiving counselling

As well as providing treatment for PMDEs in mental health clinics, BNUU's 6 counsellors have provided 1,413 counselling sessions between June 2018 and June 2020, to 695 clients, consisting of 626 PMDEs and 69 caregivers.

**Table 3: Category and sex of people counselled**

| Category of counselling client | PMDE | Caregiver | Total |
|---|---:|---:|---:|
| Male | 224 | 26 | **250** |
| Female | 402 | 40 | **442** |
| (Sex not recorded) | 0 | 3 | **3** |
| **Total** | **626** | **69** | **695** |

## 2.4 Treatment, including pharmacological treatment, counselling, psychoeducation and psychosocial support

### 2.4.1 Treatment

Improving skills and the mental health clinic process as laid out in 2.3.1 above increased client confidence in the mental health clinics. At the time of the endline data collection, BNUU had treated 1,663 patients in total, and of these 1,073 patients with chronic conditions (e.g. psychosis, epilepsy) either on their own or in combination with other conditions. Adherence to treatment and utilisation of the services are an indication of an improved service. In KIIs, clients reported that most of the barriers to accessing services like long waiting hours at the mental health clinics and limited drug supplies were solved in the first two and a half years of the project. The patients and caregivers also report that they have enough time with the HWs to talk about their diagnosis and they appreciate the home visits during which the patient, caregiver and family have more time to discuss strategies to support the patients more effectively.

### 2.4.2 Counselling

PMDEs and their caregivers also report that BNUU's counselling and SHG activities helped reduce isolation that most of them felt as a result of the illness. More results are provided in table 4 below.

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[5] A total of 18 patients have a dual diagnosis of epilepsy *plus* either psychosis (n=7), depression (n=5) or developmental disorders (n=6). 'Epilepsy/seizure' denotes the number of patients diagnosed with epilepsy only, but without a secondary mental health condition (n=960).

[6] 'Other' diagnoses are predominantly other combinations of conditions (e.g. dementia and depression, alcohol use disorders and psychosis etc.). The only 'other' diagnoses of additional conditions are drug use disorders (n=1) and self harm/suicide (n=1).

**Table 4: Clients counselled by project area and outcome[7] of the sessions**

| Project area | Reduced symptoms | Patient improving | Patient not improving | Not applicable | No improvement | Outcome not recorded | Total |
|---|---|---|---|---|---|---|---|
| Kalongo town council | 58 | 66 | 21 | 9 | 0 | 2 | **156** |
| Wol subcounty | 76 | 98 | 11 | 3 | 0 | 5 | **193** |
| Lukole subcounty | 63 | 71 | 21 | 30 | 1 | 3 | **189** |
| Paimol subcounty | 41 | 70 | 26 | 12 | 0 | 8 | **157** |
| **Total** | **238** | **305** | **79** | **54** | **1** | **18** | **695** |

### 2.4.3 Mobilising and providing psychosocial support.

This is one of the key functions of BNUU's counsellors. During one-on-one therapy, they work with the client or caregiver to identify the psychosocial support required to support the patient. As of June 2020, 1,174 patients and caregivers were enrolled in 61 self-help groups and others reported that they were more involved in community activities like participating in religious activities, other community groups (women's groups, farmer groups, youth groups), and young PMDEs had returned to school, to mention a few.

## 2.5 Protection of Human Rights.

PMDEs and caregivers report some improvement in the way they are treated by the community, and health workers. As a principle of mhGAP, it is the health workers' role to make sure that during treatment, PMDEs and their caregivers feel that they are treated with dignity and respect. PMDEs and caregivers explained that rude health workers and waiting 3-5 hours to see the clinician, as well as lack of medicines, were the reasons they did not like attending mental health clinics. These were solved by training HWs, BNUU counsellors and VHTs on the rights of patients and how their conduct affects or enables PMDEs to exercise these rights. PMDEs reported that they felt respected by both the district health staff and BNUU staff. Some even used the words "felt loved" because BNUU listened to them and addressed their concerns. These concerns included making sure that there were enough medicines for everyone on mental health clinic days, reducing the time spent at mental health clinics, visiting them at home and providing counselling services as close to the home as possible. We explain how training PMDEs and their caregivers on human rights helped them to exercise these rights below.

## 2.6 Attention to overall wellbeing

It can be argued that all the project activities were designed to improve overall wellbeing. The activities range from those provided to reduce symptoms of Mental Disorders and Epilepsy (MDE) (treatment and counselling), educate the PMDEs and caregivers about the management of MDEs, raise awareness in the community, train and encourage PMDEs and caregivers to form SHGs and the training provided to the SHGs to improve their effectiveness. All these activities worked to improve symptoms, the home and community environment so that the patient and caregiver could enjoy overall wellbeing.

All four mental health clinics[8] were able to provide a steady supply of essential medicines for mental health for the clients who needed medication.

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[7] Outcomes in this table are those recorded at each client's final/most recent session at time of endline only

[8] Four mental health clinics per month are held at three health centres, plus the Dr. Ambrosoli Hospital in Kalongo.

### 2.7 Greater knowledge and understanding among duty bearers

All three health centres and the hospital conducted monthly mental health education sessions at the beginning of every mental health clinic. This was in addition to the community education sessions run by BNUU staff and VHTs and the mental health education programmes on community radio.

**Research question b)**
*How do duty bearers (Religious Leaders; Traditional Leaders and Healers; Village Health Teams etc.) define mental illness? What do they attribute to be the cause of mental illnesses? How can they tell that a person has a mental illness? What interventions are available to treat people with mental illnesses? Who provides these interventions? How can you tell that a person with mental illness has been cured?*

At baseline, we found that duty bearers provided varied definitions for mental health and mental illness. HWs, members of VHTs and Health Unit Management Committees had a better understanding of mental illness and epilepsy than duty bearers who are outside of the health system. Most of their definitions referred to observable but overt symptoms of mental illness, characteristics of schizophrenia and the manic phase of bipolar disorder. Many understood that mental health problems affect the brain and consequently people's behaviour. However, they all pointed out that as a health department they had not done much to provide services for PMDEs and their caregivers. They attributed this to lack of skills and limited availability of medication.

Other duty bearers such as staff from Agago District's community development office, religious leaders, traditional leaders, and local council leaders at village level believed that PMDEs were destructive, violent and lazy, but they were all in agreement that mental illnesses and epilepsy were diseases of the brain. They attributed the cause of the disorders to a number of reasons ranging from stress, drug use, possession by evil spirits, brain infections or trauma. At baseline all these duty bearers recommended that persons with these symptoms seek treatment from traditional healers or the health centres. However, they decried the limited services at health centres including lack of technical know-how and medicines.

**Extract from the Baseline Study**
*According to most of the Local Council at village level (LC1s), people with mental illnesses and/or epilepsy can access services from traditional healers, the health center or Kalongo Hospital (Dr. Ambrosoli Hospital). However, the majority mentioned the traditional healers or use of local herbs. Two of the LC1s reported that there were no services in their area for such conditions.*

At endline, HWs and members of the village health teams were better able to articulate the definitions of mental health, mental illness and epilepsy. They attributed this to the training, the tools provided to enable them to do their work and the opportunities to put these tools into practice.

> *"We have carried out awareness raising in the villages on market days, during radio talk shows, at funerals and after church services. We have taught the community to know and identify mental illnesses using the symptoms and where to seek services. Our people now know that mental illnesses are treatable at the health centre."*
> Local Council chairperson from Paimol sub county

Other duty bearers also reported improved knowledge and understanding of mental health, mental illness and epilepsy. They attributed this to the trainings by BNUU staff, and the opportunities provided to interact with PMDEs and their caregivers during SHG meetings and trainings and the SHG advocacy activities. Community Development Officers (CDOs) in particular supported BNUU field officers to train patients and caregivers on how to form SHGs, how to register them with the sub county and how to apply to participate in poverty eradication programmes provided through the government. LC1s have been involved in addressing human rights abuses at village level including supporting affected PMDEs to access services from the relevant offices that handle such matters. Their active work with SHGs of PMDEs points to an improved understanding of mental illness including corrected misperceptions and biases.

## 2.8 Advocacy

**Research question c)**
*What issues have people with mental illness and their caregivers living in Agago District advocated for?*

At baseline, SHGs in the project area, CDOs, Health Unit Management Committees (HUMCs), LC1s and one HW mentioned that there are a number of SHGs formed by people with various vulnerabilities like people living with HIV/AIDS, women, youth, and people with disabilities. However, they added that there were no SHGs formed or run by people with mental illness and/or epilepsy in any of the four beneficiary areas. In one subcounty the Assistant Community Development Officer (ACDO) reported that they were trying to integrate some of them into groups of people with audio and visual disabilities. HUMC respondents also listed groups of People Living with HIV/AIDS (PLHA) and women.

The respondents also reported that at baseline, the groups mentioned above carried out some advocacy activities, most of them lobbying for financial support for livelihoods or for inclusion into existing government programmes. One HW did not think PMDEs would be able to do advocacy effectively saying that it is:

> *"Very limited for them to advocate for their rights because people don't take what they communicate as important"*
> Health worker

As at the second year (second six-months May - November 2019) of the project, 25 SHGs with a total membership of 482 made up of 246 PMDEs and 238 caregivers had been formed. An additional 36 SHGs made up of 390 PMDEs and 298 caregivers were formed in the third year of the project, up to June 2020. All groups were trained in how to run SHGs, human rights and advocacy. The CDOs helped them register with the subcounty and trained them to access government run poverty eradication programmes.

Early this year (2020), BNUU conducted a Baseline Study for its new project funded by The National Lottery Community Fund (TNLCF). An analysis of both BNUU and SHGs reports for Quarter 1, Year 3 (Dec 2019-Feb 2020), revealed that 7 SHGs in Lukole subcounty (comprising of 51 Males and 88 Females of which 66 of them are PMDEs and 73 are caregivers) and the 8 SHGs in Paimol subcounty (comprising of 58 Males and 95 Females of which 80 are PMDEs and 73 are caregivers) were advocating for Agago District to recruit more health workers at the health centres for Paimol and Lapirin (in Lukole subcounty) – both HC IIIs. Their request was successful and each of the HCs were allocated a new health worker.

In addition to this, the report also listed the following advocacy activities:

1. Three groups in Lukole subcounty, namely Lacan Pe Nino, Lubanga Twero and Wakonye Kenwa advocated to Agago District about the poor road access by the patients to the health centre in Lukole Sub County (Lapirin HC III) and Agago District has already awarded the contract for the repair of the road. The poor quality of the road has prevented some PMDEs from attending the MH clinics.
2. The SHGs in Paimol subcounty have lobbied the subcounty leadership to enable them to benefit from government programmes/benefits designed for disadvantaged people in the community. So far 3 PMDEs have benefited from the government disability grant and they were each awarded a grant of UGX 1,000,000 (approximately 200 GBP).

The same National Lottery Community Fund Baseline Study reported that some SHGs were supporting those experiencing human rights abuses. For example, members of Opar Piwa SHG in Arii-Wii Parish have been closely monitoring and following up on the case of a rape of a PMDE by one of the community members. The perpetrator has been arrested and has been sanctioned for a Court hearing in Patongo subcounty. However, the family fear that they may not be able to attend court because their limited income hampers their ability to pay for travel costs.

## 2.9 Barriers to support

**Research question d)**
*What do people with mental health problems consider to be the barriers to accessing support and treatment in the project areas? Which of these has the project addressed to improve access to mental health services?*

At the end of the first year of the project, BNUU staff held a participatory data analysis (PDA) session for project beneficiaries. The beneficiaries decided to discuss barriers to treatment and identified the following:

1. Long distances to the health centres coupled with limited transport. At the session, one participant from Lukole subcounty stressed this while shedding tears and asked BNUU to really do everything possible to turn the situation around. She said *we always walk over 20 km to reach Lapirin HC III (in Lukole subcounty) from Wol village - Ngudi Parish, our journey to Lapirin HC III [in Lukole subcounty] always starts a day before clinic date, we prepare and carry with us some food items that can be eaten for at least two days. We tried but many have failed to come back for follow-ups - not because they are unwilling to do so but because it requires a lot to reach Lapirin HCIII in Lukole for mental health services*.
2. Repetitive cases of mental health medication running out at the health centres in the first year was a barrier to most PMDEs. Participants across all the project areas stressed that their fellow patients/caregivers have refused to come back for repeat prescriptions because whenever they come to the health centre they leave without medicine.
3. At times caregivers are not allowed to get treatment for patients who cannot make it to the health centres in person for follow-up appointments, causing them to stop treatment. A caregiver of a physically disabled PMDE from Paimol subcounty explained this by saying *at times it becomes very hard for me to transport my patient to the health facility, and whenever I present this to the health workers, they don't consider and I go back home unserved*.

BNUU was not able to solve the problem of distance but instead increased the number of home visits for patients with children, disabled and elderly persons who did not need medicine or those with children who had stabilised on medication. For those stable on treatment BNUU would deliver drugs every other month to give the patient and caregiver a break from making the trip to the MH clinics. Psychoeducation sessions for those with children with development disorders and behavioural disorders as well as the elderly with dementia were also conducted during home visits. BNUU also presented the problem of repeated drug shortages to the district authorities. The district put in place a system to make sure that mental health medicines were available on mental health clinic days to the extent that sometimes negotiations with HCs from neighbouring districts were made to borrow drugs which were replaced when the national medical stores delivered new stock.

4. Limited family support from many caregivers of PMDEs. One participant in Paimol subcounty testified that she missed her medicine in August 2018 because her mother decided to work in the fields on the mental health clinic day instead of bringing her for her repeat medication. Another respondent from Otumpili parish in Lukole sub county said *my husband left me in the house with children and went to another woman after I was diagnosed with epilepsy, now I am the one responsible for every livelihood issue in the home, I always miss coming for follow-ups whenever I fail to get money for transport from the village to the health centre*.
5. The majority of participants at the PDA session stressed that PMDEs who experienced some side effects from the medication have declined to come back for treatment because they felt weak.
6. The participants talked about the poor health seeking behaviour of PMDEs, giving two examples. The first being that their colleagues (PMDEs) always decline to come back for follow-up treatment

whenever they start registering some reduction in symptoms and second, that participants lamented that other PMDEs are addicted to alcohol and they choose to go and drink even on mental health clinic days instead of coming for repeat medication making them break the treatment chain.

7. Limited knowledge about mental illnesses coupled with limited information about mental health services in the community.
8. Caregivers of PMDEs with psychosis find a lot of difficulties in convincing and bringing patients to the health facilities. The caregivers reported that sometimes they fail to convince their patient to come back for follow-up visits. A participant went ahead to explain that at times they succeed in bringing these psychotic patients to the mental health clinics but they run away before they are attended to by the health workers.

BNUU counsellors solved these barriers by carrying out psychoeducation at home and involving all family members to participate in coming up with ways to support the PMDEs. Mostly this worked because caregiving was now a shared responsibility and other family members took up more farming and domestic chores or more caregiving roles. Psychoeducation included making sure that the patient and family understood the illness, its signs and symptoms and management. Home visits allowed the counsellors to spend time with the families addressing their concerns, misconceptions and answering any questions. BNUU saw improved clinic attendance and adherence to treatment at the end of year 2 when compared to the end of year 1. The staff also discussed management of the side effects of medicines during home visits, counselling sessions and visits to the mental health clinic.

**Table 5: Number of clients counselled, and number of counselling sessions held, per project area, from July 2018 to June 2020**

| **Project area** | **Total number of clients counselled** | **Total number of counselling sessions** |
|---|---:|---:|
| Kalongo town council | 156 | 377 |
| Wol subcounty | 193 | 325 |
| Lukole subcounty | 189 | 341 |
| Paimol subcounty | 157 | 370 |
| **Total** | **695** | **1,413** |

**Table 6: Number of clients counselled, and number of counselling sessions held, by diagnosis, from July 2018 to June 2020**

| **#** | **Diagnosis** | **Total number of clients counselled** | **Total number of counselling sessions** |
|---|---|---:|---:|
| **1** | Depression | 293 | 688 |
| **2** | Epilepsy/Seizure | 210 | 304 |
| **3** | Psychosis | 54 | 137 |
| **4** | Epilepsy & Psychosis | 40 | 73 |
| **5** | Epilepsy & Alcohol Use | 26 | 62 |
| **6** | Psychosis & Alcohol Use | 18 | 30 |
| **7** | Developmental Disorder | 9 | 15 |
| **8** | Alcohol Use Disorders | 8 | 14 |
| **9=** | Depression & Psychosis | 7 | 16 |
| **9=** | Epilepsy & Self Harm/Suicidal | 7 | 28 |
|  | Other | 23 | 46 |
|  | **Total** | **695** | **1,413** |

9. Fear of stigma and discrimination has made some people afraid of seeking mental health services. A female participant from Kalongo town council reported that her neighbour usually tells people she

doesn't have a mental health problem and yet at times she experiences seizures that last a long time.

BNUU stepped up awareness raising activities in year 2 and also talked about how stigma affects access to services. They conducted awareness raising in the communities and on radio talk shows. They involved PMDEs and caregivers in these awareness raising activities so that the community could learn first-hand how stigma affects the lives of PMDEs. LC1s also supported these awareness raising sessions and they were responsible for moderating discussions between BNUU staff, PMDEs, caregivers and the community. They made sure that the community members participated in identifying ways they could support PMDES and their caregivers. 74% of PMDEs and caregivers in the endline surveys reported perceived low levels of stigma compared to 37% at baseline.

10. Most participants said they always forget their mental health clinic appointment dates, others also said they not only forget appointment dates but also the time for taking their medicines.

BNUU purchases airtime on community radio to broadcast messages announcing MH clinic days. PMDEs were also assigned to VHTs whose job was to visit homes during the week of the mental health clinics to remind them to attend.

11. PMDEs spend a long time waiting at the mental health clinics before they are seen. Lapirin HC III in Lukole subcounty has very few health workers and many patients. Some PMDEs complained that they do not come back for follow up appointments because of the time spent at the mental health clinics which makes them become weak from hunger.

After negotiations with the district to allocate more HWs to the mental health clinics, BNUU designed a clinical protocol to improve the manner in which PMDEs were served on clinic days. The protocol when implemented reduced mental health clinic waiting times from 3-4hrs to 90 minutes per person. Once word got out that the clinics were run in a more efficient manner, more PMDEs and caregivers returned to seek treatment.

## 2.10 Community members' behaviour towards PMDEs and their caregivers

**Research question e)**

*How does the community behave towards PMDEs and their caregivers? What is the reason given for this behaviour? What structures are available to support people with mental illness in the community? What type of support do these structures provide? How much do community members in the four project areas (Kalongo Town, Wol, Paimol and Lukole subcounties) define mental illness and epilepsy? What do they attribute to be the cause of mental illness or epilepsy? How can they tell that a person has a mental illness or epilepsy? What proportion of these communities know that mental health problems and epilepsy are not contagious?*

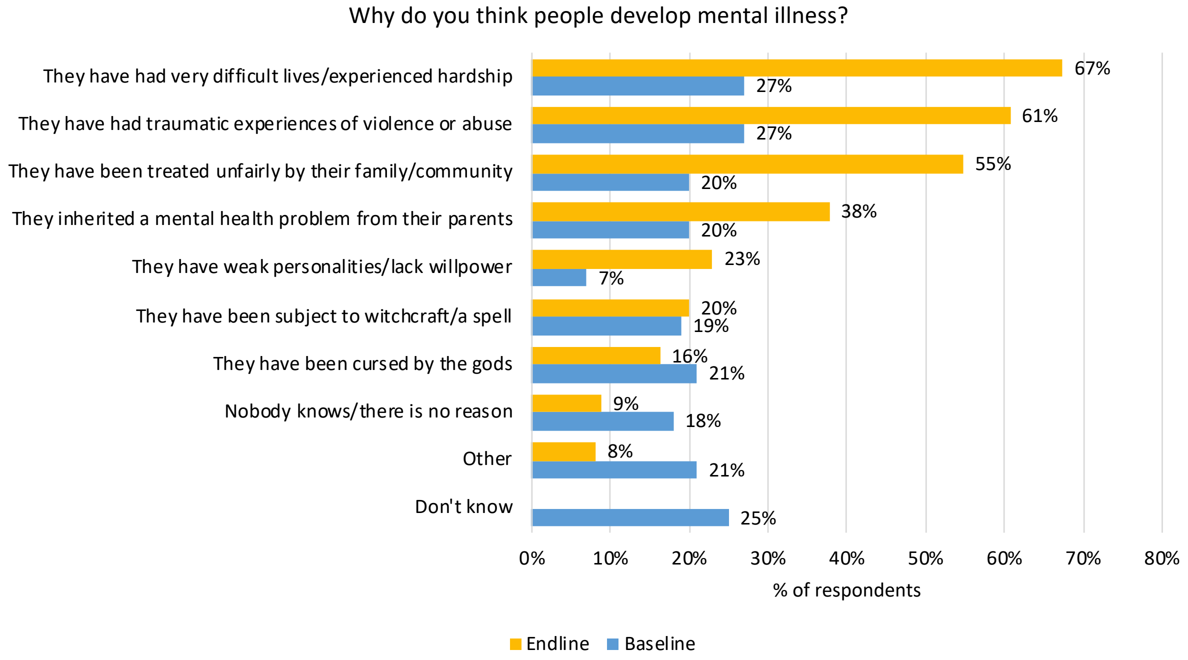
At baseline 365 respondents were sampled to participate in the community survey. At endline a different approach was used because of the COVID-19 pandemic and the restrictions and limited ability to be in the field. Instead the team asked community members who were willing to participate in the survey. 135 community members responded.

**Table 7: Comparing the responses of community members at baseline and endline.**[9]

| Statement | Baseline respondents (highest response) | Endline respondents (highest response) |
|---|---|---|
| Mental illness can spread from one person to another, just like an infectious disease (Q1.1) | 45% agreed | 18% agreed |
| People who have had mental health problems include famous pop stars, football players, and presidents (Q1.2) | 49% agreed | 90% agreed |
| Sometimes, mental health problems cause actual physical pain (Q1.3) | 82% agreed | 87% agreed |
| Anybody can develop mental health problems at some point in their lives (Q2.1) | 78% strongly agreed | 87% strongly agreed |
| It is best to avoid anyone who has mental problems (Q2.2) | 57% strongly disagreed | 82% strongly disagreed |
| No one has the right to exclude people with mental health problems from their community (Q2.3) | 51% strongly agreed | 76% strongly agreed |
| I would not want to live next door to someone who has mental health problems (Q2.4) | 65% strongly disagreed | 82% strongly disagreed |
| We need to adopt a far more tolerant attitude toward people with mental health problems in our community (Q2.5) | 68% strongly agreed | 86% strongly agreed |

### 2.10.1 Community understanding of the causes of mental illness and epilepsy

**Figure 1: 'Why do you think people develop mental illness?': baseline and endline**



Community respondents were asked why they thought people develop mental illness and epilepsy, and their responses were recorded against the statements listed in figures 1 and 2.[10] At baseline most

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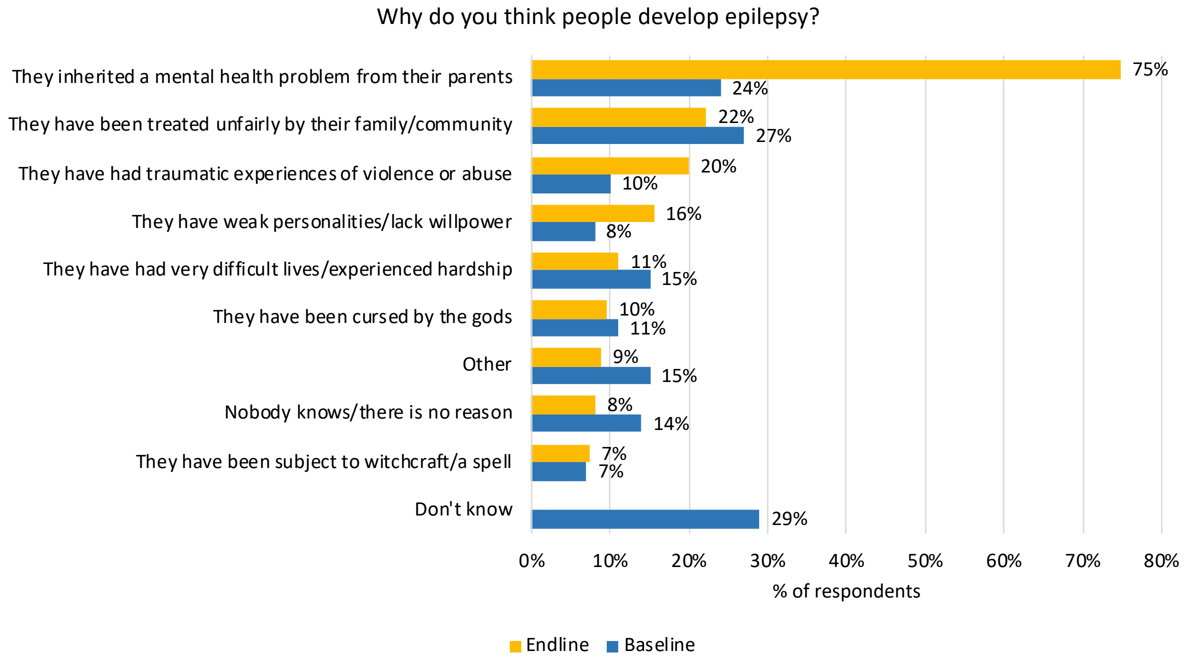
[9] The respondents were asked to respond to the statements in table 9 using options on a Likert scale i.e strongly agree, agree, neither agree nor disagree, disagree and strongly disagree. The table below compares highest responses for each question at baseline and at endline.

[10] Please note that respondents could give multiple reasons, which is why total % of respondents exceeds 100%

community respondents attributed the cause of mental illness to people having had difficult lives/experienced hardship, or having had traumatic experiences of violence or abuse (27% each). This was followed by 25% of people who did not know what caused mental illness, 21% who attributed the cause to a curse from god, 20% who attributed the cause to genetics (inherited from parents) and 19% to witchcraft.

At endline, larger percentages of respondents attributed the cause of mental illness to people having had difficult lives/experienced hardship (67%) or traumatic experiences of violence or abuse (61%). There were also increases in the percentage who said unfair treatment by family/community (55%) and genetics (38%). Reduced numbers of community members attributed the cause to a curse from god (16%) and genetics (3%). However, attribution of mental illness to weak personality/lack of willpower increased to 23%, whereas being being subject to witchcraft/a spell was given by a similar percentage of respondents (20%) as it was at baseline (19%). Both of these will need addressing through future community sensitisation activities.

**Figure 2: 'Why do you think people develop epilepsy?': baseline and endline**

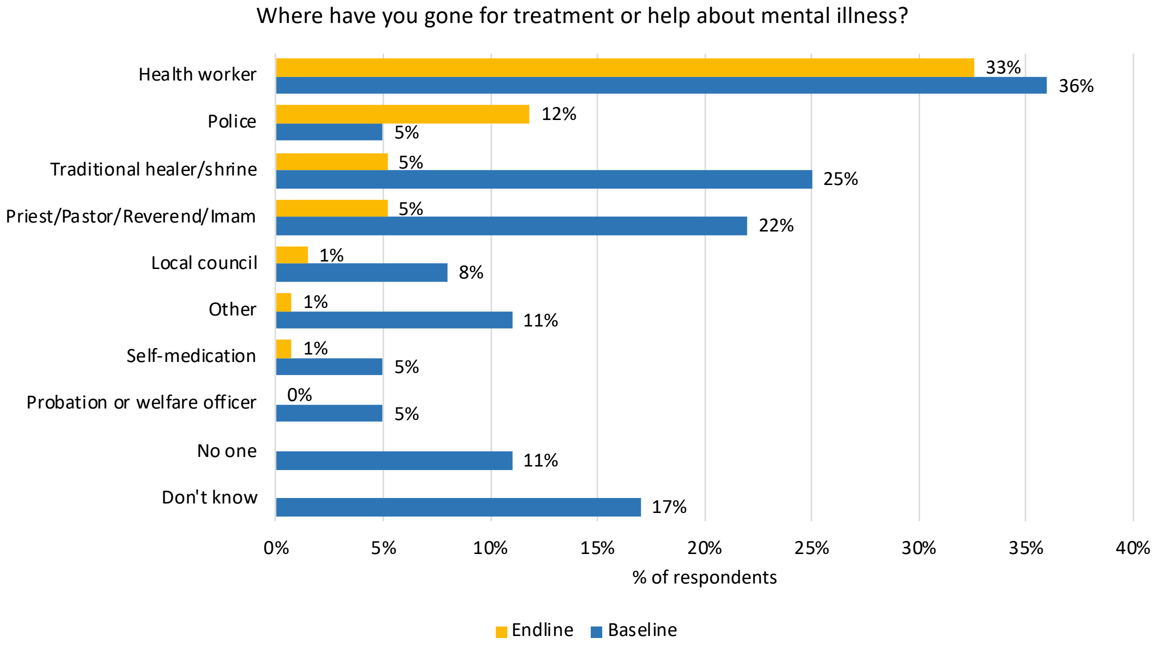


As for the cause of epilepsy, at baseline the top causes mentioned were not knowing a cause (29%), poor treatment by family/community (27%), and genetics (24%). At endline the responses changed to genetics being cited as the top cause (75%) followed by being treated unfairly by their parents/community (22%) and traumatic experiences of violence or abuse (20%). The percentage attributing epilepsy to a weak personality increased to 16% at endline. One suggestion for the reason behind this is that epilepsy can cause personality disorders, leading to the misconception that this happens the other way round.

At baseline, 64% of community members knew someone with epilepsy and 21% knew someone with a mental illness. The percentage of respondents knowing someone with epilepsy increased significantly to 87% at endline, whereas those reporting that they knew someone with a mental illness increased slightly to 24%.

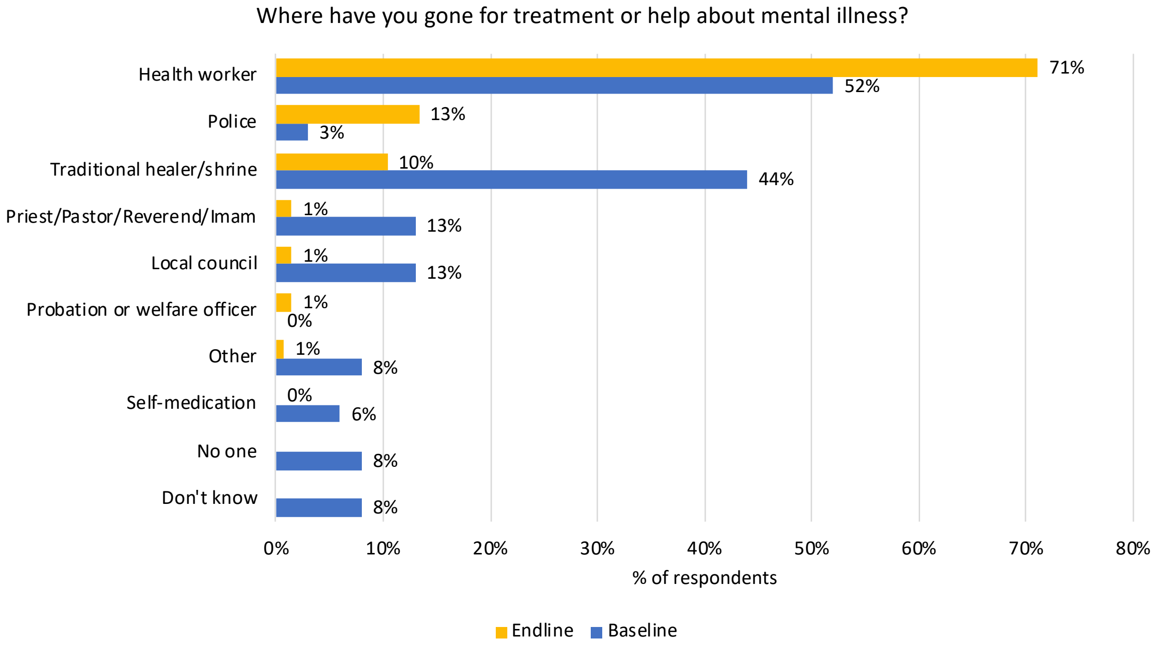
### 2.10.2 Community understanding of where to seek treatment or help for mental illness and epilepsy

**Figure 3: 'Where have you gone for treatment or help about mental illness?': baseline and endline**



At baseline 36% reported that they would take someone with mental illness to a health worker for treatment, compared to 33% at endline. At baseline 25% reported they would use a traditional healer in comparison to 5% at endline and 22% would have used a religious leader at baseline compared to 5% at endline.

**Figure 4: 'Where have you gone for treatment or help about epilepsy?': baseline and endline**



### 2.10.3 PMDE work and chores

**Figure 5: What kind of work/chores do people with mental illness do?**

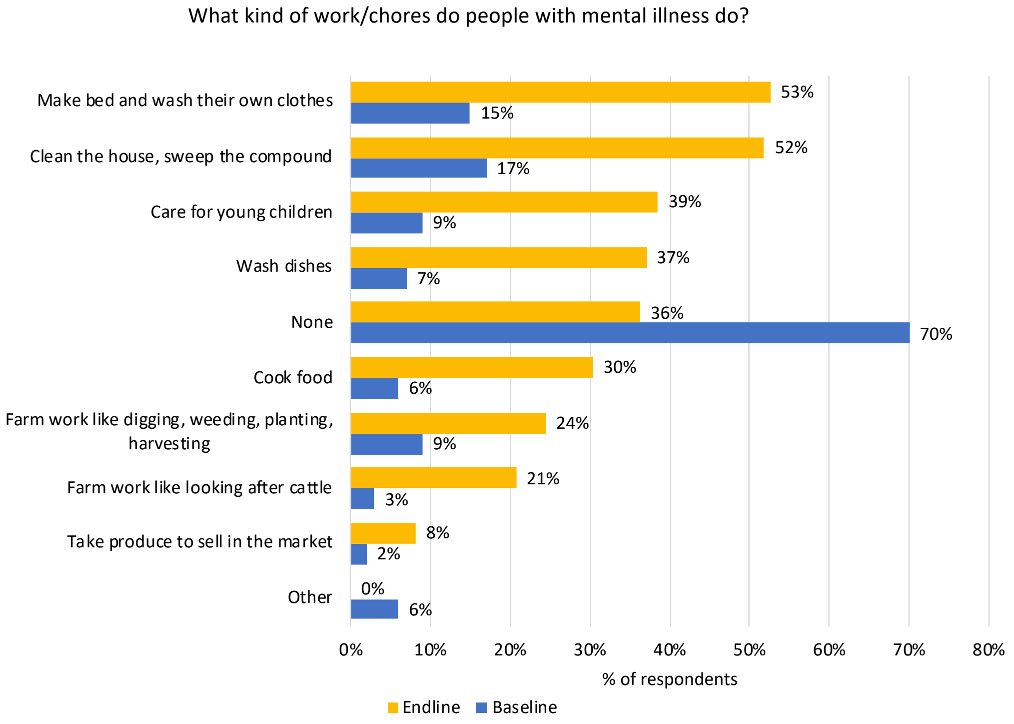
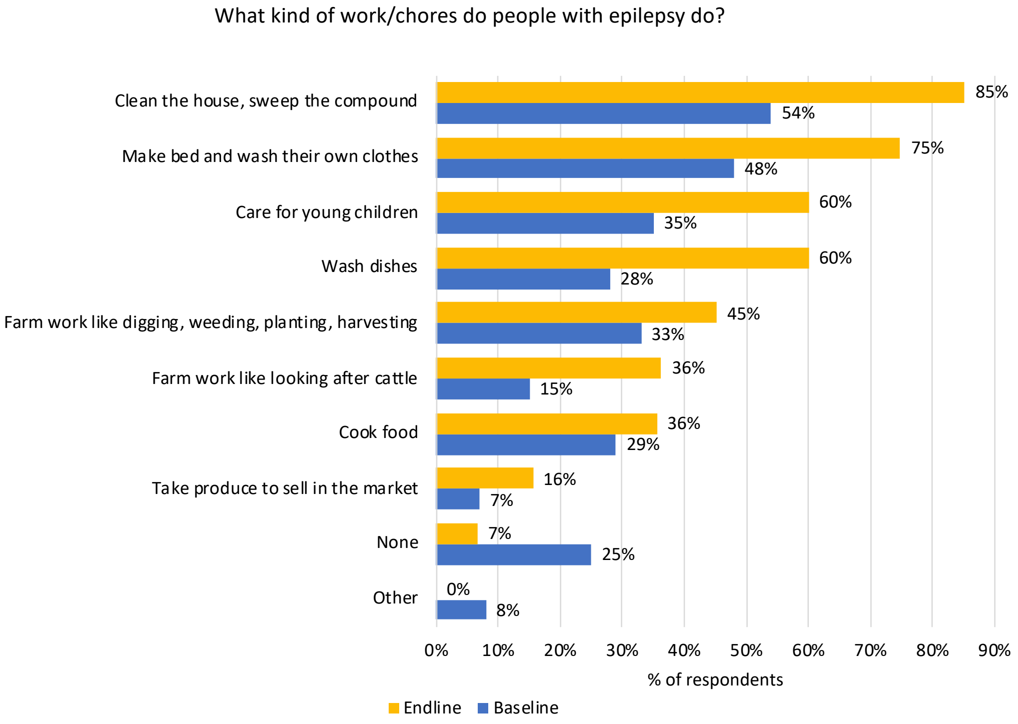


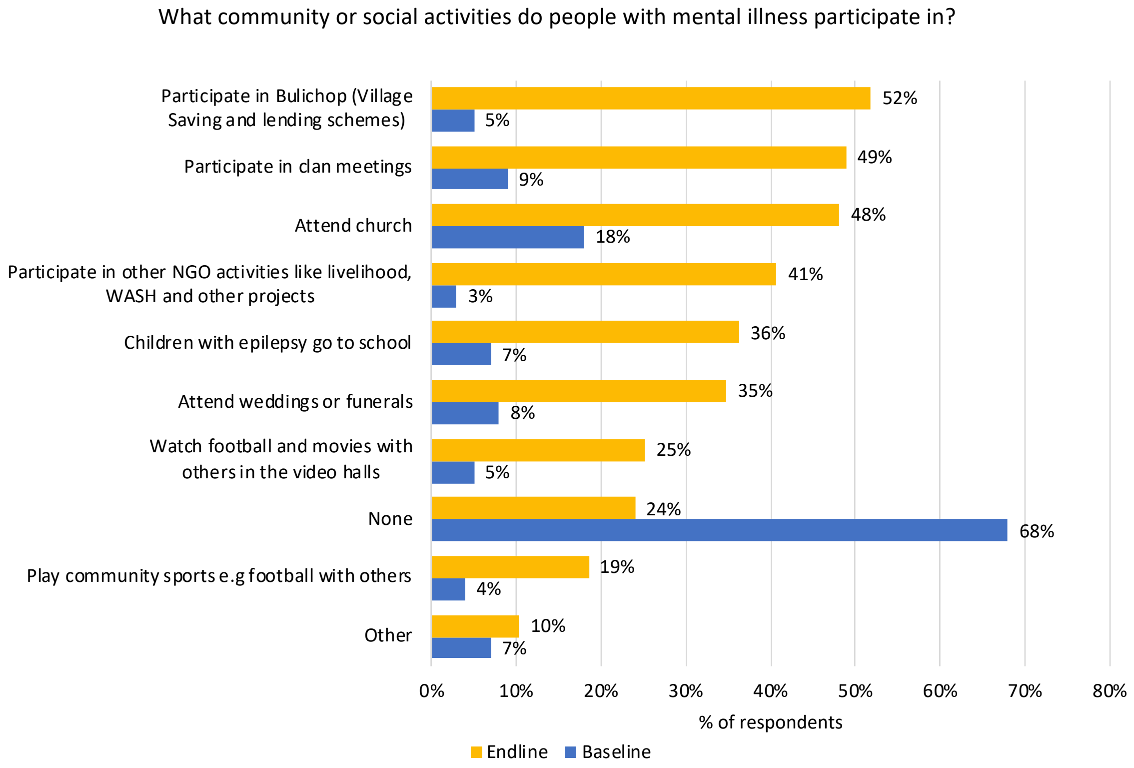
**Figure 6: What kind of work/chores do people with epilepsy do?**



At baseline 70% of the respondents said that PMIs do not perform any work or chores while about half of respondents (48%) said that people with epilepsy make their beds and wash their clothes and 54% said they clean the house or sweep the compound. At endline this had improved significantly for PMIs - 36% said PMIs do not do any work or chores. The number of people believing that people with epilepsy cannot do chores also reduced for all chores listed on the questionnaire, with an overall of 7% saying people with epilepsy do not do chores, and increasing for every chore listed.

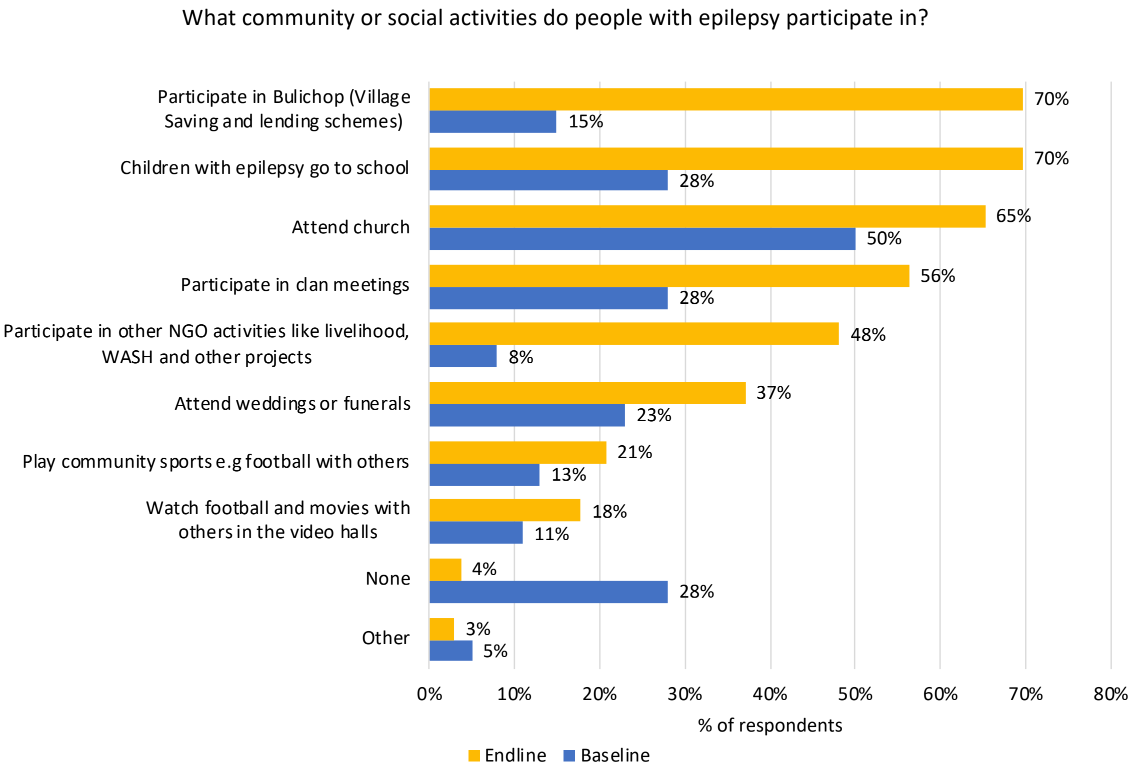
### 2.10.4 PMDEs' involvement in community or social activities

**Figure 7: What community or social activities do people with mental illness participate in?**



At baseline, the majority of respondents said that people with mental illness do not participate in any community activities (68%). This has dropped to 24% at endline, with a greater percentage of respondents stating that people with mental illness are included in every activity listed. The activities that the most community respondents at endline stated that people with mental illness are involved in are: village saving and lending schemes (52%) – up from 5% at baseline; clan meetings (49%) and attending church (48%).

**Figure 8: What community or social activities do people with epilepsy participate in?**



People with epilepsy faced less exclusion from community activities at baseline than people with mental illness did. The community or social activity that community members most frequently said that people with epilepsy participated in was attending church (50%) followed by children going to school and participation in clan meetings (28%).

28% at baseline said that people with epilepsy do not participate in community activities, whereas this dropped to 4% at endline. Also at endline, 70% of community respondents stated that people with epilepsy participate in village savings and lending schemes, and the same percentage stated that children with epilepsy attend school.

This shows that over the course of the project, communities have become more inclusive for PMDEs. Participation in community and social activities has significantly increased for both people with mental illness and people with epilepsy.

# 3 PROGRESS AGAINST THE PROJECT RESULTS AND ASSUMPTIONS

Comparing the results from the Baseline and Endline Studies helps us assess whether the project has made significant strides towards reaching its results. Below is an assessment of the project's progress towards the results committed to the funder.

## 3.1 Result 1: To enhance the provision of mental health support to those in need.

### 3.1.1 Indicators

70% of trained counsellors, HWs and VHTs demonstrating appropriate knowledge and skills in the mhGAP intervention guide and lay counselling guide regarding diagnosis and treatment of mental illness/epilepsy, following training in Year 1 in the four project areas.

At baseline, 50% of healthcare workers, 58% of village health teams and 100% of counsellors demonstrated appropriate knowledge and skills regarding diagnosis and treatment of mental illness and epilepsy'.

### 3.1.2 Expected Observable Change

In order to assess progress at endline, we assessed the correct tools for diagnosis, psychoeducation, counselling and home visits. We sampled and assessed forms used by HWs, VHTs and the counsellors. All the sampled forms belonged to patients who had been contacted at least six times by any of the above depending on which form they use. From the assessments of the use of these forms it is safe to say that the HWs, VHT and Counsellors are using the appropriate skills to diagnose and treat mental illness and epilepsy.

### 3.1.3 Actual Observable Change

HWs assessed were able to follow the mhGAP diagnostic criteria to arrive at an appropriate diagnosis. The treatment plans reviewed were in line with mhGAP guidelines and in year 2 we saw an increase in client attendance as the team applied/used the mental health clinic protocol.

The counsellors were provided with a counselling guide, a client intake form, a counselling session form and a psychoeducation form. From the analysis of forms sampled, counsellors were able to demonstrate the correct application of mhGAP principles, psychoeducation talking points and psychosocial support guidelines for each disorder.

At first counsellors carried out home visits but in year 2 they trained VHTs to carry out home visit assessments to create more time for counselling. VHTs would then flag families that needed the attention of the counsellors or health worker. Counsellors followed up issues raised during follow up home visits while HWs followed up issues raised during mental health clinics.

All the forms filled in were used correctly and provided a clear picture of the patient's condition each month. Therefore, we can conclude that 100% of the HWs and Counsellors demonstrate appropriate knowledge and skills in the mhGAP intervention guide and lay counselling guide regarding diagnosis and treatment of mental illness/epilepsy.

## 3.2 Result 2: Reduce the percentage of PMDEs experiencing psychological distress

Percentage of targeted PMDEs over the project period who score below the clinical cut-off on the CORE-10 outcome measure for psychological distress[11] at the end of the year they joined the project.

### 3.2.1 Indicators

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[11] If they score 11 or above after one year of support, then they are still experiencing psychological distress.

At baseline 8% of PMDEs assessed using core 10 scored 10 and below, meaning the remaining 92% of PMDEs scored as being psychologically distressed. The endline target was 50% of all clients assessed using core to score 10 and below on Core 10.

At endline, we assessed 182 PMDEs using core 10, and only 24% of these scored 11 or above. This means that the majority of these (76%) scored 10 and below which is a good result.

**In addition to the core 10 score, the project aimed to measure the percentage of targeted PMDEs over the project period who report that they are able to function in everyday life.** At baseline 23% reported that they were able to function in everyday life. The project target is 70% of PMDEs accessed reporting that they function in everyday life which corresponded to the CORE 10 scores. At endline 66.5% of PMDEs assessed reported that they were able to function and had not experienced any thoughts or feelings that prevented them from doing their work.

### 3.2.2 Expected Observable change

Over the three years of the project we will make changes/adjustments in response to beneficiary/stakeholder feedback regarding the project's impact on the beneficiaries' lives and mental health. We hope that the feedback will improve over the course of the project as we make these changes.

### 3.2.3 Actual Observable Change

BNUU staff included annual PDA sessions with project beneficiaries as an avenue to receive feedback about the project activities. In year one the project beneficiaries shared feedback on barriers to services and in year 2 they shared feedback on what have improved, and identified barriers requiring more interventions to be addressed.

## 3.3 Result 3: To promote take-up of services

The target for the number of PMDEs diagnosed with mental illness/epilepsy over the course of the project was 1,824. At the time of collecting endline data, 1,663 PMDEs were diagnosed and treated for mental illness or epilepsy, and 695 PMDEs and caregivers were counselled.

The project also aimed to measure the number of people attending the monthly mental health clinics, with a target of 48 per month, and the number of PMDEs attending counselling sessions with the project counsellors each quarter, with a target of 45 per quarter. Mental health clinic attendance has exceeded the target by an average of 19 attendees per month, and attendance during 68% of months exceeded this target. Meanwhile there have been over four times as many counselling sessions per quarter as was originally targeted (185).

**Table 8: Take up of services compared to target – mental health clinics and counselling sessions**

| Service | Target | Average Jun 2019 – Jun 2020 |
|---|---|---|
| Mental Health Clinics | 48 (per month) | 67 (per month) |
| Counselling Sessions | 45 (per quarter) | 185 (per quarter)[12] |

Figures 9 and 10 below show the number of counselling sessions conducted per month, and the number of clients counselled per month from June 2018 – June 2020. The spikes in demand in June and October 2019 correspond with harvest season, which is when domestic violence can be most rampant. This can occur due to conflict over resources such as crops harvested, animals etc., for example if men sell off crops harvested and animals available without the consent of their partners/wives.

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[12] Data on average counselling sessions per quarter is based on completed quarters at the time of endline data collection which occurred during June 2020, i.e. Q3 & 4 2018, Q1-4 2019, and Q1 2020 (July 2018 – March 2020)

**Figure 9: Number of clients counselled per month**

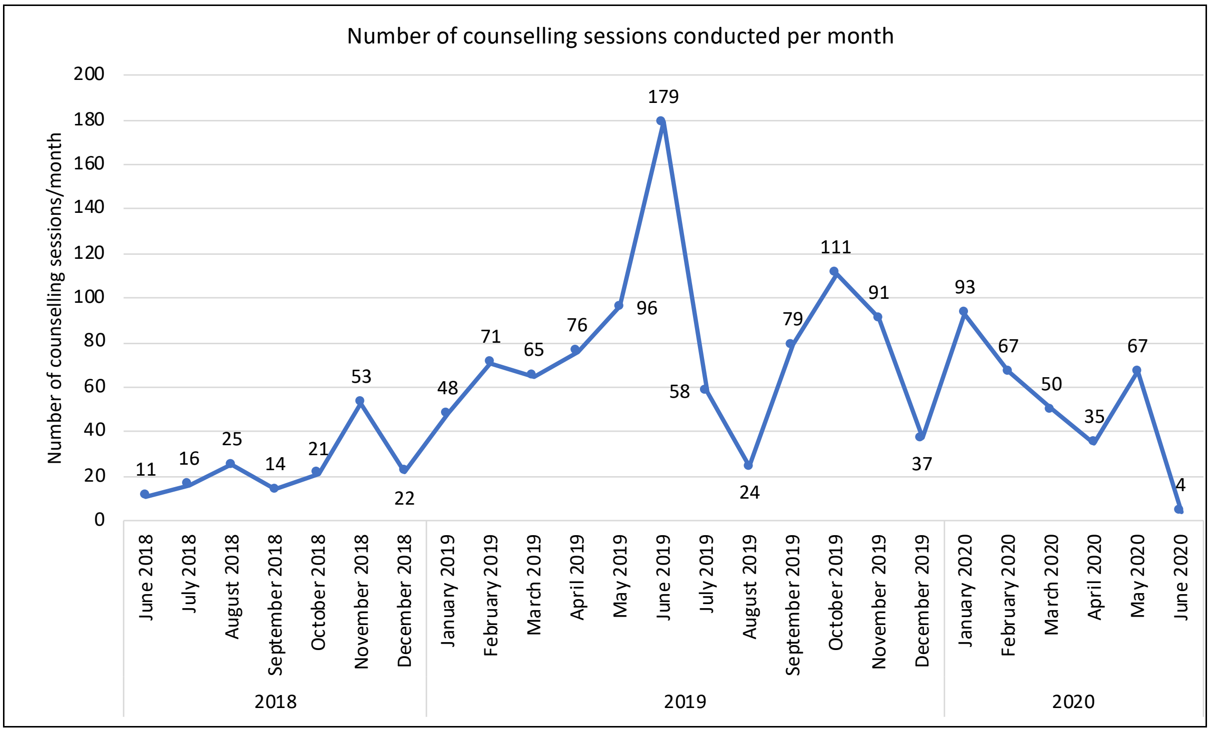
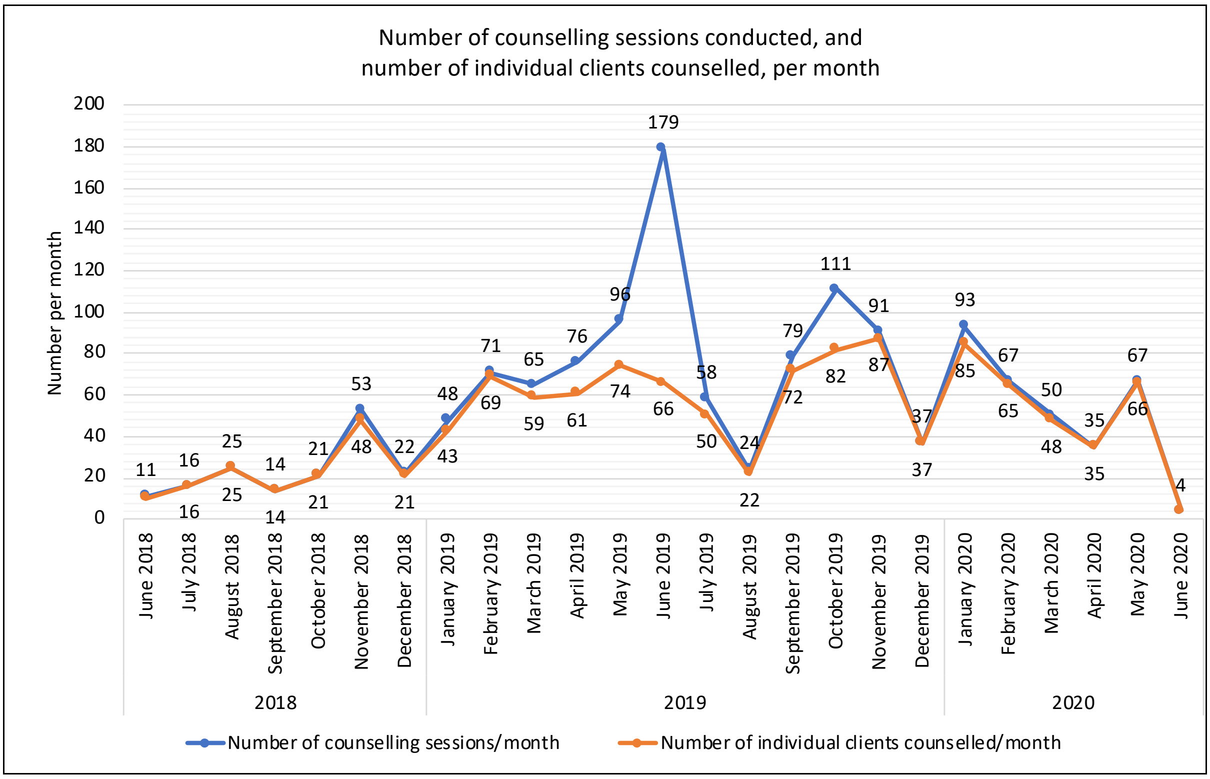


**Figure 10: Number of clients counselled, and number of individual clients counselled, per month**



### 3.3.1 Expected observable change

We expect that the number and level of barriers will reduce. We are fairly confident that the barriers of lack of knowledge and lack of service availability will be reduced; we also hope that this project will help to reduce the barrier of stigma (which is harder to change and likely to take longer than the life of this project).

### 3.3.2 Actual Observable Change

At the end of the project, the number of community members who had a better understanding of mental illness and epilepsy had improved. All key informant respondents were better able to describe mental illnesses and all mentioned that they knew of the mental health services provided by the MH clinics. All the community leaders reported that they now refer clients to the MH clinics and three of the community leaders reported that at least one of their children was accessing services.

There was a change in community members' perception of how PMDEs should be treated. For example, the community survey tool reported improvements in communities' attitudes and empathy towards PMDEs (anyone can get mental illness from 78% at baseline to 86% at endline, and community members should not discriminate against PMDEs from 51% at baseline to 76% at endline).

## 3.4 Result 4: To reduce levels of stigma in the community

### 3.4.1 Indicators

The project also aimed to measure the percentage of targeted PMDEs who report low levels of perceived stigma and discrimination. The baseline figure was 37% of PMDEs reporting low levels of stigma. The project aimed to increase this to 50% (target 50%). At the time of collecting endline data, 74% of PMDEs sampled reported that they feel low levels of stigma, surpassing the 50% target.

The project also aimed to measure the percentage of community members surveyed who understand that mental illness is not contagious. At the baseline 55% of all community members reported that they understood that mental illness was not contagious - slightly higher than the target which was set at 50%. At the endline 81% of community members surveyed responded that mental illness is not contagious.

In addition to the two stigma indicators mentioned above, the project also aimed to measure the percentage of targeted PMDEs reporting that their families have an improved and more supportive attitude towards their mental illness. At baseline 30% pf PMDEs reported that their families had a supportive attitude towards them. The project set a target of 50% of PMDEs measured reporting improved and supportive attitudes from their families. At endline 70% of the PMDEs sampled reported that their families were supportive towards them - a marked improvement from 30% at baseline.

### 3.4.2 Observable change

We expect members of the communities in which we are working to have more positive perceptions of people with mental disorders and epilepsy by the end of the project.

There has been progress towards improving some of the negative perceptions that the community had at baseline. Those that have changed significantly include the fact that community members now agree that MDEs are not contagious, community members should not exclude people with mental health problems from their community and can co-exist with others as neighbours, and that the community should adopt a far more tolerant attitude towards people with mental health problems. However, a lot more needs to be done to improve community attitudes towards PMDEs' right to work and engage in meaningful activity.

## 3.5 Result 5: To empower PMDEs and caregivers to advocate for appropriate support

### 3.5.1 Indicators

To measure this result, N4A and BNUU chose three indicators. These are:

1. Percentage of targeted PMDEs and caregivers who are a member of a mental health self-help group. baseline 0, target 17%
2. Percentage of the PMDEs and caregivers who join SHGs, who attend at least two-thirds of meetings within a year after starting.
3. Number of self-help group members who have carried out an advocacy[13] action within the past year. The project planned to support at least 10% of PMDEs and their caregivers to participate in advocacy.

### 3.5.2 Observable changes

At the start of the project there were no SHGs owned or run by PMDEs. We also found that PMDEs were not members of other SHGs in the community. At endline 1,174 PMDEs and caregivers joined SHGs - 83% of PMDEs were reached, surpassing by far the project target of 17%. 73% of PMDEs and caregivers who joined SHGs attended at least two-thirds of the meetings.

At baseline there were no known advocacy actions by PMDEs. By endline, 567 SHG members (40%) were involved in human rights monitoring and identified and supported their leaders to come up with advocacy messages. They were represented by 11 SHG leaders who presented their asks to various leaders at the district level.

The Endline Study found that SHGs had conducted 27 human rights monitoring activities. The issues ranged from solving problems around how PMDEs were treated by family, to supporting PMDEs to seek justice for crimes committed against them.

Fourteen advocacy issues were raised during the project period and of these, four were resolved; the district leadership is reviewing the rest. The issues that were resolved included a dangerous road with a collapsed bridge in Lukole subcounty; inadequate health workers in Lukole and Paimol subcounties; bad road network in Paimol subcounty; inadequate supply of mental health medication in the four health centres.

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[13] Advocacy action means “an ask or request relating to mental health/epilepsy and aimed at sub-national duty bearers.”

# 4 PROGRESS AGAINST RECOMMENDATIONS MADE AT BASELINE

## 4.1 Mental treatment act/mental health bill

Recommendation: Join organisations lobbying for the repeal of the mental treatment act and the passing of the mental health bill 2016. Also join them to lobby cabinet to approve the MH policy.

BNUU is an active member of the district NGO monitoring committee. The new MH act came into law in 2018. There is slow movement on MH policy at national level.

## 4.2 Awareness raising

Recommendation: Target awareness raising sessions and mental health education with each of the target groups and the general community. Messages should address knowledge gaps as well as confront current misconceptions offering true facts in a manner that makes sense to the community.

BNUU produced an awareness raising guide and an MH clinic mental health education guide to help disseminate messages that were designed in response of the findings of the baseline. For the most part, we can see that community and caregiver attitudes have changed and 69.8% of PMDEs and caregivers who participated in the Endline Study reported that they feel optimistic about their future. 73.6% reported that they have not been treated badly by their community and 90.7% reported that they no longer hide their problems from others.

## 4.3 Medicines and psychiatric nurses

Lobby for improved supply of mental health medicines. Lobby for the recruitment of psychiatric nurses at HC III level. The psychiatric nurses also practice as general nurses which increases the chances of the HCs providing an integrated service.

BNUU has made efforts to ensure that all medicines are available during the mental health clinics. This was a result of negotiations with the District Health Officer and ‘in charges’ of HCs in sub counties where we are not working.

At the start of the project in 2018, Agago District had no specialised mental health worker on its payroll and relied on neighbouring Pader, Kitgum and Gulu districts for specialised services. The Dr. Ambrosoli Mission Hospital had a psychiatric nurse (PN) who was attached to the HIV/AIDS clinic and after negotiations between BNUU and Dr. Ambrosli Hospital, the PN was able to support mental health clinics once a week for just over two years until she sadly died earlier this year. During this time, two PNs who were away on study leave returned to work in Agago but unfortunately, they have not been added to the district payroll. This means that there is no PN in Agago District at the moment, only the two volunteer PNs who offer some support to the MH clinics.

## 4.4 Training health workers

Recommendation: Train HWs on the assessment, management and follow up of PMDEs. The project should also train other actors in PHC to carry out their roles towards PMDEs and improve the quality or appropriateness of the services. For example, HUMCs should ensure that their HCs have an adequate supply of medicines and that each HC has what it needs to provide MH services. VHTs on the other hand are required to raise awareness about the availability of MH services, refer patients and follow them up to make sure that they are adhering to treatment. VHTs like LC1s and CDOs are responsible for making sure that PMDEs enjoy their rights.

BNUU has put this recommendation into practice by developing guides and training different actors to use these guides. VHTs work with the awareness raising guide and home visit checklist; HWs and Counsellors use the counselling and clinic protocols, diagnostic tools and psychoeducation tools; CDOs were trained using the SHG guide. All these actors now work together, each doing their part to make the project work successfully.

### 4.5 Duty bearers

Build the capacity of community duty bearers to understand and execute their role in supporting PMDEs in the community. This capacity building should include the ability to seek out and support PMDEs instead of waiting for them to come to the duty bearers for services/advice.

Community members and duty bearers have been at the receiving end of awareness raising messages and training workshops. For the most part they now show support to PMDES and their caregivers. However more targeted awareness raising is required for them to support livelihood initiatives of PMDEs when they start during the TNLCF project.

### 4.6 Capacity building for the Community Development Office

Build the capacity of the Community Development Office to support groups of/and PMDEs ensuring that they are benefiting from government programmes but also lobbying for them to access other services like health, education and security. The CDO is responsible for making sure that all vulnerable groups are catered for during the planning, implementation and monitoring of services at district level.

The CDOs have played a great role in supporting PMDEs and caregivers through involvement of PMDEs and caregivers in the local government planning and budgeting process. The majority of the PMDEs and caregivers participated in the planning process and it enabled them to voice their needs/concerns/priorities and as a result their issues were included in Agago District's 5-year development plan. For example, issues of inadequate numbers of health workers and psychiatric personnel including the psychiatric personnel and the issues of poor road networks that hinder access to health centres. Also, the CDOs supported guiding the SHGs on how to register with the local authority by fulfilling the requirements for registration. Furthermore, they ensured that SHGs benefit from government programmes such as the disability grant where three PMDEs received UGX 1 million each. The CDOs have been educating people on the rights of PMDEs and have helped them to identify referral pathways (where to go for help when PMDEs' rights have been abused).

# 5 Conclusion

Overall, this project can be deemed a success. Almost all the key deliverables have been met apart from the indicator on communities' understanding of the causes of mental illness and epilepsy – though these have improved somewhat, with fewer believing they are the results of curses, there are still a significant proportion who believe they are caused by weakness or poor willpower. This should not be seen as a failure as attitude change takes time. The project has demonstrated that the mhGAP-IG can be applied successfully to poor resource settings if adapted to make diagnosis and treatment easier for PHC health workers. The provision of counselling to PMDEs and their caregivers has played an important role, and demand for this has meant the amount of counselling sessions provided has greatly exceeded all targets. Counsellors' frequent home visits have widened their reach, and enabled the inclusion of caregivers and other family members, supporting them to better understand, care for and support their relative with mental illness and/or epilepsy. The project has also provided evidence that should support greater discourse on the relationship between sustained awareness raising activities and access and utilisation of MH services as well as community acceptance and support of people suffering from mental illness. Finally, the project has demonstrated the importance of self-help groups and how self-help can be used to keep PMDEs and their caregivers safe in the communities that they live in.

## 5.1 Lessons learned

- The lack of specialist mental health personnel in the district has been a challenge. Although negotiations between the hospital and BNUU meant that a psychiatric nurse was able to support mental health clinics once a week for the first two years of the project – however, since her death there has been no replacement.
- A key barrier to many PMDEs and their caregivers accessing mental health services, is having to travel large distances to do so – which many cannot afford to do in terms of both time and money. This has led BNUU to provide MH services closer to people's homes, and conduct more outreach work with clients in their communities.
- Drug shortages have been another factor putting clients off clients returning for follow-up appointments, as they can see the journey as wasted if they're unable to collect the medication they need.
- There is a case to be made for specialising in mental illnesses like depression, anxiety and psychosis, as well as epilepsy, rather than focusing on all the mental health conditions encompassed by mhGAP. The BNUU team has the expertise and there is availability of medicines in Uganda for these conditions through the government. Also, depression is one of the most common conditions in terms of the number of people who are likely to experience it at some point during their lifetime, yet is invisible and requires a great deal of education/awareness raising, including among general healthcare workers. Other conditions such as dementia, developmental disorders and alcohol/drug use disorders require specialists in those areas. However, there is of course much interconnectivity between different issues like alcohol abuse and psychosis/epilepsy, so it will always be necessary to have consideration of all conditions to some extent.
- Community awareness and word of mouth means that people from outside the beneficiary areas have come for support, and show it is not reasonable to expect demand to be restricted to beneficiary areas only. People seeking support cannot be turned away, even if they have travelled from outside the beneficiary areas; yet the additional demand from them is not necessarily factored into the resourcing of the programme. It shows that there is a wider demand for MH services which needs consideration.

## 5.2 Future ambition

N4A and BNUU have received a grant from The National Lottery Community Fund (TNLCF) to support 25 SHGs with livelihood inputs in order to boost their income generating abilities and address the poverty that many PMDEs and their caregivers face. The impact of poverty and mental illness has been studied over the years, the conclusion being that poverty and mental illness are bedfellows each exacerbating the other in a cyclic manner that can only be broken by interventions that target both treatment for mental illness and support for people with mental disorders and/or epilepsy (PMDEs) to participate in work and meaningful activity.

These livelihoods not only provide an opportunity for PMDEs to work but also seek to dispel any myths and misconceptions about the ability of PMDEs to carry out viable income generating activities. The scale of this intervention is enough to provoke dialogue around PMDEs’ capabilities as well as the challenges that they will need to overcome in order to earn incomes in communities where so many of their family and neighbours face daunting challenges to earn an income.

It builds on the legacy and impact of the Comic Relief funded project, which has created the conditions for the livelihoods interventions to be possible.

# Appendices

## Appendix 1: Diagnostic tools

1. Alcohol Use and Alcohol Use Disorders Symptom Checklist
2. Behavioural Disorders Symptom Checklist
3. Clinical Diagnosis Form
4. Dementia Symptom Checklist
5. Depression Symptom Checklist
6. Developmental Disorders Symptom Checklist
7. Drug Use and Drug Use Disorder Symptom Checklist
8. Epilepsy Symptom Checklist
9. Psychosis Symptom Checklist
10. Suicide Symptom Checklist
11. Home Visit Form
12. Clinical Notes
13. Counselling Form
14. Follow Up Tool

## Appendix 2: Manuals

1. BNUU Outreach Clinic Protocol
2. BNUU Outline for Awareness Raising on Mental Ill Health and Epilepsy
3. BNUU Outline for Training Non Health Workers on mhGAP
4. BNUU Counselling Protocol
5. BNUU Guide to Delivering Health Talks at Mental Health Outreach Clinics
6. BNUU Self-help Group Facilitator’s Guide

## Appendix 3: Psychoeducation tools

1. Psychoeducation tool for Child and Adolescent Mental and Behavioural Disorder
2. Psychoeducation checklist for Self-harm or Suicide
3. Psychoeducation Checklist for Psychosis
4. Psychoeducation Checklist for Epilepsy
5. Psychoeducation Tool for Disorders Due to Substance Use
6. Depression
7. Dementia Psychoeducation Checklist