









# **Puntland State of Somalia**

# **PLHIV Annual Forum Final Report**











# ANNUAL ADVOCACY FORUM FOR PLHIV LEADERS AND CWS IN PUNTLAND-SOMALIA

Implemented by: ISDP

Funded by: UNICEF

**Venue: at RAYAN PARK HOTEL** 

Location: Garowe Date: 25th, 26th - Nov-2023

**Period:** (25<sup>th</sup> – 26<sup>th</sup> **November 2022**)

**Garowe, Puntland, Somalia** 

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#### 1. Introduction

PLHIV Annual Forum is a meeting/platform to facilitate networking opportunities for PLHIV leaders (from Puntland), the leaders came together to discuss about building relationships among themselves and share knowledge/experiences and the roles they have within their society. With consideration given to, devoting more time to improving networking and discussion among themselves on key issues affecting their lives.

It is built upon a broader foundation that includes improving and maintaining the dignity of the individual living with HIV; supports and enhances the individual's physical, mental, emotional and sexual health; and, which, in turn, among other benefits, creates an enabling environment that will reduce the likelihood of stigma and discrimination and other violations against the PLHIV community.

It encompasses the full range of health, economic and social justice issues for people living with HIV, and espouses the fundamental principles that responsibility for HIV prevention should be shared and that policies and programmes for people living with HIV should be designed and implemented with the meaningful involvement of people living with HIV (GIPA Principles).

HIV-related stigma and discrimination are more increasingly recognised as a huge barrier to combating AIDS in sub-Saharan Africa and elsewhere. Stigma and discrimination are a health and human rights issue. They pose obstacles to achieving universal access to prevention, treatment, care and support. Stigma and discrimination are associated with lower uptake of preventive services, testing and counselling; reduced and delayed disclosure of HIV sero-status; and postponing or rejecting care, seeking healthcare services outside one's community for fear of breach of confidentiality.

International civil society and organisations such as the International Community of Women Living with HIV and AIDS (ICW), the International Planned Parenthood Federation (IPPF) and the Joint United Nations Programme on HIV/AIDS (UNICEF) have spearheaded global initiatives to measure stigma and discrimination. They support countries through means such as advocacy, strategic planning, capacity building, and resource mobilisation to address stigma and discrimination faced by people living with HIV (PLHIV).

The Greater Involvement of People Living with HIV/AIDS (GIPA) is a principle that was first advocated in 1983 by PLHIV in Denver, formalised at the 1994 Paris AIDS summit and endorsed in 2001 by the United Nations General Assembly. GIPA aims to realise the rights and responsibilities of people living with HIV and enhance the quality and effectiveness of the AIDS response. The rationale is that through the involvement of individuals and communities vulnerable to, and living with HIV, will improve the relevance, acceptability and effectiveness of programmes.

Hence the PLHIV annual Forum was designed and meant to empower PLHIV in Puntland to organize themselves and decide their own leadership once for all.









The forum was part of the new grant 2021—2023 for Somalia to empower PLHIV and review the enabling environment for PLHIV by supporting themselves in deciding their own leadership and taking point in all issues affecting the lives of those living with, affected by and most vulnerable to HIV in Puntland.

This is a final training report of three days training for **PLHIV leaders** from four districts of Puntland (North East Zone of Somalia) held at **Rayan Park Hotel, Conference Hall in Garowe, Puntland on 25<sup>th</sup> to 26<sup>th</sup>, November 2022.** The training was co- organized by ISDP and Puntland AIDS Commission in close cooperation of the KVP & PLHIV Technical Advisor for Somalia as one of the activities for the HIV/AIDS mitigation/reduction project aimed at key vulnerable populations and PLHIV funded by UNICEF (Global Fund) and implemented by ISDP. The participants were all members of the PLHIV community in Puntland and members of Daryeel Network for PLHIV in Puntland, as well as case managers and outreach workers implementing the Prevention and Care Programme.

The forum was facilitated by KVP & PLHIV Technical Advisor for Somalia as the lead facilitator.

#### 2. HIV Related Stigma in Somali context

People living with HIV or AIDS (PLHIV) in Puntland, Somalia experience considerable stigma and discrimination. From an extensive desk review and interviews carried out with HIV stakeholders (including with PLHIV and their Networks) by UNDP, evidently showed that these marginalized groups face major stigma and discrimination, which affect their human rights on a daily basis.

Globally, it is widely accepted that a protective legal and regulatory framework can help reduce stigma and discrimination associated with HIV, in order to promote effective national responses to HIV and AIDS. Punitive laws and practices deter those most at risk of HIV from seeking the essential HIV services they need.

In Puntland, and other parts of Somalia, the level of stigma is documented to be very high, and likely to prevent people living with HIV from coming out openly to seek health services. According to the MICS4 of 2011 in Somalia, only about 1 in 10 people expressed accepting attitude towards people living with HIV when asked a series of four questions on attitude towards people living with HIV. According to the PLHIV Stigma Index 2020, Stigma and discrimination, in Puntland, like in other settings, manifests itself in various forms at the individual, family and community levels. Many tags were used to describe HIV in a manner that is stigmatizing. Some of the tags included: the lion; the killer; Tiger; thinning disease; the bad one; the three word disease. According to the general population, these names were chosen because the HIV/ AIDS disease is the worst of all diseases and once you are infected, the ultimate end is death. PLHIV face stigma at different levels including:

**Self-Stigma among PLHIVs:** Many PLHIVs in Puntland suffer denial, not accepting their status and at individual level, many PLHIVs declined to disclose their status even to the closest family members,









friends and relatives. The PLHIV discussants in the PLHIV Stigma Index Survey 2017 indicated that they felt ashamed of themselves due to community perceptions about HIV and as a result, many of them kept off public/ social events. For fear of making their HIV status public, some senior government officers resorted to using anonymous sources to receive their medications while others opted to seek ART services from neighbouring countries. This was according to findings from the FGDs.

Locally, PLHIVs opted to seek services from distant ART Centers in order to avoid close relatives and friends. At the ART Centers, some PLHIVs registered with names different from their real names, so that they are not identified by those known to them. When visiting the ART Centers for services, the PLHIVs used face masks, so that they are not noticed by those who knew them.

At the family level: PLHIVs were disowned by family members including parents, siblings and children. Cases of divorce and separation were rampant not only among discordant couples but even among concordant couples, especially where blames were shifted to one of the spouses. From the survey, 42.7% of the PLHIVs had at least once been abandoned by their spouses and 56.0% isolated in their household. About 47.5 % of the PLHIVs had been once or more times abandoned by family or sent away from the village.

**Workplace related stigma and discrimination**: according to the survey Focus Group discussions, both in the general population and PLHIVs, there were cases of HIV stigma related job losses, both in the private and public sectors, including in some of the key government institutions. PLHIVs seeking employment were denied opportunities while PLHIVs in employment lost their jobs as a result of their HIV positive status.

At community level: the majority of Somali communities kept their children off PLHIVs and did not allow them to play with children from PLHIV households. In schools, parents withdrew their children from schools where the children interacted with children from PLHIV households. According to some 51.5% of surveyed PLHIVs, Some parents did not think it is safe to have their children play with HIV positive children in school. As in the case of rental houses in which the PLHIVs were denied opportunity to rent,

Stigma and discrimination at the health service delivery point: HIV stigma and discrimination at the health service delivery points was identified as an issue, through the FGDs with the PLHIVs and through interviews with Key informants. It also emerged from the KIIs with the health service providers and health planners. Persons who tested positive for HIV were discriminated and were either provided with sub optimal quality health services or in certain instances denied health services. Most cited cases revolved around delivery assistance for PLHIVs and surgical procedures. As a mandatory requirement, clients were subjected to HIV tests prior to surgical procedures. According to both the PLHIV discussants and interviews with other Officials, majority of private healthcare providers did not perform the surgical procedures when the clients tested positive. Some service providers failed to disclose HIV status to the clients once tested positive and did not provide the necessary referrals for comprehensive care and support services. The public sector was not spared, and pregnant women did not receive quality services when they tested positive for HIV. From the survey, 37.6 % of the PLHIVs had been given poor quality











health services, at least once, as a result of their HIV status, while 36.4 % had at least once been delayed to receive healthcare services or received inferior care.

According to the PLHIVs, the health providers did not maintain confidentiality of client information. In some instances, patients in inpatient facilities (wards) vacated the facilities after they received information that one or some of the clients sharing the facilities was HIV positive. Fear of confidentiality loss was one reason the communities did not seek HCT services from HCT centres in their neighbourhood.

Globally, it is widely accepted that a protective legal and regulatory framework can help reduce stigma and discrimination associated with HIV, in order to promote effective national responses to HIV and AIDS. Punitive laws and practices deter those most at risk of HIV from seeking the essential HIV services they need.

#### 3. Objectives of the Forum and Training

PLHIV are excluded from issues pertaining to decision making processes of HIV response, improving the lives of PLHIV in general and soliciting all forms of support for themselves. Therefore, People living with HIV need to connect and improve the relationship they have among themselves, with their communities, Government and donors.

Hence the main objective of holding PLHIV Annual Forum was to enhance their internal and external relationships, improve their decision making processes and discuss issues regarding their networks and their future as individuals and community.

Network specific issues to discuss included but not limited to:

- a. Determine the members' vision of the network moving forward,
- b. Identify potential leaders from the network to be capacitated,
- c. Determine the network leadership and Board of Directors

#### 4. Methodologies

The methodologies used during the training and forum included:

- 1. Plenary sessions
- 2. PPT presentations
- 3. Group Work (Discussions)
- 4. And brainstorming











#### 5. Key Activities (per sessions)

#### Day 1

#### **Opening Remarks**

The HIV Programme coordinator for ISDP, Mr. Mohamed Gurey, welcomed the participants and advised them to take advantage of the forum and its contents for their empowerment. He emphasized their commitment in reaching key milestones to change their lives and the lives of other people living with HIV in Puntland for the better. He further advised them to participate in the decision making processes regarding their lives and learn all the skills and knowledge represented in the training for further usage in their communities.

The next speaker at the opening was Mr. Ali Hassan from UNICEF, who indicated that group effort and commitment is required from them to change their lives for the better. He further informed the importance being united for their cause and the role of the forum in enhancing their objective, he further advised the participants to take advantage of the event.

Finally, Mr. Saadaq Hersi, from the Puntland AIDS Commission (PAC), declared that the forum is officially open and he further advised the participants to take advantage of this opportunity, by learning the skills and transforming the knowledge into practical application.

After the official opening, the participants and facilitator introduced themselves. Then the lead facilitator with the intent to ensure proper administration of the forum, the facilitator asked the participants to develop ground rules that will guide the behaviour of all participants during forum sessions/hours. Some of the norms set are listed below:

- Silencing/switching off mobile phones
- Equal and active participation by all
- Punctuality (on arrival and during breaks)
- Respects opinions of others
- Avoid side talk and unnecessary movement
- Raise a hand in the event of asking a question or making a point

#### Session 1 Benefits of PLHIV Annual Forum

After presenting the agenda and objectives of the forum, the facilitator started with: What are benefits of Annual Forum for PLHIV in Somalia?

The facilitators indicated that by holding the PLHIV Annual Forum, regional leaders of people living with HIV benefit by realising:

- That they are the decision makers in all avenues related to their lives.
- The PLHIV leaders can share problems and concerns in their respective regions and brainstorm lasting solutions.











- The PLHIV leaders will discuss among themselves the best approach to coping and dealing with the stigma and discrimination they face in their communities.
- The PLHIV leaders contribute guidance that is not theoretical, but practical, personal and relevant when it comes to proposing, soliciting and receiving social support for PLHIV
- In addition to that, the PLHIV leaders can discuss and agree on implementing advocacy initiatives
  for PLHIV members in their respective zones, and define mutual goals and create awareness about
  shared challenges, leading to supporting the development and enactment of policies that better
  serve people living with HIV (PLHIV).



#### Session 2: Topics for discussion

The following topics were decided for discussion including

- Establishing working relationships among PLHIV across the regions and zones,
- Discuss obstacles affecting PLHIV in their communities and possible scenarios to reduce or eliminate such barriers,
- Discuss policy issues including changes to mandate, constitution and bylaws of existing networks and leadership and the role that PLHIV can play in decision making processes,
- Discuss possibilities to seek support from all avenues, resource mobilization through both public and private sector, social protection issues, Education and health care, vocational skills

#### Session 3 Self Help Groups

The session started with the facilitators asking why do PLHIV need self- help and support? In response to that the following issues were presented

Groups of friends or colleagues often develop naturally – in the home or community. We are used to working or socializing in groups – in our family, at work or sports clubs, for example:.

- Groups can also be set up for people to share feelings, or organize activities, about particular subjects of concern to them.
- ➤ HIV and AIDS usually raise difficulty and personal issues such as health, relationships, financial security, death or feelings about sexuality. Other people's prejudices and discrimination and wider social and economic issues also cause many problems for people affected by HIV.











➤ Many people affected by HIV – both those of us with HIV and those of us who are family or carers – feel that support or self-help groups can reduce some of these pressures. Working together and sharing ideas and problems can help people in many emotional and practical ways.

#### How to form self help groups:

To form a support group, or self-help group, it is important to be clear about:

- why you want to get together. Some groups may be formed simply for members to have a place to talk to each other and share feelings and experiences.
- ➤ Other groups of people may join together to work towards a common goal or need, such as campaigning for improved medical care or providing information about HIV and safer sex.
- For Groups may work with or without a particular leader or organizer, but it usually helps if everyone is clear about how the group should work.

#### Benefits of Working as a group

Working as a group can:

- ➤ Help people feel that they are not isolated and alone with their problems
- Provide a way to meet people and make friends
- ➤ Help individuals to become more confident and powerful
- Provide a basis to organize activities led by the members
- ➤ Make links between people from different backgrounds and increase understanding and tolerance
- ➤ Help to share resources, ideas and information, for instance about the latest available treatments or local support services
- Make others in the community more aware of the situation facing people in the group by increasing the visibility of people living with HIV
- > Lead to change by creating a public or political voice.

#### Obstacles to forming groups for PLHIV

There may be problems in working as a group, as well as benefits:

- In some places it is not possible to be public about HIV status, which makes people reluctant to join a group in case other people find out
- Many groups fail because the biggest need of their members is money and other material and economic support a small self-help group is unlikely to be able to solve this problem
- > Group members often have different needs and expectations, which can lead to conflict and disappointment
- ➤ Often a few dynamic individuals set up the group and, when these people are no longer involved, the group can lose its way

Hence the day was wrapped up

#### Day 2

The day started with recap of previous day and the facilitators thanked the participants for keeping a sharp mind



#### Session 1: PLHIV Social and Economic Support

During the session social and economic support were deeply discussed as follow:

SOCIAL AND ECONOMIC SUPPORT FOR PLHIV require the following two steps

- > Employment And Economic Empowerment
- ➤ Monitoring And Responding To Human Rights Violations

Employment And Economic Empowerment can be achieved through:

- Can be achieved through:
- Access to full education, skills training and employment opportunities for PLHIV, in particular, YPLHIV
- Further education and retraining opportunities for PLHIV, in particular, YPLHIV
- Support of productive financial service linkages including, micro finance and cooperatives for women in particular

Monitoring And Responding To Human Rights Violations can be achieved through:

- Gathering evidence
- Putting into place systems to record, monitor and respond to cases of rights violations
- Putting into place and operationalizing systems of redress
- Training service providers
- Supporting networks of PLHIV to function and monitor.

#### Suggested steps include:

- Map current laws, policies and programmes Criminalization, punitive and restrictive laws
- Punitive law enforcement
- Protective Laws
- Map actions for reform and revision











- Map stakeholders and partners
- Gather and analyse evidence
- Identify challenges to and opportunities for positive change
- > Determine and/or mobilize the resources
- Advocate
- > Mobilize political and organizational leadership
- Adapt and reform current policies and laws
- Remove legal barriers
- Reach out to others who have been engaged in addressing human rights violations of PLHIV and share lessons learned
- > Address stigmatizing attitudes and discriminatory practices
- Document cases and the impact of human rights violations and respond to violations by taking actions
- > Review the organizational management
- Monitor progress and evaluate the success
- Partner with human rights and legal groups
- Advocate with the National Human Rights Institutions

#### **Session 2: PLHIV empowerment**

The next topic to discuss was PLHIV empowerment, which in short was presented as follows

As used here, the term 'empowerment' is an expanded and more inclusive approach to achieving the Greater Involvement of People living with HIV/AIDS (GIPA) principle, which has underpinned the response to HIV since the beginning of global efforts to respond to the epidemic].

Empowerment within the context of Positive living requires the meaningful involvement of people living with HIV – individually and as networks and organizations – and enabling people living with HIV to become leaders of change and the decision makers for their own lives.

To achieve such outcomes, and to ensure that PLHIV empowerment is addressed appropriately, concerted efforts and resources must be dedicated to support PLHIV and networks of PLHIV to be equal partners.

The meaningful participation of national networks of PLHIV in country-level AIDS commissions and country coordinating mechanisms (where available), for example, requires support to the network so that it may remain a strong, sustainable, accountable, representative and skilled organization.

Self-empowerment of PLHIV requires resources and programmes that reach PLHIV and do so through rights-based and people-centered approaches – allowing 'information' to be inculcated into 'knowledge' and positive change.

The topic included what steps to take to ensure PLHIV empowerment and to improve the level and quality of involvement of PLHIV; the facilitators listed the following follow-up steps

- ✓ Advocate
- ✓ Reach out to the local network of people living with HIV.
- ✓ Determine priority areas and programmes











- ✓ Mobilize political and organizational leadership
- ✓ Adapt current policies and guidelines
- √ Address stigmatizing attitudes
- ✓ Review organizational management
- ✓ Determine resources
- ✓ Monitor engagement and share good policy and practice



#### **Closing Remarks**

The HIV Program coordinator for ISDP Mr. Mohamed Gurey concluded the forum, with the help of Puntland AIDS Commission regional coordinator Mr. Saadaq Hersi and they both thanked the facilitators and participants

1. Obstacles

During the course of the annual forum, no obstacles were observed











## Annex I: Forum Agenda

Day 1

No	Time	Topic	Responsible person
1	8:00 – 8.30 am	Arrival and Introduction and opening	ISDP, MOH, PAC and UNICEF
2	8:30—8:45 am	PLHIV Annual Forum Objectives	Aidrus Barre
3	8:45 – 9.00 am	PLHIV Network update on PLHIV situation in Puntland regions	Daryeel Network
4	9:00-9 :15 am	Brief Description of PLHIV Network and how it works	Aidrus Barre
5	9:15-10:00 am	Social Protection programmes for PLHIV	Aidrus Barre
6	10:00- 10:30 am	Group Discussion: Policy issues (changes to mandate, constitution and bylaws of PLHIV networks) and PLHIV role in leadership and decision making processes (including extra roles within the network)	Facilitator/participants
7	10:30-10:45	Tea break	All
8	10: 45-11: 30 am	Working relationship among PLHIV and Policy Issues	Facilitator/participants
9	11.30 am - 12:30 pm	<u>Discussion: Effective Resource Mobilization</u> seeking support from all avenues including Government and private sector, social protection issues, Education and health care, vocational skills etc	Facilitator
10	12.30pm – 1.30pm	LUNCH	
11	1.30pm – 3.00pm:	Self help groups in detail	Facilitator
12	3.00 PM	Closure	All

### Day 2

No	Time	Topic	Responsible person
1	8:00 - 8.30	Arrival and Registration	
	am		ISDP



Sternas .		o Fight AIDS, Tuberculosis and Malaria
8:30—8:45	Recap of previous day	Facilitator
8:45 – 9.00	PLHIV Network Situation Analysis	
am		Daryeel/Facilitator
9:00-9 :15 am	On going social protection programmes and PLHIV beneficiaries	Aidrus Barre
9:15-10:00 am	Update on Outreach, case management and Drop in center	Aidrus Barre
	Update from ISDP on CCE Support groups	Aidrus Barre
10:00-		
10:30 am		
10:30-10:45	Tea break	All
am		
10: 45-11: 30 am	Discussion: Network Governance Issues	Facilitator/participants
11.30 am - 12:30 pm	Stigma and discrimination recording and reporting	Facilitator
12:30 pm	Stigma and discrimination recording and reporting <b>LUNCH</b>	Facilitator
12:30 pm 12.30pm –		Facilitator
12:30 pm		Facilitator
	am 8:45 – 9.00 am 9:00-9:15 am 9:15-10:00 am  10:00- 10:30 am 10:30-10:45 am 10: 45-11:	am  8:45 – 9.00 am  9:00-9:15 am  On going social protection programmes and PLHIV beneficiaries  9:15-10:00 am  Update on Outreach, case management and Drop in center  Update from ISDP on CCE Support groups  10:30-10:45 am  10: 45-11: Discussion: Network Governance Issues



**END**