UNAIDS STRATEGY DEVELOPMENT

UNAIDS STRATEGY REVIEW	
Focus Group Discussion Synthesis	
Country	Malawi
Discussion Theme	HIV in Humanitarian Settings
Organizer	CSO Advocacy Forum on HIV and Related Conditions
Date of Submission	14th September 2020

Background

Organization leading discussion: **JONEHA**

Date of the Focus Group discussion: **31st August 2020**

Theme to be discussed: **Access to HIV services in Humanitarian settings in Malawi.**

JONEHA with support from CSAF members was tasked to lead a Focus Group discussion with People Living with HIV residing in Humanitarian settings to understand PLHIV's lived experiences in accessing HIV treatment and prevention services in times of crisis and natural disasters. The exercise was also meant to generate feedback and recommendations for the new five-year UNAIDS Strategy, specifically highlighting areas for improvement and new focus areas with the aim of keeping HIV services in humanitarian setting central to the Global AIDS Strategy which forms the basis for global targets and strategy for HIV, TB and Malaria.

Participants

In total there were 23 PLHIV participants drawn from 7 districts across Malawi namely: Nkhotakhota, Blantyre, Nsanje, Salima, Chikwawa, Mzimba and Karonga. The names and contact details of all participants are listed in the table 1 below. The majority of the participants came from the Southern region, which is one of the hardest hit regions with natural disasters. Participants represented local networks and organisations working with PLHIV and included: women living with HIV; young women; PLHIV support groups leaders, PLHIV Expert Clients.

Table 1

Participants list

The process

UNAIDS Malawi Staff initially conducted training to the local facilitators through several zoom sessions. The training was based on guidance from the headquarters of UNAIDS in Geneva. Topics covered were the objective of the exercise, theme for Malawi, how it ought to be done and the platform to be used, key questions, number of participants, duration, timeframe and funding. In the training process; key questions were simplified to ease facilitation. An initial list of participants which was later reviewed was drawn. The Focus Group discussion was conducted via zoom and took approximately 5hrs; 1.5hrs for orientation to the technology, 3.5hrs for the main discussion. The discussion was facilitated by David Kamkwamba from JONEHA and Maureen Luba from AVAC

Challenges

All participants indicated that they had never used zoom or any online engagement platform before. This made participation challenging for all. Almost 85% of the participants either had no smart phone or computer to use. This cohort of the participants had to either travel a minimum distance of 30 km or use a borrowed computer at a cost. Another challenge was unstable or weak network signals in some areas. Also, the discussion was done in the local Chichewa language. This meant transcribing and translating the

whole discussion into English for the international audience. This demanded a lot of additional project implementation time than envisaged. Basically there was no budget for the activity and resourcing funds locally took longer than expected. The available funds were less than 50% of the estimated budget. This challenged transport, airtime and other unforeseen costs like paying for computers, transcribing and translation, IT support for participants. Finally; Participants had monetary expectations.

Introducing the theme

The discussion started with an introduction to the purpose and expectations of the focus group discussion. The facilitators went through the objectives of the discussion and the specific questions to guide the discussion and how the result of the Focus group discussion will feed into the UNAIDS Strategy development process.

Discussion Agenda

The Focus group discussion was guided by the following agenda

Draft Agenda: HIV in Humanitarian Settings Malawi Focus Group Discussion

Objective

The purpose of this focus group discussion is to draw out insights from Malawi community members that have lived experience of humanitarian settings and can speak to HIV issues within these settings. These insights will feed into the ongoing development of the new five-year UNAIDS Strategy, which will be finalized in March 2021.

Overall Structure

1. The focus group discussion will run from 1 – 3 hours
2. All participants will be encouraged to provide their inputs as freely as possible
3. There will be no breakout groups in order to simplify the technology requirements for all participants
4. The focus group discussion will take place in local languages as much as possible to ensure that all participants are able to share their insights as richly as possible
5. The questions will be kept broad to illicit spontaneous and genuine responses, and facilitators may sometimes prompt participants to think about specific issues if they have not come up organically

Agenda

1. Introduction to the purpose and expectations of the focus group discussion (15 minutes)
    a. Introduce the UNAIDS Strategy development process and how this Focus Group Discussion fits into the broader picture
        i. UNAIDS Strategy development process
        ii. The topic of HIV in humanitarian settings in Malawi

iii. How the results of this Focus Group Discussion will feed into the UNAIDS Strategy development process?

b. Agree on technology etiquette during the meeting

i. All participants will ensure that they are fully attentive to the meeting throughout and not distracted by other work or activity around them

ii. All participants will mute their mics when they are not speaking

iii. Participants will raise their hands to make a contribution and facilitators will monitor to ensure that all raised hands are called on

iv. Participants will unmute their mics to make a contribution and will then unraise their hands and mute themselves again

2. Introduction to humanitarian settings in Malawi (25 minutes)

a. Overview of the kind of humanitarian settings that Malawi has experienced in the past few years (5 minutes)

b. **Question for participants: What kind of humanitarian settings have you experienced in the past five years?** (15 minutes)

c. **Question for participants: What kind of humanitarian settings are you concerned about for the future?**

3. What has worked well in terms of HIV in humanitarian settings? (30 – 45 minutes)

a. **Question for participants: What do you think worked well in the response to the humanitarian settings you experienced in terms of HIV issues? (15 minutes)**

i. Facilitators to prompt participants to bring up the following issues if participants haven't brought them up: access to testing and treatment, access to prevention services such as condoms, promotion of health seeking behaviour, prevention and services for GBV, psycho-social support

b. **Question for participants: What organizations or actors did you see responding well to HIV issues during humanitarian settings? (15 minutes)**

c. **Question for participants: Who were the groups of people that were particularly well reached on HIV issues during the humanitarian settings? (15 minutes)**

i. Facilitators to prompt participants to bring up the following issues if participants haven't brought them up: Women, men, young women, young men, children, sex workers, gay men and other men who have sex with men

4. What have been the most important challenges or failings in HIV issues in humanitarian settings? (30 – 45 minutes)

    a. **Question for participants: What do you think has not worked well in the response to the humanitarian settings you experienced in terms of HIV issues? (15 minutes)**

        i. Facilitators to prompt participants to bring up the following issues if participants haven't brought them up: access to testing and treatment, access to prevention services such as condoms, promotion of health seeking behaviour, prevention and services for GBV, psycho-social support

    b. **Question for participants: What organizations or actors do you think did not respond well to HIV issues during humanitarian settings? (15 minutes)**

    c. **Question for participants: Who were the groups of people that were not well reached on HIV issues during the humanitarian settings?**

        i. Facilitators to prompt participants to bring up the following issues if participants haven't brought them up: Women, men, young women, young men, children, sex workers, LGBTI, men who have sex with men

5. How can HIV issues be better addressed in the future in humanitarian settings?

    a. **Question for participants: What can you recommend for a better response to HIV issues in humanitarian settings in the future? (15 minutes)**

    b. **Question for participants: Do you have any recommendations for specific organizations or actors? (15 minutes)**

    c. **Question for participants: What are you recommendations for better reaching those whose needs have not been met well in the past? (15 minutes)**

        i. Facilitators to prompt participants to bring up the following issues if participants haven't brought them up: Women, men, young women, young men, children, sex workers, LGBTI, men who have sex with men

6. Prompting any final thoughts on the topic – asking for quick answers (5 -10 minutes)

    a) Questions for participants

CONTINUE: What is working that we must continue to do?
STOP: What must we stop doing, if not stopped will ensure failure
START: What are we not doing that we must start doing?

7. Wrap up and thank you to all participants (2 – 5 minutes)

Discussion

HUMANITARIAN SETTINGS IN MALAWI	
What kind of humanitarian settings have you experienced in the past five years?	• The following are the most common types of humanitarian settings experienced across the country; a. Floods resulting in people being displaced from their homes, destruction or loss of property, crops being washed away, drugs and health passports lost. b. Heavy rains mostly damaging houses and roads making it difficult for community members to access health and other social services c. Drought leading to food insecurity d. Participants also considered COVID 19 as an emergency which has negatively impacted the lives of many people across the country. How this affect people Living with HIV • Flooding was reported as the most common natural disaster which mainly affects those residing in riverbanks and lower and flat settings increasing the demand for sanitation and health supplies. When flooding occurs, district health workers are pushed to higher ground leaving a few health workers under severe pressure to serve the growing need for health services sometimes leading to closure of health facilities. For PLHIV this may mean facing a disruption in access to HIV treatment and care services which puts them at an increased risk of drug resistance and disease progression. • Heavy rains are another form of natural disaster which negatively impacts access to HIV services for PLHIV. Heavy rains usually damage houses and roads rendering them impassable and making it difficult for PLHIV to access treatment and care services from health facilities. • A healthy and balanced nutrition is important for people living with HIV. It helps to maintain a healthy and quality life for PLHIV as well as help boost their immune system. Drought is another common type of natural disaster experienced across the country which mostly leaves PLHIV with little or no food

	for their households, making their nutritional status compromised and their bodies susceptible to other opportunistic infections. Direct quotes from participants: "My house was damaged due to floods as such Iam living in borrowed house. Iam reproached because of my HIV positive status. Long distance affects me because I need more money for transport. I normally have to borrow or do piece work to get transport money and sometimes fail to repay. This hinders my ability to adhere as sometimes I can't afford to go to the health center." "Many people were affected by floods and heavy winds which blew off houses and crops in the fields were washed away. As such people had little or no food at all. This has contributed to high risk of malnutrition." "When the house falls down or the roof is blown off due to heavy rains of wind people relocate. This disturbs your psychological state causes you to lose drugs. It becomes difficult to access health services including treatment because health passports will have been destroyed or lost. So a person is subjected to risk of stopping taking treatment. And then there is the issue of long distances because the roads will have been destroyed and bridges washed away. This makes it difficult for people to travel to the health centre to access treatment. For the needy when a house falls or roof blown off; they are left wondering how they will get support to build another house or repair the destroyed one. They end up erecting non-permanent house which can further easily be destroyed by any heavy rain or wind. This is concerning because life becomes heavily disturbed as they live a life of many unmet needs."
What kind of humanitarian settings are you concerned about for the future?	Participants mentioned the following humanitarian settings they are concerned about in the future; • Heavy rains and flooding: for the past few years Government has been advising those residing in river banks and low land to move to uplands to mitigate the impact of flooding during the rainy season. Despite the advice from Government they have resisted and opted to stay. This is largely due to the fact that the majority of these people depend on gardening and irrigation farming as the means of earning a living. For them moving to upland would mean losing income. There is also a tendency to prioritize farming over health and hence

	even in times when health services are accessible, people would prefer to work in their gardens to earn a living. • Generally, participants were also concerned about the mismatch between their problem and the relief support they get during humanitarian situations. Often the relief support provided is not adequate and this puts a lot of economic pressure on PLHIV. Direct quotes from participants: "Mostly people in the area are affected by heavy flooding. These are people who live by the river banks and depend on gardening around these areas. So when heavy rains come they are negatively affected. But when they are advised to move to upland areas; they resist. They claim this is their ancestors place. These people also have a problem of not going to access treatment at the health center. They prioritize farming than health."
WHAT HAS WORKED WELL	
What do you think worked well in the response to the humanitarian settings you experienced in terms of HIV issues?	There are a number of things that have worked in ensuring uninterrupted access to HIV and other health services. When natural disasters occur, people are relocated to higher ground and accommodated in camps where they are able to access social services including sanitation and health supplies. Important to mention that the government has been one of the key and early responders during humanitarian situations and have been leading efforts to relocate those affected to higher and safe places. One of the key interventions by Government has been a swift shift in policy and guidance to provide 6 monthly ART refills to avoid treatment interruption. A number of NGOs have also supported those affected with food and sanitation supplies. Access to EID, Viral load and PMTC services has also remained a priority during humanitarian settings for both Government and other supporting Organisations. Previously increased sexual activity and GBV cases have been reported during humanitarian settings a situation which has prompted most organisations to include and prioritize access to HIV prevention and GBV services in their package of services provided in humanitarian settings. Overall, participants mentioned continuity of treatment as having worked very well during various humanitarian situations

	Direct quotes from participants: "It's true despite the humanitarian situations we have gone through services have not been disrupted. We used to take drugs once a week on Tuesdays but now we can go and receive them every working day. We no longer have long queues at the ART clinic. People raised fears that the COVID-19 pandemic will bring about scarcity of supplies which will make drugs not being available but there has been no disruption of treatment." "During our humanitarian situation, government responded by introducing a 6 months multi month scripting so we could receive treatment only twice per year. We felt relieved from going to the health centre frequently given the long distances that we used to travel. In the camps; there were also bad things like sexual violence."
What organizations or actors did you see responding well to HIV issues during humanitarian settings?	The following Organisations were mentioned as the key players and early responders; 1. The Government; the District social welfare 2. Red Cross 3. Care Malawi 4. WFP, 5. Traditional leaders 6. Ndi Moyo Palliative Care, 7. SSDI, 8. Baylor, 9. Ward Councilors, 10. Member of Parliamentary, 11. Peace Joy Foundation.
Who were the groups of people that were particularly well reached on HIV issues during the	The following Groups were adequately reached with relevant HIV services during humanitarian settings; a. Women living with HIV; especially those who are pregnant are always a priority b. Young people living with HIV c. Children living with HIV and the elderly

humanitarian settings?	
WHAT HAS NOT WORKED WELL	
What do you think has not worked well in the response to the humanitarian settings you experienced in terms of HIV issues?	A lack of sufficient resources: • Given the increase in GBV and sexual exploitation • Long registration processes to access humanitarian support, leaving people waiting for long period before accessing the needed support. • Lack of privacy especially in camps is also another challenge. When people are relocated to camps women and girls are put in the same tent with men with limited privacy. This puts them at an increased risk of being raped. • ART distribution and counselling is usually done in a very small space with no privacy, increasing stigma • Access to quality HIV services for Sex workers, key population and the youth is also hampered by lack of privacy and segregation to treatment access. • The support given to the affected does not normally have a sustainability approach or an element of developing self-reliance. Some direct quotes from participants: "Usually people experience a mis-match between their problem and the relief support they get during a humanitarian experience like when the roof has been blown off one is given buckets and blankets. Sometimes a whole camp for displaced people can be flooded with utensils when their actual need is food. Also given our medical conditions; the support we get in such situations is inadequate. In addition; because of a humanitarian situation like crops being washed away; people are forced to go for credits like for fertilizers. This puts a lot of economic pressure on people living with HIV." "COVID-19 came as an emergency and there has not been adequate PPEs. At the health centre its difficult to observe social distancing and so we feel our protection against Corona virus is limited. During the humanitarian crisis, its like starting all over in your life. Like health passport books and drugs are lost. So there is confusion and hopelessness for many. So even if security is there but others take advantage like girls who have reached reproductive age get into early marriages so they get support on their needs. This becomes a problem for life to normalize."

	"Most of the times the organizations were looking at the material side of support like food, clothes, kitchen utensils etc. But they did not touch on HIV and AIDS support services. There were very few organisations that were supporting HIV and AIDS but not those that have been mentioned. On the government side the disaster risk reduction management department which is responsible for coordinating all disaster responses has never looked into HIV and AIDS needs. They are more concerned with issues like shelter, beddings and food not HIV and AIDS."
What organizations or actors do you think did not respond well to HIV issues during humanitarian settings?	The following Organisations and institutions did not respond well; a. The district Assembly b. WFP; despite being one of the early responders, participants felt that the food supplies provided were not adequate and left many in dire need. c. The Government; the Department of the disaster risk reduction management department which is responsible for coordinating all disaster responses has never looked into HIV and AIDS needs d. Action Aid; being the principal recipient for Global Fund grant has a key role in ensuring that PLHIV regardless of their setting has access to HIV services. During the most recent natural disasters, Action Aid failed to reach those in need with the relevant HIV services needed. Direct quotes from participants: "Not many organisations come forth to assist but we have sometimes seen government rushing to collect database. But the needed support does not come forth to the people."
Who were the groups of people that were not well reached on HIV issues during the humanitarian settings?	The following groups were not adequately reached with HIV services in Humanitarian settings a. Female sex workers b. AGYW living with HIV c. Key Populations; MSM, transgender Direct quotes from participants "During a humanitarian situation people are just grouped together. There is no privacy when people are sent into camps during relocation. So women and girls are at the risk of being raped. Also the place for waiting to receive drugs is not spacious. Its difficult to receive condoms and drugs due to

	flooding of rivers. Sex workers, key population and the youth do not have a segregated treatment access. In this case their rights are not provided for."
HOW CAN WE DO BETTER IN FUTURE	
What can you recommend for a better response to HIV issues in humanitarian settings in the future?	For a comprehensive, well-coordinated and robust response during humanitarian settings the following need to happen; • It will be important to make sure that organisations providing relief support should reach the affected directly, not through village heads. Going through village heads breeds corruption and leave the intended beneficiaries with no access to the intended support. The support should target primarily those living with HIV because they are the most risk • Access to food for PLHIV should be a priority. Taking ARV on an empty stomach makes one dizzy and weak and may force people to stop taking their drugs resulting in higher default rate • In terms of channelling of support, funds and resource meant for supporting PLHIV in humanitarian setting should be channelled through NAC who will further channel the resources to organisations like NAPHAM which has database for people living with HIV in all the 28 districts. And at district level NAPHAM would be responsible for identifying those PLHIV in need of humanitarian support services. • There is also need to increase access to HIV prevention and GBV services • The humanitarian support being provided should build in an element of self-support and sustainability. Direct Quotes from Participants: "Government and NGOs must use existing structures like support groups when reaching out for humanitarian support for people living with HIV. This will help in giving the support to the appropriate people as often they use village heads which makes the support not to reach the right people. It is our wish that in future support groups are used to reach people living with HIV." "Government should always be engaging us in decision making and the planning process because these days they are not regarding us as we just hear things have happened. We need to be engaged so we take the message to the grassroots. Government needs adequate data for people living with

	HIV. This will help them to target support based on information from the data base."
Do you have any recommendations for specific organizations or actors?	• Government should assess NGOs to understand what kind of support they have managed to provide to people living with HIV in humanitarian settings. Government should even go further to verify with people living with HIV if they have indeed been assisted. This will help address the tendency among some NGOs who claim to have supported PLHIV when in actual fact they have not. • WFP has been doing a great in providing food supplies, however this is usually not enough to cater for all those who are affected. In future humanitarian settings they need to increase the amount of food supplies and priority should be given to PLHIV
What are your recommendations for better reaching those whose needs have not been met well in the past?	For population groups that have not been reached adequately during humanitarian situation the following should happen; • Government should have their information recorded well in advance so that when the support comes everyone affected is on the priority list and support provided to the affected on time. • In case of international support coming to Malawi, resources should be channeled through NAC which is better placed to channel the resources to organizations that have adequate information of the affected PLHIV groups. This can restore an efficient system for a targeted distribution of support. • The affected including key populations, sex workers and the youth should be given space to express their needs as opposed to being given what they don't need.

RECOMMENDATIONS FOR THE NEW UNAIDS STRATEGY

CONTINUE: What is working that we must continue to do?	The following should continue; • Advocacy and awareness campaigns on treatment adherence. • Civic education on humanitarian crisis in the affected districts. This will help people to know how to handle a humanitarian crisis. • Rolling out Community ART groups to ensure uninterrupted access to ART
STOP: What must we stop doing, if not stopped will ensure failure?	The following must stop; • Leaving PLIHV out of the planning conversations on how to handle access to services in humanitarian settings • The top down approach in humanitarian management. This is what has helped greatly to kill small grass root structures like support groups and CBOs.
START: What are we not doing that we must start doing?	We need to start doing the following: • UNAIDS and other organizations should start funding CBOs as it was before. Because in the past the money used to support various needs of many people living with HIV like messages, condoms in a short time. So now CBOs stopped functioning because Global Fund through NAC stopped funding CBOs. The money is going to big organizations like project hope, Dream and Christian aid. This has left small community structures dead. This should be included in the UNAIDS next strategy and plans • The roll out of youth friendly services and one stop centers should be done thoroughly across Malawi. Government should ensure these services are available in all districts not just being done by selected organisations.

Conclusion

Participants were appreciative of the opportunity to give their input to the UNAIDS strategy. They said they had learnt many things including use of internet for meetings. They asked for more opportunities to conduct such discussions.