

DISCRIMINATION ON HIV: AN EPIDEMIC



**Series of Monitoring and Documentation
on Human Rights Violations in Indonesia**



PERKUMPULAN
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INTRODUCTION

HIV/AIDS prevalence in Indonesia is the highest in Southeast Asia region. From 2005 to 2015 the cumulative numbers of HIV cases are 191.073 and 77.121 of AIDS cases.ⁱ Over the last ten years, various prevention efforts have been made by the government, ranging from harm reduction program in 2006, prevention of transmission to sexual transmission, prevention of mother to child transmission (PMTCT), to Strategic Use of ARV (SUFA) in 2013. However, these programs still cannot solve HIV/AIDS problems in Indonesia.

One of the causes that has made HIV/AIDS prevention program ineffective is the highly frequent stigma and discrimination against people living with HIV/AIDS (PLHIV) and populations with a high risk of HIV/AIDS (commonly known as the 'key population'). The Executive Director of UNAIDS stated that stigma is the biggest challenge inhibiting prevention program at community, national, and global level.ⁱⁱ The assumption that risk behavior is something that violates local norms and values has become the basis for erroneous view on HIV/AIDS. In Indonesia, key populations with a high risk of HIV/AIDS infection are injecting drug users, men who have sex with men, and risky sex behavior. Most of the societies still have a misperception of the key populations as people with immoral behavior. Marginalization of PLHIV and key populations seem to be considered legitimate as social punishment.

As an institution that focuses on the fulfillment of human rights for the community, including PLHIV and key populations, we consider it necessary to monitor the stigma and discrimination against PLHIV and key population. We conduct monitoring and documentation through online media related to news that contains elements of stigma and discriminatory acts against PLHIV and key populations throughout 2016. Hopefully, our monitoring can help map the current situation on stigma and discrimination issues surrounding HIV/AIDS in Indonesia.

MONITORING AND DOCUMENTATION METHODS

Data collection was generated through media monitoring techniques. The purpose of media monitoring is to learn about the information, control and forecast changes on specific issues.ⁱⁱⁱ Media content related to HIV/AIDS issues containing stigma and discrimination against of PLHIV and key populations was read, recorded, and then documented. The data was collected and analyzed to see patterns and trends that were formed, such as forms of stigma, forms of discrimination, environment of stigma/discrimination, and human rights violations against HIV/AIDS-positive women and children. The analysis in this report can be studied and developed into other advocacy products

Data collection was conducted periodically every week, from January to December 2016. We monitored mainstream online media for its promptness, practicality, and flexibility. Accessed media included local and national media with the following list:

Table 1. List of Online Media

No.	Media Name	Total	No.	Media Name	Total
1	Republika	8	26	Merdeka	1
2	Tribun News	8	27	Lampung Post	1
3	Okezone	7	28	Rima News	1
4	BeritaSatu	6	29	Hallo Riau	1
5	MetroTV News	4	30	Radar Kaltim	1
6	Sindo News	4	31	Tribun Batam	1
7	Liputan 6	3	32	Siaga Indonesia	1
8	Antara News	3	33	Pos Kota	1
9	Kompas	3	34	Radar Pekalongan	1
10	Pikiran Rakyat	3	35	Prokal	1
11	Go Riau	3	36	Suara Jatim Post	1
12	Pro Kaltim	3	37	Harian Riau	1
13	Tempo.co	2	38	Suara Merdeka	1
14	Viva News	2	39	Rakyat Sulsel	1

15	Pontianak Post	2	40	Harian Terbit	1
16	Radar Kalimantan Utara	2	41	Harapan Rakyat	1
17	Pojok Jabar	2	42	Metropolitan	1
18	Tribun Manado	2	43	Pedoman Makassar	1
19	Solopos	2	44	Berita Sumut	1
20	Medan Satu	2	45	Koran Kaltim	1
21	JPNN	2	46	Sorot Gunung Kidul	1
22	CNN Indonesia	1	47	Radar Cirebon	1
23	Potret News	1	48	Berita Jatim	1
24	Sriwijaya Post	1	49	Radar Kaltara	1
25	Klik Samarinda	1	50	Indopos	1
Total = 102					

Table 1. List of Online Media.

In order to filter the information which was relevant to the topics, the right keywords were required.^{iv} We entered keywords such as 'HIV/AIDS', 'HIV/AIDS patients', 'Voluntary Counseling and Testing (VCT)', 'ARV (antiretroviral) problems', 'mandatory VCT', and 'rejection of PLHIV'. We considered these keywords as representative and relevant to news on HIV/AIDS that we were targeting. The use of these keywords was also part of the early process of selecting data.

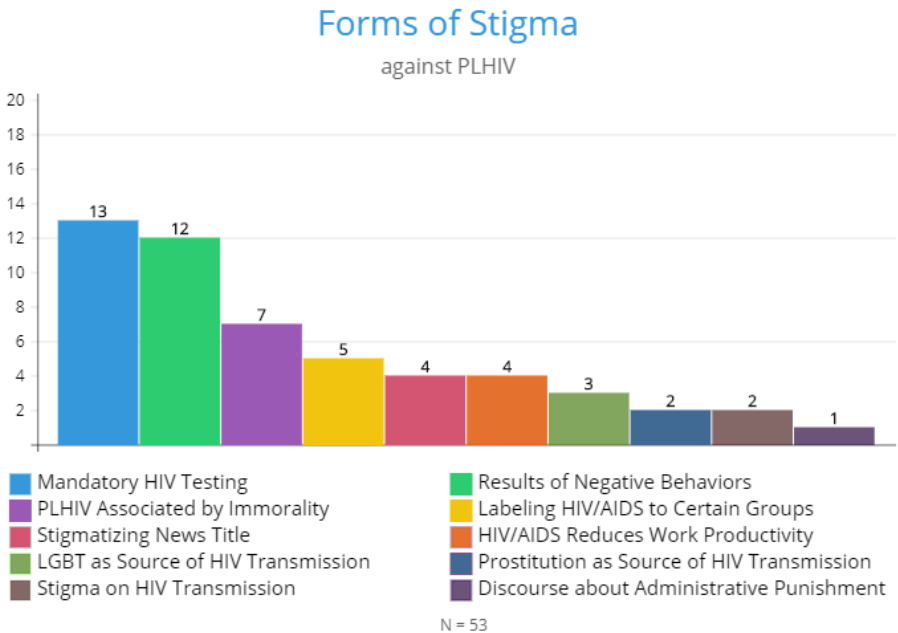
We realized that not all of cases of stigma and discrimination against PLHIV were covered by the media. Due to time constraints, we restricted monitoring to only online media, and it was also possible to capture news in the print media. Another weakness in this media monitoring was the incomplete details of online media coverage. Furthermore, the subjectivity of narrative interpretation on stigma and discrimination was also a constraint in the process of documenting the data. This media monitoring did not take into account data accuracy based on the credibility of the monitored media.

After we collected the news, then we summarized its contents into variables determined by the data collector team. Overall, the components that we set were sufficient to document the news. Through these components, we processed the data and analyzed the pattern.

DATA RESULT AND ANALYSIS

Stigma and discrimination seem to be the social punishment for PLHIV that can occur in various forms, such as rejection and alienation of PLHIV. Stigma and discrimination are often referred to as a unity. Stigma received by PLHIV often is followed by discriminatory treatment. However, the principles of stigma and discrimination are two separate and distinct things. The definition of stigma, in general, is a negative feature that is attached to a person because of the influence of the environment.^v Whereas discrimination is defined as the differentiation of treatment based on skin color, group, tribe, economy, religion and so on, which has an impact on the fulfillment of human rights.^{vi} Therefore, in this chapter, we will explain forms of stigma and discrimination separately.

Stigma against PLHIV



There are 102 news articles that we documented. A total of 53 news articles are included into the category stigma on PLHIV. As can be seen in the table, we categorize the news into 10 different categories according to the similarity of issues and criteria. The most common form of stigma that we found was mandatory VCT, consisting of as many as 13 articles. It consists of mandatory screening for pregnant women, mandatory VCT in companies, once-a-month mandatory VCT for civil servants, and mandatory VCT for people with risky behavior.

Mandatory VCT is a violation of human rights. HIV testing should be voluntary, not mandatory. It is part of the people's right to decide what is good for themselves and their health. World Health Organization (WHO) has stated their objection to mandatory VCT policies in many places.^{vii} Mandatory VCT does not only lack justification, but also potentially undermines the effectiveness of HIV prevention programs.

The fault of the paradigm on HIV/AIDS as a result of negative behavior was ranked as second most frequent news, ie. 12 news articles. Based on our collected news, HIV/AIDS is often identified with what most people considered as immoral behavior, such as free sex, drugs use, and homosexuality. Since stigma is easily generalized by many people the stigma on PLHIV as immoral people is easily accepted by the public.

Many of the news articles that associate PLHIV with immorality suggest low public and media understanding of risk behaviors of HIV/AIDS. Lack of understanding the information in society has led to an increase in stigma and discrimination against PLHIV. Risky behaviors are behaviors that carry a high risk of HIV infection to someone.^{viii} These risky behaviors include alternate use of non-sterile syringes, unsafe sexual intercourse, receiving blood transfusions contaminated with HIV virus, and mother-to-child transmission. Using unsterile syringes, for example, does not only refer to the context of drugs use, but also in the process of making tattoos, or other activities involving non-sterile syringes. Likewise, both people with heterosexual and homosexual orientation are susceptible to unsafe sexual intercourse.

Another type of stigma that sprung up on the news that we documented was the labeling of HIV/AIDS carrier to certain groups. There are five news articles with this content. Populations who are considered as carriers of HIV/AIDS include foreign tourists, Indonesian migrant workers, and housewives. Foreign tourists are considered to have the potential to transmit HIV/AIDS to people in

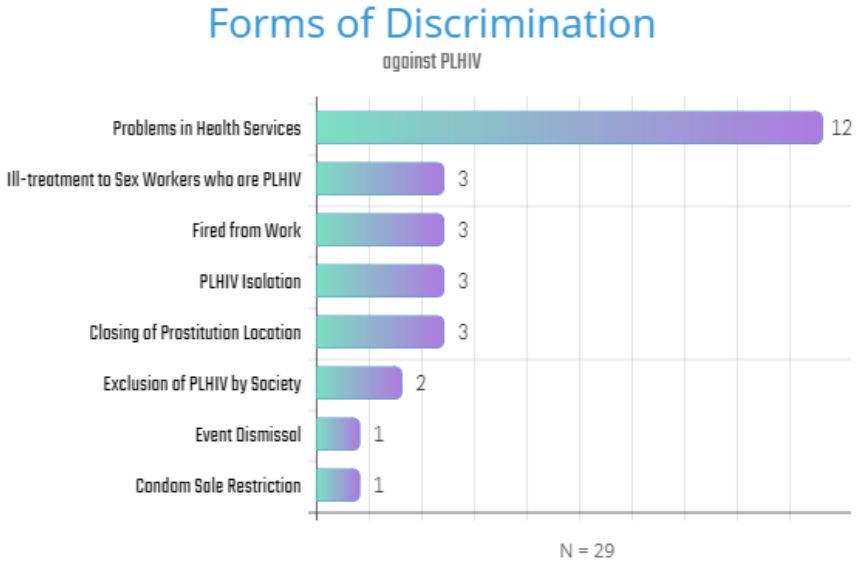
Indonesia due to a misunderstanding about free sex behavior alleged to them. The same allegation is also made against Indonesian migrant workers and woman migrant caregivers returning to Indonesia, who are also considered as bringing back the dangerous virus home. Women are regarded as the most vulnerable populations to transmit HIV/AIDS as it can also be threatening the housewives population. In many cases, housewives are infected from their husbands who live with risky behavior.

None of these views are based on scientific evidence, and will potentially lead to discriminatory practices against these populations. As we have mentioned, HIV/AIDS can only be transmitted through certain ways. HIV infection does not discriminate.

High coverage of news with stigma element is caused by the role of the media. In delivering the news, many of the media used a title that stigmatizes PLHIV and key population. We regard it indirectly contributing to the stigma of PLHIV. Insensitivity to HIV/AIDS issues is another factor that has caused a large number of stigmatized news articles in the media. This reflects the need to increase the journalists' understanding of HIV/AIDS.

Furthermore, there are other forms of the stigma that can be seen in the following table, which are not as many as the previous issues. However, that news also largely contributes to increasing stigma against PLHIV. This leads to their unwillingness to be seen as part of PLHIV and key population. Due to this unwillingness they choose to neither reveal their HIV status, nor access the treatment. This only makes HIV prevention in Indonesia more difficult. Therefore, positive discourses supporting PLHIV and key population must be developed to make them willing to reveal their HIV status and access the treatment.

Discrimination against PLHIV



From the 102 news articles that we documented, 29 consist of discrimination elements. Then, we categorized them into 8 forms of discrimination against PLHIV, based on similarity of raised issues.

The picture above shows that the most frequent form of discrimination is in the fulfillment of the right to health that is accessing health services. A total of 12 news articles that we have raised are problems of PLHIV access to health services. Some of the news articles are related to:

- Rejection and return of PLHIV patients by hospitals including children with HIV/AIDS.
- Rejection of PLHIV patients claiming health insurance.
- The difficulty in accessing health services due to cost problem.
- Surgery rejection of PLHIV who will give birth.

In relation to the problems in accessing services, health providers usually argue that they have no specific surgical tools for PLHIV.^{ix} However, if we look at the facts that HIV/AIDS is part of a national program, where first class healthcare facilities have been encouraged to be able to provide HIV treatment, this claim is questionable. Even if such resources are not available,

the health-care providers must use referral mechanisms to fulfill the patients' rights. Thus, if health care workers refuse to provide health services or refer the HIV/AIDS patients to health facilities with better services available, it can be said that health workers have been discriminating PLHIV.

Other forms of discrimination that we documented are the closing of prostitution locations and the criminalization of sex workers. The closing is based on an assumption of HIV/AIDS transmission through prostitution. In some parties' opinion the closing of the prostitution "localization" and punishing the sex workers will make it stop, and will eventually stop the spread of HIV/AIDS. However, the impact of closing the localization is an obstruction in the HIV/AIDS prevention programs. Sex workers who initially accessed ARV services are now difficult to reach because they have moved to more remote places. As a result, the spread of HIV/AIDS gets wider because it is no longer controlled. In addition, the closing of localization violates a person's right to privacy. Every person has the right to freely determine what to do with his or her body. The closing of localization has made it difficult for sex workers to do their work and as a result they become more vulnerable to violence. Thus, it will increase stigma, discrimination, and vulnerability to HIV.^x

With regard to issues of employment, a form of discrimination that has happened is termination of employment due to HIV/AIDS status. In three articles of news that we encountered, termination of employment due to PLHIV occurred in government agencies such as civil servants and members of the Indonesian National Armed Forces. Employees in government agencies are required to be free of HIV/AIDS because they do not provide a good example of being a public servant, so HIV/AIDS testing is conducted to know their status. If the results are positive, some action will be taken to such employees.

In this case, there are two types of discrimination. First, mandatory HIV testing for employees that violates the right to privacy and the right to control over their bodies. Second, termination of employment on PLHIV is a violation of the right to work and the right to non-discriminatory treatment. Moreover, mandatory testing and laying-off employees due to HIV/AIDS status also violate the Ministry of Manpower and Transmigration Decree No. 68/MEN/IV/2004 concerning Prevention of HIV/AIDS in the Workplace.

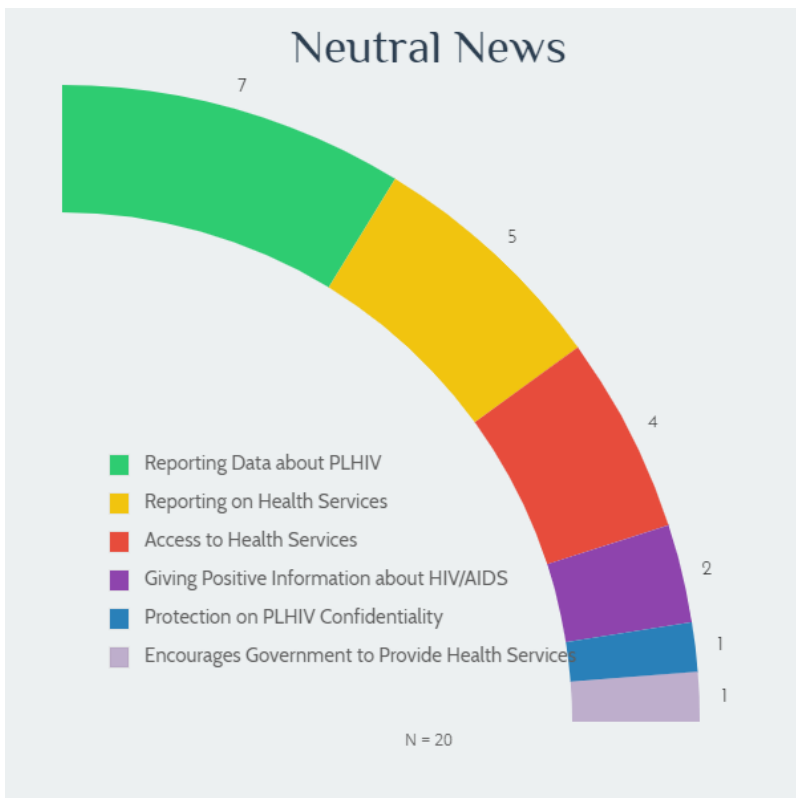
Discriminatory actions often experienced by PLHIV being shunned by people around him and being refused when accessing health services. Healthcare workers often place PLHIV in special rooms in order to prevent PLHIV patients

from transmitting the disease to other patients. This happens even though there is no risk factor for HIV/AIDS transmission, for example, with PLHIV who are being treated for fever. This isolation also occurs in the detention centers and correctional facilities, where detainees or prisoners who are known to be HIV/AIDS positive will be placed in special cells in order not to infect others.

There was actually no reason for the isolation because there was no risk of transmission. For example, there is no need to place PLHIV who are treated for fever in a special room. Even if they are placed in a the same room as the HIV/AIDS negative patients, HIV/AIDS transmission still will not happen when risk factors for transmission do not exist. Risk factors for this transmission include alternate use of non-sterile syringe, transmission from mother to child, and unsafe sexual intercourse.

Neutral News

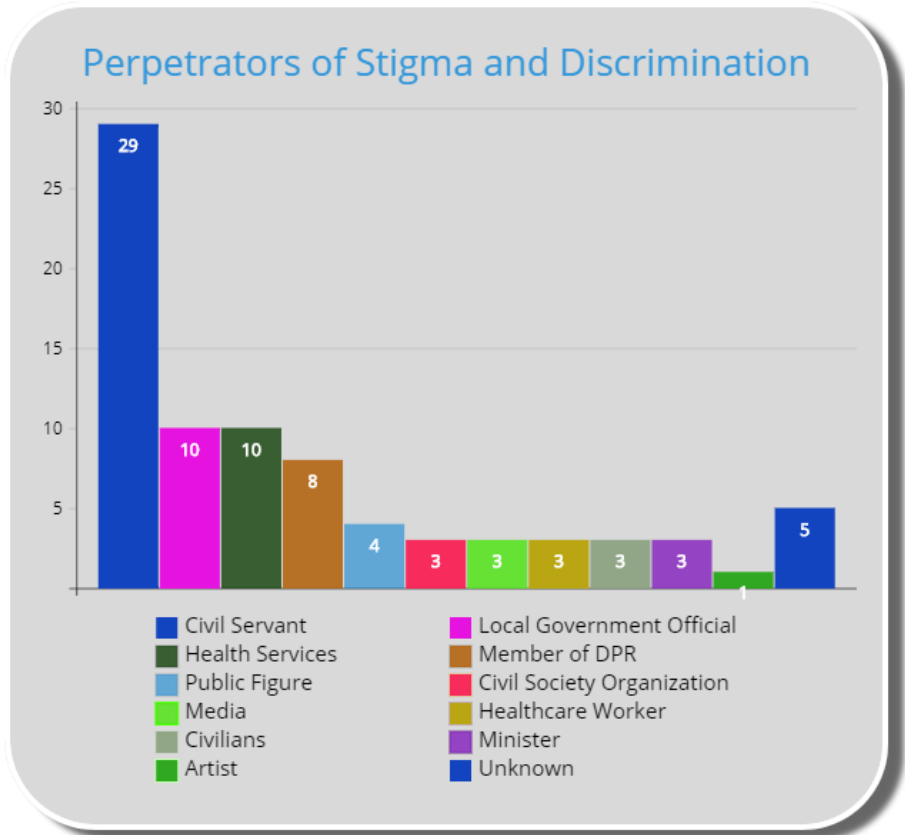
Based on the data finding, we realize there are forms of some actions that cannot be classified as stigma or discrimination. This group of news article does not explicitly contain stigma and discrimination to PLHIV, instead it only contains facts related to HIV/AIDS issues, or it can be categorized as neutral news. Our documentation found as many as 20 of the 102 news articles that contain neutral news.



The diagram illustrates that the most frequent form is the exposure of data about PLHIV, consisting as many as 7 news articles. The mapping aims at finding out the number of PLHIV in the area in order to decide the most appropriate HIV/AIDS program to be conducted. By data mapping, hopefully, the government can close the gap between health care facilities and the number of patients to fulfill all the needs of PLHIV and facilitate them to reach the service.

Furthermore, this neutral news, or even news that is positive, is important to raise, because neutral and positive news can balance the negative ones, so assumptions about HIV/AIDS are not all negative. It is hoped that more neutral and positive news can help to decrease stigma and discrimination against PLHIV as well as key population.

Perpetrators of Stigma and Discrimination



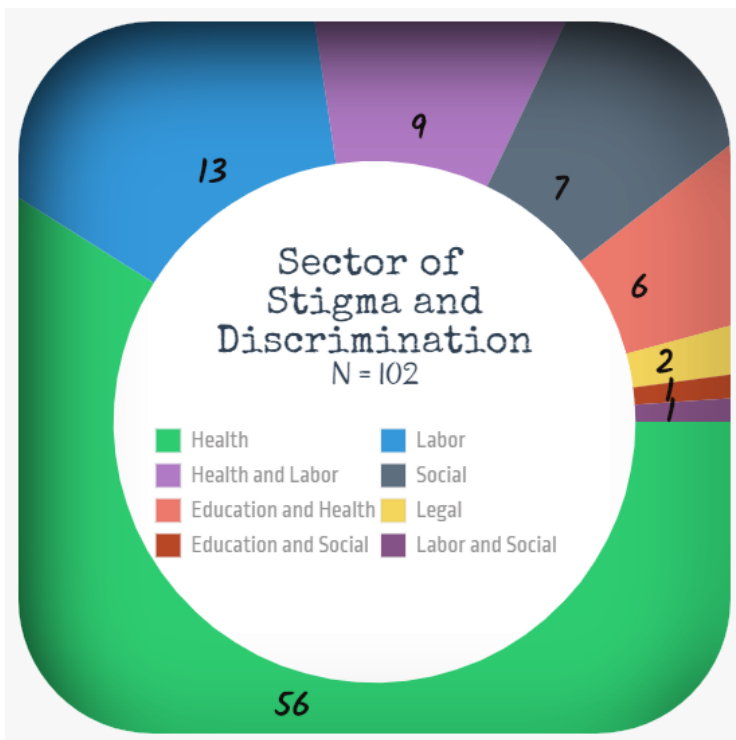
From the table above, it is suggested that the parties who have stigmatized and discriminated PLHIV mostly come from government institutions, such as Ministry of Social Services, Ministry of Health, Ministry of Religious Affairs, Ministry of Manpower and Transmigration, and the AIDS Commission (KPA). In addition, local officials and health care providers are also the parties who stigmatize and discriminate PLHIV most frequently. Ironically, they are servants of the community who should have honored non-discrimination principles in implementing and providing services.

For example, the aim of KPA establishment is to make HIV/AIDS prevention more intensive, comprehensive, integrated and coordinated. This fact has not

necessarily prevented KPA from becoming the perpetrators of stigma and discrimination against PLHIV. Another example is local governments' failure to fulfill their obligation to provide the best health care facilities. The existing health care facilities are still not friendly to PLHIV and discrimination that they receive from health workers has only made them increasingly unwilling to access health services.

The legislative function represented by People's Representative Council (DPR), also contributes to stigma and discrimination against PLHIV. Policymaking by the DPR should accommodate all the needs of PLHIV. But in fact, it is short from expectations. There are many district bylaws that discriminate PLHIV, such as those that make VCT obligatory.

Sector of Stigma and Discrimination



In the above diagram, stigma and discrimination against PLHIV are most common in the health sector, with 56 out of 102 news articles. This finding is not surprising because the main problem of HIV/AIDS is the matter of health.

The health-related problems constitute lack of availability of ARV and VCT clinics, difference of treatment of PLHIV where they are considered as unequal to other patients, mandatory HIV testing for pregnant women, and so on.

The rejection that was often received by PLHIV has led to a discouraging condition that makes them feel uncomfortable. This will potentially lead to a decline of PLHIV's health and other HIV/AIDS prevention programs. Moreover, the occurrence of stigma and discrimination practices in health services show that the PLHIV's right to health has not been fulfilled. As explained in the General Comment of the United Nations (UN), the right to health consists of 4 (four) basic elements, i.e. availability, accessibility, acceptability, and quality.^{xi}

The next sector that also shows a lot of practices of stigma and discrimination is the employment sector. Our documentation shows 13 news articles that contained stigma and discrimination in the employment sector. For example, one of them is the mandatory VCT for employees to know their HIV status. We notice that the low level of public knowledge about HIV/AIDS makes them afraid to interact with PLHIV. Therefore, most employers require HIV testing for employees. The assumption that PLHIV are not able to be productive at work has also caused mandatory HIV testing in the workplaces. Some news articles mention that government institutions will crack down, and even fire employees who are HIV/AIDS positive.

In many other sectors, problems of HIV/AIDS are always there as a result of the low public understanding about HIV/AIDS. The State has been using the wrong approach in preventing and handling HIV/AIDS. Overlapping regulations, maladministration, health services that are short from expectations and discrimination by health workers are problems that have yet to be solved.

CLOSING REMARK

Based on the analysis of monitoring and documentation on stigma and discrimination against PLHIV, we arrive at the following conclusions:

- A total of 102 news articles regarding stigma and discrimination against PLHIV were collected during 2016.
- There are 53 stigma-related news articles, of which the most frequent news concerns mandatory VCT conducted to find out about a person's HIV/AIDS status, comprising about 24.5%.
- There are 29 news articles on discriminatory practices. Most of the news is related to the problems arising when PLHIV access health services, which amounted to 41.4%.
- There are 20 news articles, or 19.6%, that have neutral content about PLHIV and HIV.
- The most frequent perpetrators of stigma and discrimination are civil servants who provide public services, with the highest percentage coming from ministries of various sectors at 37.3%.
- As much as 55% of the stigma and discrimination that we documented occurs in the sector of health care services.

Stigma and discrimination received by PLHIV from their social environment can inhibit the process of prevention and treatment. This situation only makes things worse considering that HIV issues are complicated. It is important to eliminate stigma and discrimination against PLHIV. The more the public care about HIV/AIDS, the better the chance to stop stigma and discrimination.

ENDNOTES

ⁱ Direktorat Jenderal Pengendalian Penyakit dan Penyehatan Lingkungan, berdasarkan Surat Direktur Jenderal P2PL, Kementerian Kesehatan Republik Indonesia.

ⁱⁱ Ade Latifa, *Peran Masyarakat Madani dalam Mengurangi Stigma dan Diskriminasi terhadap Penderita HIV dan AIDS*, Pusat Penelitian Kependudukan – LIPI, 2011.

ⁱⁱⁱ The Institute for Poling and Marketing, *Media Monitoring*, 2012, pg. 3.

^{iv} Multisensor, *Empirical Study on Media Monitoring and Internationalisation Resources*, 2014.

^v Definition based on Kamus Besar Bahasa Indonesia (KBBI) Online.

^{vi} *Ibid.*

vii “Statement on HIV testing and counseling: WHO, UNAIDS re-affirm opposition to mandatory HIV testing”, http://www.who.int/hiv/events/2012/world_aids_day/hiv_testing_counselling/en/ accessed on 7th March 2017.

viii “Apa yang dimaksud dengan perilaku berisiko tinggi?”, <http://spiritia.or.id/art/bacaart.php?artno=1001#Resti>, accessed on 28th February 2017.

ix “RSUD Cililin Tidak Layani Bedah Caesar Pasien HIV/AIDS”, <http://www.pikiran-rakyat.com/bandung-raya/2016/04/04/rsud-cililin-tidak-layani-bedah-caesar-pasien-hivaid-365702>, 4 April 2016.

x Organisasi Perubahan Sosial Indonesia (OPSI), *Catatan Penelitian Dampak Penutupan Lokalisasi*, 24 June 2016.

xi PBB, Komentar Umum Komite PBB untuk Hak-Hak Ekonomi, Sosial dan Budaya No. 14. *Hak atas Standar Kesehatan Tertinggi yang Dapat Dijangkau* (Art. 12 ICESCR), E/C 12/200/4.