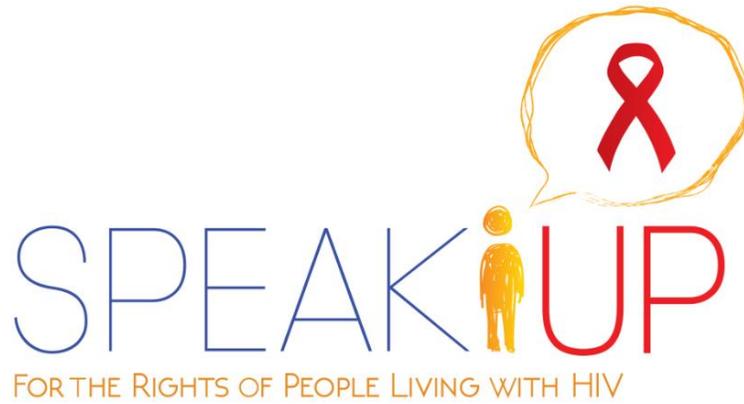


## **M-Coalition Report On “Speak Up” Initiative**

Documentation on HIV violations and Law Reform (Lebanon)



### **Summary of report:**

1. Summary of the project.
2. Events.
3. Role of Coalition
4. Outcome (laws- medical- media)
5. General recommendations.

## **1. Summary of the Project: “Speak Up”:**

This project mainly targeted the different parts of the lives of people living with HIV (PLHIV), from healthcare settings to their different rights, their family and friends, community, workplace and governmental settings.

People living with HIV have been experiencing violations to their basic human rights within diverse settings. So this project consisted on a monitoring system to convey the findings of a qualitative research study exploring the different types of violations and to disseminate the measures taken by a coalition of 15 NGOs (including M-Coalition) to address the reported violations. And finally highlighting some advocacy, legal and media strategies.

### **HEALTHCARE SETTINGS:**

- a. Violations in healthcare settings: by healthcare settings we mean private and public hospitals, private laboratories, pharmacies and private clinics. A study was generated from 50 PLHIV, who reported a wide range of stigmatized and discriminatory behaviors, which include breach of confidentiality, maltreatment, fear, neglect and sometimes denial of access to healthcare services. Participants reported that healthcare providers have breached the confidentiality of the patients by informing visitors, friends, family members and colleagues about patients’ HIV status without the latters’ consent. Sometimes family members would know about their relatives’ HIV status before patient does. In certain pharmacies, where participants conducted HIV rapid tests, pharmacists would inform the person in front of everyone.
- b. Patients started experiencing maltreatment from healthcare providers, sometimes pointing at their patients and whispering among each other and laughing.
- c. Healthcare providers were seen to fear from people living with HIV. Sometimes hospitals put a sheet summarizing the patient full name, disease and rom number placed at the nurses’ station in certain floors.
- d. Participants also reported that their surroundings knew about their HIV status upon meeting people they know in the national AIDS Program while they were waiting their turn in the room, and no separate appointments are taken to collect HIV medications from the ministry, so people would wait together in the same room.

- e. Other identified gaps is the way doctors and nurses convey critical information regarding patients' HIV status. Physicians were reported to strictly inform patients about their HIV status without providing any information about the disease or offering any type of support or referral.

#### FRIENDS AND FAMILY:

- a. People living with HIV face stigma and discrimination in their entourage by family members and by their friends. Misconceptions about the ways of which a person might be infected with HIV led family members and friends to isolation of PLHIV.
- b. Some families ask their infected sibling to leave the family place and village fear of discrimination towards them.
- c. Some families and friends tend to blame and label the PLHIV for being involved in risky and taboo behaviors. Such blaming and labeling was reported to leave great impact on the mental health and wellbeing of PLHIV.
- d. Many people suffer from double marginalization due to their HIV status and because they are part of other discriminated communities, for example LGBTQ, sex workers and drug users. This makes PLHIV more vulnerable.
- e. Participants reported being affected by scandals provoked by family members and friends. Invasion of privacy harms sometimes the access of jobs.

#### Community:

- a. Denying access to education has been witnessed in private universities and schools, who request HIV status prior to admission. Sometimes this deny goes to kids of PLHIV.
- b. Some people reported that their surroundings knew about their HIV status upon meeting people they know in non-governmental organizations and they were object of neglect, isolation and breach of confidentiality.
- c. Some people experienced threat and blackmailing on social media platform in exchange of money for their secrecy.
- d. Some lawyers would refuse to defend someone or take a case based on his HIV status.
- e. Sometimes a religious person would try to convince the PLHIV's fiancé out of marriage due to his HI status. Individuals reported that religious leaders are not being supportive in general.

### Workplace:

- a. Many individuals experienced arbitrary expulsion from work, usually in the private sector. And because firing someone because of his HIV status or without notice or compensation, the management would force PLHIV to resign for personal reasons.
- b. The invasion of employees' privacy at the workplace has been stated by participants, which would leave a negative impact on the person living with HIV.
- c. Among the major concerns of PLHIV was reported to be their inability to access this breach of basic human rights "work".

### State- Internal Security Forces:

- a. Some cases reported that her rights were violated within a police station. When the security forces knew about her HIV status and mentioned this info in front of all prisoners. The PLHIV lost his job and friends and now has to immigrate.

### Negative consequences:

These violations against PLHIV had major consequences on their lives. Many lost their jobs or remain unemployed due to HIV testing as a condition for employment. Also their inability to access insurance, healthcare services and education and their social life. Which include that many PLHIV do not have a profession and not covered by NSSF. Moreover, private insurance companies are costly and do not provide insurance for PLHIV. Which put PLHIV in a vicious circle which affects their overall wellbeing. In fact, the isolation they face from their families, friends and community, their inability to be productive members within society and their constant fear of being discovered brings distress to their daily lives. Alongside, their mistrust within the system to file any complaints.

## **2. Events:**

- a. Many meetings were held between "speak up" coalition as preparatory work towards an advocacy strategy. Which included 16 organizations: M-coalition, Lebanese Association for Family Health (LAFH), Marsa – sexual health center, Arab foundation for Freedom and Equality (AFE), Mosaic, Skoun – Lebanese

addictions center, LebMASH, Lebanese AIDS Society (LAS), Civil Council Against Addiction (CCAA), Islamic Health Society (IHS), Oui Pour la Vie (OPV), Dar El Amal, Jeunesse contre la Drogue (JCD), Association of Justice and Mercy (AJEM). This preparatory meetings addressed with the coalition members were about consultation and brainstorming. Many discussions took place before final decisions saw the light. Different kinds of issues and difficulties were faced before we emerged with the identification of 3 areas of interest we should face and work on:

- Remove HIV testing from pre-employment requirements.
  - Address unethical medical practices.
  - Remove HIV from insurance companies' exclusion criteria.
- b. In the process of cooking the advocacy strategy, other kinds of meetings were held with relevant stakeholders and decision makers in Lebanon. Reciting meetings with the MP. Dr. Atef Majdalani; Dr. Nakib (the manager of the National AIDS Program), Dr. Awar (ministry of Labor); and Dr. Jacques Mokhbat, who informed us that it takes a lot of time intervening at the level of insurance companies to remove HIV from their exclusion criteria, and we must have leverage on them first. Also he explained that the awareness raising is key to the removal of HIV testing from pre-employment requirements.
- c. All these meetings with coalition members and stakeholders and events and research led to a preparatory work which helped the formulation of the advocacy and legal media strategies, which are:
1. Identifying violation pattern from the data collected.
    - a. Unethical medical practices:
      - i. Breach of patient confidentiality.
      - ii. Branding of medical files.
      - iii. Deny access to healthcare services.
      - iv. Stigma and discrimination.
    - b. Arbitrary expulsion from work.
    - c. Denying access to work.
    - d. Threats and intimidation.
    - e. Denying access to private insurance.
  2. Identifying 3 areas of interest with coalition members:
    - a. Remove HIV testing from pre-employment conditions.
    - b. Address unethical medical practices.

- c. Remove HIV from insurance companies' exclusion criteria.
- 3. Conducting a swot analysis on the 3 identified areas of interest, which results revealed:
  - a. Targeting unethical medical practices have the highest chance of succeeding at this moment.
    - i. Meetings with important stakeholders shall confirm the SWOT results.

#### **4. Outcome:**

We proposed a strategy for work on advocacy to be effective in the face of all the data collected concerning these violations. This strategy is divided in two main points, the case itself and legal work.

##### a. The case:

To regulate and sanction breach of confidentiality and unethical practices at health premises with following determining factors:

1. The readiness and willingness of the public opinion and its gate keepers; the parliament status; and the current balance of power.
2. Since because of the political deadlock situation it's hard to work on legislations, we decided to work at the level of ministerial and administrative decisions.
3. To feed and mainstream into an ongoing effort that needs no further legislative actions. Mainstreaming the cause of confidentiality and make the public opinion more prone to support and less defensive.
4. Include HIV related issues in the general public priorities.
5. To go for either a legal approach or for a low profile and discrete decision makers lobbying.
6. Include other non-governmental organizations with different work scope than HIV related issues, in order to stress on the fact that the advocacy strategy benefits not only PLHIV but the general public as well.

- This advocacy goal is to embed within the healthcare system policies to protect the patient's confidentiality and to protect him from stigma and discrimination.
- The objective of this advocacy is to include within the standards of the accreditation system a section about patients' confidentiality or medical ethics.
- The approach of this advocacy campaign is to go for a low profile lobbying with the system decision makers and takers, and toward a conservative and cautious public opinion and community mobilization discourse. Also a legal work supporting the case producing legal memos and procedures to be incorporated within the system, order of physicians, order of nurses and MoPH laboratory department.

b. Legal work:

We issued a draft legal strategy targeting all violation patterns called the rights and obligations of the people living with HIV. Below we will site the initial proposal for the advocacy strategy from the legal side of view:

- I. The types of advocacy from the legal side: we can site these different levels.
  1. Sensitization and awareness.
    - a. Reviewing the rights and principles in the laws:
      - The right to health and therapy; The right to an informed consent; - The patient's right to the task of issuing the medical file; The right to privacy and confidentiality; The right of equality and protection against discrimination; The right to work; The right to physical and psychological integrity; The right to personal freedom; The right to proprietorship; The right to education; The right to defense and fair trial; The right to marriage and Family; The right to participate in social and political and cultural life; the right to housing; the right not to exploitation and abuse; the right to equality; principal of non-arbitrariness using the right; principal of refraining from arbitrary detention; the principal of criminalization of torture and cruel treatment; principal of criminalization of threats, intimidation and extortion; principal of

criminalize miscarriage of justice; the principal of the prohibition of murder and abuse.

b. precision of the administrative and individual practices violating these principles:

- the refuse of the hospitals and private clinics to receive PLHIV; the non-respect of the patient's privacy; discrimination; threatening; refuse of job applications; work expulsion; non-payment of dues and compensations.

## 2. Strategic Litigation:

Strategic litigation is the access to justice to activate the law or to dedicate a right especially when the legislative power is absent. It's important to create a legal team capable of cooperation and preparation of legal files, and to study the risks and damages that might result from strategic litigation on the person or the group.

## II. Methodology:

The legal approach depends on this methodology:

1. Finalizing the legal research: that requires a survey on all the legislative texts (laws; decrees; decisions) also all the binding international charters and conventions in every desired country.
2. Completion of field research: which requires the compilation and labeling of all complaints and violations.

We suggest to label the complaints per this order:

- International human rights violations: from the state and its institutions and individuals.

Human rights: the existence of laws that violates the international charts.

The non-protection of human rights.

Not to strengthen and promote human rights.

- Human rights violations: public or private institutions; or violations of rights.

We suggest to classify the complaints per these standards:

- Gender.

- Professional status.
- Economic and social status.
- Education level.
- Age; etc...

5. General recommendations:

- a. General recommendations on the sensitization and awareness level:
  - Organizing activities like group discussion sessions and conferences.
  - Organizing meetings with deputies.
  - Communication with Media and informing them about all issues on the table, plus creating a network communication.
  - Publishing researches.
- b. Recommendations on the ministerial and public administration level:
  - Depending on each country we are working in, these recommendations may include creating mechanisms to take advantage of universal health coverage; pushing hospitals to receive PLHIV; ensure the right of PLHIV to have access to medications and health services...
- c. Strategic litigation level:
  - Strengthen modern and developed jurisprudences about the right of PLHIV.
  - Working on advocacy and supporting the public opinion.
  - Attracting media for the cause...
- d. Legislative reform.
- e. Other general recommendations:
  - HIV is not considered an occupational disease and testing for HIV before accepting someone to work should be banned.
  - The privacy of the patients should be sacred by law.
- f. Media strategy:
  - The media strategy is one of the tools to reach our advocacy campaign tool. Using media is our way to tackle the mentioned violations which are breaching confidentiality, stigma and discrimination in health premises. This strategy campaign will focus on social media tools to raise awareness and to reach our objectives in 3 areas of interest (work setting; healthcare setting and insurance company). Which led to determine the focus of this year's advocacy and media strategy.

- The media campaign shall be communicated with the national AIDS program since we are all working on the same points of interests.
- The targeted audience mentioned below is part of the wide audience behind TV, Social media, radio and website, therefore we can customize messages for these categories:



#### Implications on future interventions:

- Awareness raising among families; employers; religious leaders; media personnel; healthcare providers and others.
- Within advocacy pan, the next steps would be:
  - Collet further violations data;
  - Target insurance companies;
  - Reinitiate the work on the pre-employment tests required;
  - Evaluate the HIV draft law according to this project's outputs.
  - Follow-up on this year's measures taken.