Mainstreaming Human Rights in the Governance of HIV/AIDS Response in Indonesia: A Study of Children with HIV/AIDS in Jakarta and Surakarta

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ABSTRACT

This research aims to compare the advocacy model of Children Living with HIV/AIDS (CLWH) informal-- non-professional and formal--non-professional network, represented by Lentera Anak Surakarta (LAS) and Lentera Anak Pelangi Jakarta (LAP) respectively. The characterization of the network was adapted from Lhawang Ugyel conceptual framework on four types of social network based on their personnel types and formality. Meanwhile, the comparison was made under the metric of 3 advocacy channels; legislation, political and mobilization process. This research found out that LAS informal—non-professional advocacy model reflected a more dominant usage of law and political channel compared to LAP formal—non-professional model since LAS was rising from marginalized society hence they need well lobbying politically and involving in legal drafting. Meanwhile, LAP had shown a more systematic maneuver on the socialization and mobilization channel of advocacy. This was because LAP was formally driven by academia spectrum that could establish methodical movements of CLWH advocacy; thus the engagement with policymaker was less prioritized, even though it was still an essential element of its advocacy.

Keywords: Children *Living With HIV/AIDS, Advocacy, Lentera Anak Surakarta, Lentera Anak Pelangi*

ABSTRAK

Penelitian ini bertujuan untuk membandingkan model advokasi Jaringan Anak-anak dengan HIV / AIDS (CLWH) informal - non-profesional dan formal-non-profesional, masing-masing diwakili oleh Lentera Anak Surakarta (LAS) dan Lentera Anak Pelangi Jakarta (LAP). Karakterisasi jaringan diadaptasi dari kerangka kerja konseptual Lhawang Ugyel pada empat jenis jejaring sosial berdasarkan jenis dan formalitas personilnya. Sementara itu, perbandingan dibuat di bawah metrik 3 saluran advokasi; proses legislasi, politik dan mobilisasi. Penelitian ini menemukan bahwa model informal LAS non-profesional advokasi mencerminkan penggunaan yang lebih dominan dari jalur hukum dan politik dibandingkan dengan model formal-non-profesional LAP sejak LAS meningkat dari masyarakat yang terpinggirkan sehingga mereka perlu melobi politik dengan baik dan terlibat dalam penyusunan hukum. . Sementara itu, PAP telah menunjukkan manuver yang lebih sistematis pada saluran sosialisasi dan mobilisasi advokasi. Ini karena PAP secara formal didorong oleh spektrum akademisi yang dapat membentuk gerakan-gerakan metodis advokasi CLWH; sehingga keterlibatan dengan pembuat kebijakan kurang diprioritaskan, meskipun itu masih merupakan elemen penting dari advokasinya.

Kata Kunci: Anak-anak yang Hidup Dengan HIV / AIDS, Advokasi, Lentera Anak Surakarta, Lentera Anak Pelangi

INTRODUCTION

Until December 2016, the number of Children Living with HIV (CLWH) in Indonesia is recorded to be around 5.000 and growing. Despite the significant amount, the attention regarding CLWH is overshadowed by the spotlight on the adults with HIV. As this research is being conducted, CLWH faced bold discrimination and constraints in accessing their fundamental rights. The most significant hardships in enjoying their fundamental rights mainly lie in their desire to living naturally within the society and access toward education. It is known that considerable spectrum of CLWH in Indonesia had been excluded from their neighborhood and discriminated in their school, as they are being bullied by their peers and pushed out to move to the other school by the parent's committee. Therefore, the advocacy for the guaranteeing CLWH ease access to their basic right urgency has been escalated.

Children in the context of development studies are believed to be the next generation who will continue the development that has been initiated by previous generations. Roger Hart (2014) in reference to Colin Ward, an observer of human behavior, describe that his work much discusses the central role of children in development which one of them believe that the existence of children in the development process can create a just and more better community. With this perspective, the urgency to guarantee the fulfillment of Child Rights in various sectors is essential due to securing the future of a nation. In this endeavor, the legal basis for the guarantee of children's rights has been outlined in the 1989 United Nations Convention on Child Rights which contains points of protection of the rights of the child. Although almost 30 years of this convention in the initiation, the problem of child rights violations still occur in various corners of the world. The rights of children are still not become the priority in many issues given their involvement that is not as intense as adult involvement. This has resulted in the community of children being ruled out of hatching problems as experienced by the community of children living with HIV AIDS.

Within the critical situation, several advocating actors emerged to solve the CLWH problem. The two of the most significant and vocal in advocating CLWH access to their fundamental rights are Lentera Anak Surakarta, in Surakarta, Central Java and Lentera Anak Pelangi in Jakarta. These two advocating actors had their uniqueness in showing their concern toward CLWH in Indonesia. Lentera Anak Surakarta (LAS), led by Puger Mulyono, was initiated in 2012 by a marginalized spectrum of society, namely *Tukang Parkir* (Indonesian term for parking attendant), LGBT and sex worker community.

This LAS's movement was triggered by the marginalized community because the children inside LAS themselves are marginalized. In short, LAS has been able to provide a sustainable shelter for CLWH despite many rejections from the society. Besides, LAS was uniquely succeeded to build the most sustainable CLWH shelter in Southeast Asia, started with minimal resources and support from society, as they are marginalized society. In Jakarta, Lentera Anak Pelangi (LAP) was established in 2009 under the initiation of academicians of Universitas Katolik Atma Jaya Jakarta. LAP was first established under the fund of United Nations Development Program in the first year of its operation. However, LAP has been able to sustain even after the UNDP funding ended. In addition, LAP also innovates the systematic advocacy model for CLWH, especially in Jabodetabek (Jakarta, Bogor, Depok, Tangerang, Bekasi) region.

RESEARCH FOCUS AND LITERATURE REVIEW

This research paper is written aiming to compare the distinct advocacy model conducted by Lentera Anak Surakarta and Lentera Anak Pelangi Jakarta. As seen, this research selected two cities in Indonesia; Surakarta and Jakarta. Jakarta was chosen as it is the capital city of Indonesia, a place where the CLWH related government agencies and complicit information about it centralized. Then Surakarta is a city in Central Java, where the marginalized society advocacy outstandingly worked, as it succeeded in establishing the first sustainable shelter for CLWH in Southeast Asia. Besides their achievements, both cities have the unique constraint faced too.In Jakarta, the major challenge for the advocacy to take care of is the CLWH family acceptance. Family acceptance is universally urgent since family assistance is the one ill need at first before any other help from medical institutions (Evans and Becker 2009). In this capital city, CLWH mostly comes from a decent family with a decent living as well.

Furthermore, our correspondent Natasya Sitorus (2017) elaborate that the CLWH in Jakarta is mostly not being completely abandoned by their family, only their family members are reluctant to take care of this CLWH. *"Lentera Anak Pelangi believes that as long as the kids still have their guardians who can take care the children, either it is their grandparents, uncle, aunty or anyone on their family member, they will stay with their family."* Natasya (2017) added. Thus the advocacy came to educate their family in living with CLWH. The constraint of CLWH in Jakarta was also the government perspective on equality mentioned in this subchapter. In Jakarta, it caused several cases where CLWH health was dropped due to the mistreatment given by the school. Not stopping on the technicalities, in Jakarta, the case of CLWH being bullied by the other students and pressured by the parent's committee was also a troublesome constraint for the advocacy to get rid of (Interview with Natasya, 2017).

In Surakarta, the challenges are distinct compared to Jakarta. The constraint of CLWH right assurance in this city mainly came from the surrounding society resistance toward their presence among them, in which it was mitigated from stigma toward HIV/AIDS. This resistance had caused other problems toward CLWH right assurance in Surakarta, regarding shelter and education in particular. An example of issues regarding shelter that face by LenteraAnak Surakarta Puger Mulyono (2017) the founder told us the story where they need to move due to social rejection towards their settlement on every village they tried to lived in, "When we first arrived there (LAS Shelter nearby Solo Balapan Train Station), it was still the first night we stay, community surround that shelter tried to evict us." (Interview with Puger, 2017). CLWH in Surakarta had to live nomadically without any settled shelter due to the rejection by their neighborhood as people living next to them were pushing them out from where they live. Compared to Jakarta, CLWH in Surakarta were majorly abandoned by their family or parentless from death due to HIV.

Social Rehabilitation Section Head of Surakarta Office for Social Affairs, Toto Sumakno that manage CLWH cases in Surakarta explained that besides the death of the CLWH parents, several possibilities put CLWH to be taken care by the shelter. *"In most cases the condition where the guardian of the children infected by diseases that could potentially harm the condition of the children become the reasons why the need to move the child to Lentera Anak Surakarta."*(Interview with Toto, 2017). Side by side with this leaving the child to live alone in the society will cause the rejection towards them. With this condition, society rejection toward CLWH was indeed a vital constraint. In the education sector, the challenge is quite similar with Jakarta, in which there were less psychosocial support and more discriminative behavior by school community toward CLWH.

Within the broader context, some research concerning the basic rights of the individual with special needs had been done in the past. Mahabbati (2012) in her writing advocated that inclusive education should be implemented in a fun manner so the students could better enjoy and internalized the value of education taught in school. She also suggested the Indonesian policymaker to adopt and adapt the Australian education system in nurturing inclusivity values. A couple of years later, Mahabbati (2014) research on inclusive education toward the children with disabilities found out that in Indonesia, the tenet of inclusive education had been glorified since the early 2000s. However, her research stated that the implementation of that tenet had been constrained by the lack of facility. The government already attempted to fix that issue technically by increasing the budget and conducting extensive training for the teachers. Despite the technical efforts, the inclusive education was mostly constrained by the negative stigma toward the student with disabilities and tendency to neglect their needs as if they do not exist. Therefore, this research aims to expand the scope of discussion regarding inclusive education by examining CLWH, a vulnerable group often excluded from the debate.

Hence, this research would provide the representation of both marginalized society-initiated and institutionalized model of advocacy. In the end, this research expects to find the reasons behind the differences between the measures taken by both types of support and obstacles faced by them. By those findings, it is supposed to help many CLWH stakeholders such as advocates and the government to tackle down the similar advocacy issues.

RESEARCH METHOD

This research was conducted using qualitative method through a literature review of existing findings & legal documents of CLWH legislation and field interview. This research gathered primary data from CLWH advocacy stakeholders both in Surakarta and Jakarta. Stakeholders in Surakarta: Lentera Anak Surakarta (LAS), Social Office of Surakarta City, AIDS Caring Society (WPA), Education Office of Surakarta City, Surakarta chapter National AIDS Commission, and Universitas Negeri Sebelas Maret Academicians. Stakeholders in Jakarta: Lentera Anak Pelangi (LAP), Spiritia Foundation, The Indonesian Child Protection Commission, Ministry of Health, Ministry of Education and Lentera Anak Pelangi Assisted Family. The gathered data would be analyzed utilizing the concept of advocacy in an attempt to compare LAS and LAP model of advocacy.

Conceptual Framework: Advocacy and Network Type Model

Advocacy is an effort to renovate or change a public policy following the interest of the advocate. It includes the process of a chain of activities that aim to influence the decision making (Azizah, 2013).

In achieving that goal to create a change in the policy-making, several steps should be taken systematically by the advocates. These are the three steps (Azizah 2013):

a. Legalization and juridical process (proposing for an idea/change of the legislation)

In this process, there is legal drafting in which it includes the idea proposal, parliamentary debate, and academic seminar to present the academic draft. This process also consists of the presentation of the academic draft to the government and its feedback processing until it reached an agreement through parliamentary voting. The counter legalization and juridical process are included in this process as well. The primary activities in this process are mainly technically in the legal aspect.

b. Bureaucratic and Political Process (lobbying that idea to be accepted)

The primary concern of this process is to articulate the interest through political way through lobbying, negotiating, bargaining and collaboration. It may include the political intrigue and manipulation. Both bureaucratic and juridical process similarly involves the process to convince the proposal to be accepted. However, the significant difference between them is that: juridical process mainly concerned on what happened inside the parliament and legal drafting practically in legal term, while bureaucratic process involves more political lobbying outside the legal term, such as political intrigue and manipulation, as mentioned.

c. Socialization and Mobilization (presenting that idea to society to get public support)

Is an information dissemination process in regards to getting awareness of the legislation made and political pressure through the campaign, fund-raising, discussion, seminar, training, and mass movement. This process does not only lie to spread the knowledge to the society per se but also to influence the society effectively to the extent that the society member is willing to join the advocacy and gaining more mass. Advocacy does not only change the cognitive aspect of society but also the effective spectrum of the mass as well.

There are three kinds of actors involved in advocacy:

a. Supporting units: the one who provides funding, logistic, data, information and access
b. Ground-underground workers: the strategic planner of the advocacy that builds the mass basis, educate the political cadre and arranging mass mobilization.
c. Front liners: work as the spokesperson, negotiator, lobbyist, participant in the legislation drafting and establishing an alliance.

In classifying Lentera Anak Surakarta and Lentera Anak Jakarta, this research adapted Lhawang Ugyel conceptual framework on 4 types of social network based on their personnel types and formality, those are (1) formal-professional, (2) informal—professional, (3) formal—non-professional and (4) informal—non-professional (Ugyel 2016).

The first quadrant, formal-professional consist of general physicians, nurses and allied health professionals (Ugyel, 2016). It was considered professional since those actors directly involved in the medication process technically. It was clustered as formal since they belong to formal health institutions and associations such as hospital.

The second cluster, informal-professionals comprised of traditional healers, spiritual advisors, and herbalist (Ugyel, 2016). It was identified as professionals since, similarly, with the first quadrant, they directly engaging with the patients' medication technically. However, they are seen as informal since they don't go with formal health institutions and practice. The third group, formal-non professionals mainly formed by community and social groups/organizations (Ugyel, 2016). Different from the first two quadrants, this group was classified as non-professionals since their form of support engagement is not by direct medication but somewhat social. Notwithstanding their no-capacity in medical engagement, they are still considered formal since it was formally established organization/community with systematic vision and agenda.

The last classification, informal— non-professional includes personal communities such as neighbors, personal environment and community (or even family members) (Ugyel, 2016). It was seen to be non—professional because similar to the third group, does not directly involved in the technical health medication. This classification also considered informal since, unlike the third group, it was not formally initiated or mobilized systematically as an organization.

The table of the framework is portrayed below:

Table 1. Network Types (Ugyel, 2016)

		Network	
		Formal	Informal
CLWH Advocates/ Health Type	Professional	*Formal-Professional* Health professionals	*Informal-Professional* Non-health professionals
	Non-Professional	*Formal—Non-professional* Voluntary and Community Groups	*Informal—non-professional* Personal Communities

Source: Ugyel, L. (2016). Formal and Informal Institutions in Governance Networks: Managing Diabetes in Australia and India. *Crawford School working papers 1601*, 1-12.

This framework was chosen over the other ones since this framework could represent all spectrums in health-related advocacy network, in particular regarding CLWH. It could emphasize that the empowerment of CLWH does not only rely on medical actors work, but the advocacy and support toward CLWH have to work hand in hand of all actors in the four spectrums. By the classification, it could more specifically explain that Lentera Anak Surakarta and Lentera Anak Pelangi Jakarta were not only NGO but with more specific characteristic and roles of those. In the aftermath, it could explain why LAS and LAP took the different approach in channeling out the interest of CLWH.

Through this framework, this research would compare the LAS and LAP advocacy model based on the parameters provided in the framework. It would answer the basic question of how LAS could conduct its advocacy despite its limited resources and being initiated by marginalized society, compared to LAP that was firmly established by an academician.

RESEARCH RESULT AND DISCUSSION

Status Quo and Challenges for Ensuring Rights of CLWH in Indonesia

In the attempt of fulfilling rights of CLWH, government institutions in Indonesia have been expressing its maneuvers to raise the society's concern toward right fulfillment of marginalized community, especially CLWH. These rights, which should be applied without discrimination, were the ones that have been the primary foundation in guaranteeing the assistance toward CLWH. While at the other side, the government has been devoting more of its commitment toward CLWH protection through Indonesian legal framework, such as Undang-Undang RI No.35 Th. 2014 about Child Protection.

In verse 59 point f, it mentioned that a child with HIV/AIDS deserves to attain distinctive protection (Undang-Undang Republik Indonesia Nomor 35 Tahun 2014 Tentang Perubahan Atas Undang-Undang Nomor 23 Tahun 2002 Tentang Perlindungan Anak 2014). Besides, government effort in recognizing CLWH existence also has been portrayed in several regions, such as Surakarta that was earlier issued its regional legal framework in Perda No.12 Th.2014 about the HIV/AIDS prevention and medication. Within its Chapter 1, it already pictured terminologically that children with HIV/AIDS will be abbreviated as ADHA *(Anak Dengan HIV/AIDS)* in Indonesian term (Pencegahan Dan Penanggulangan Human Immunodeficiency Virus Dan Acquired Immune Deficiency Syndrome 2014). In advocacy studies, the society affirmation, in this case, marginalized one, is a vital element in the policy-making (Interview with Natasya, 2017). Therefore, we could admit that this step is sufficient in assuring the availability of CLWH-friendly legal framework. Although there exists a firm legal basis regarding the rights of CLWH, their implementation is still far from satisfying. In reality, many institutions have very limited knowledge about the legal framework on CLWH rights protection. In several education institutions, the inexperience of those institutions led to the CLWH discrimination in schools. Also on the health institutions, CLWH structurally faced obstacles in accessing the healthcare.

However, the most significant and fundamental constraint came from the society level. The minimum understanding of the existing legal framework and non-discriminative tenets had resulted in society resistance in accepting CLWH. This research also sees that the hardships in changing society stigma toward CLWH were also caused by the minimum knowledge about the HIV/AIDS from the medical perspective and how to live side by side along with CLWH, beside of the less portrayal of the existing legal framework. Therefore, some spectrum of society action discriminatively against CLWH even though the law protecting CLWH exists.

It is proven by the fact that even the medical agencies, an actor that should be protecting them, were also the ones discriminating them even though legally medical agencies should treat every patient fairly, such as what happened in Pekanbaru (Maharani 2014).

What also needs to be spotlighted from the CLWH rights fulfillment features on the national level is that; the research team found out that there was a unique perspective on how the government sees the interconnected principles regarding CLWH right assurance. This bias shown on the view of inclusivity of education in which seen by National Committee for Children Protection as *"providing a nondiscriminatory value in education to develop the child."* (Interview with Hikma, 2017), however, believed by the Ministry of Education (2017) that such perspective means there is no exclusivity of providing special treatment for children living with HIV/AIDS. Therefore, both regular and CLWH should be treated the same even though it would neglect the needs of CLWH for particular education curriculum such as psychosocial education for instance. By this example, we could define that the government has not yet possessed the strong fundament in defining what inclusivity and exclusivity are, causing the dilemma over whether the system should exclusively accommodate CLWH or standing on the status quo where CLWH were inclusively treated the same way with children without HIV/AIDS. The situation even gets more problematic in the education sector since education was seen as a vital means to contain the spread of HIV/AIDS, a place were otherwise CLWH and PLWH were discriminated from (Sutrisna 2013). Therefore, the discussion and advocacy to put CLWH and PLWH back to education arose.

This stance believes in the tenet that education should be inclusive in which it treats all students equally without specializing a particular group of students, in this case CLWH. The government interpretation of equality, in this situation, was "generalization" in treating all students despite of their background, including health.

This consideration derived from the assumption of the government which stated; if they accommodate CLWH "exclusively", the other spectrum of students with disabilities would insist on the same facility as the CLWH. Therefore, to provide fair and just treatment toward all range of students the government did not offer any exclusivity at all toward any. However, this idea reflects the government attempt to blend CLWH with the regular students, eradicating the stigma toward CLWH. This contention believes that the stigma would disappear as it is expected to show the society that CLWH has no difference with other students since they live normally, at least under government perception. Even though it made sense that the CLWH may fit their surrounding if they equally treated with the other students, this treatment came with a high risk toward lives of CLWH at the same time. No matter how healthy it seems from the outside, CLWH at the end of the day would still be required to undergo several medical treatments and imposed on strict restrictions in regards to their health. On this corridor, nobody could risk the lives of CLWH for the sake of equality. As an example, it is dangerous to put CLWH on the same sports exercise level with the regular students, as the CLWH would get their fatigue dropped. Providing CLWH the same food or medical treatment with the regular students could also be a threat, as CLWH lives under a series of strict restrictions (Interview with Puger, 2017). This dilemma has been problematic in CLWH right assurance for years. In the national level budgeting corridor, the allocation toward CLWH proper assurance was also overshadowed by the other sectors. This far, the government and its funding institution stand on the idea that the small amount of CLWH is a legitimate metric to put CLWH into a lower level priority in any context. In the status quo, the HIV key population is the one that is granted with the more significant share of the budget.

This policy was seen to jeopardize CLWH since it caused the domino effect toward other sectors occurred. One of them is the health spectrum where the medicine dosages of CLWH and HIV-infected adults could not be equalized, but the government still put medicine import of CLWH behind the ones for HIV-infected adults (Interview with Spiritia Foundation, 2017).

Even in the best scenario where the budget and commission exist, stigma still appears as the biggest constraint for CLWH and PLWH right assurance. Also if in some cases HIV-infected adults came from a financially sufficient family that could afford a VIP class medical treatment, they were still discriminately treated compared to other non-HIV infected patients. Such cases happened in Pekanbaru where HIV-infected adults were stigmatized as a dangerous patient that required excessive protection to interact with, such as wearing three layers of medical gloves, imposing more expensive bill and giving several treatments without the prior consent of the HIV-infected patients (Maharani 2014). That includes a less active medical treatment, even to the patients with an ailment such as a toothache (Maharani 2014). Besides the stigma, the poor execution also worsens the situation. In Manado, where the KPA (AIDS/HIV Eradication Commission) established, the HIV/ADIS socialization and prevention were stalled since the advocacy was poorly executed and managed (Katoronang 2015). Therefore, the advocacy could not yet be that progressive to champion CLWH/PLWH acceptance in society.

Lentera Anak Surakarta and Lentera Anak Pelangi Jakarta as Informal and Formal Non-Professional Advocacy Network

As seen from the types of advocacy network on the conceptual framework, there are four types of the network under their profession; formal-professional, informal-professional, formal – non-professional and informal – non-professional. This subchapter would first classify Lentera Anak Surakarta and Lentera Anak Pelangi Jakarta into two of the four cluster of the network before the comparative analysis of their role in CLWH advocacy.

This is to emphasize that they have more unique characteristics beyond their identity as NGOs. It is also to pressure the fact that their role in the CLWH advocacy is equally vital to the other two professional clusters with their medical expertise. Four of them has to go hand in hand advocating and supporting CLWH to get their rights comfortably. This chapter would elaborate on the characterization of LAS as Informal—Non-Professional Network and LAP as Formal—Non-Professional ones. The informal—non-professional network mainly represented by the personal communities while the formal—non-formal professional network consists of the more administrated voluntary and community groups.

This paper classifies LenteraAnak Surakarta as the informal—non-professional cluster of the network. LAS fits into the informal—non-professional cluster because it was firstly founded in 2012 by personal communities where CLWH lived. Listed on Surakarta Office for Social Affairs, LAS was established under the initiation of Puger, a parking attendant from Jakarta that migrated to Surakarta (Interview with Toto, 2017). Even though currently it already developed as a foundation, the informal characteristic of LAS still profoundly lying within itself. Puger Mulyono (2017) the founder of Lentera Anak Surakarta describe that the initiation of the foundation based on his concern seeing his community peers fighting their HIV/AIDS. He lives in a community where the economic level was low as the members of the community were marginalized such as sex worker, thugs, and parking attendants. The boldest characteristic of the informal—non-professional behavior of LAS could be seen on its lobbying style in advocating CLWH rights assurance to the Surakarta Government. The advocacy model developed by LAS needed to be done informally since Puger (2017) elaborated that they need to do any activity relayed to the CLWH right assurance hideously to avoid social rejection.

To channel his interest to the government, Puger was helped by his marginalized community peers such as sex worker to be connected with Surakarta Social Bureau, as the bureau concerns about a sex worker at first. Through this informal network, Puger was linked with Toto from the Surakarta Social Bureau, a bureaucrat that would have a significant role in LAS advocacy of CLWH right assurance. In growing the bond between LAS and Sukararta Social Bureau, the communication model developed by the two were informal as well, such as dinner-talk. Toto (2017) believed that despite the formal relationship of LAS and The Bureau, the informal and casual style of communication would also be significant in the networking process. Also, Mr. Toto recognized Puger as an essential actor in CLWH right assurance advocacy, despite his background of coming from the marginalized community at first. This kind of lobbying maneuver was developed gradually for years through trial and error based on their experiences in advocating CLWH right assurance.

The formal—nonprofessional corridor best reflects the movement shown by Lentera Anak Pelangi Jakarta. LAP Jakarta was classified into the cluster since it was established as a formal by the academicians from Universitas Katolik Atma Jaya Jakarta (Interview with Natasya,2017). As known, LAP was formed under United Nations Development Programme funding, in which to attain such facility it required a systematic organizational proposal to achieve the funding. As a formal institution, it could also be recognized that LAP has a systematic advocacy method and Standard of Procedure (SOP) in doing so. The most obvious characteristic of LAP as the formal—non-professional network is the more systematic and theoretical review-based maneuvers in advocating CLWH rights assurance. Besides establishing well-managed CLWH treatment schemes, in advocacy LAP was also systematically and knowledgeably executing every challenge and threat toward CLWH rights. In comparison to the informal LAS that was more hideous and avoiding the source of threat toward CLWH, LAP was more open to encountering that threat with its established and adaptable maneuvers.

Besides LAS and LAP were facing a different kind of society and challenges, the openness of LAP in its advocacy model was more likely formed from its network formality.

Even though both LAS and LAP are formal in term of their organization structure, the formality and informality of their network would be better evaluated through their maneuvers, as it is more dominant in shaping their identity as CLWH advocates. LAS is more informal and not focusing themselves establish more systematic movement either since their main concern is the Shelter where CLWH lives survival should be guaranteed first. While LAP needs to portray itself in a more formal gesture, their interest is beyond the survival of the CLWH but also in the broader line such as educating society spectrums. Therefore, the image as formal advocates needs to be built to convince society in accepting CLWH better.

As seen above, LAS and LAP as characterized as informal and formal classification. Under the professionalism metric, both of them are identified as non-professionals. This point was judged by the fact that both LAS and LAP don't possess a medical capacity to engage with CLWH as HIV/AIDS-related health professionals directly. This judgment was strengthened by the fact that both LAS and LAP are reliant and in intense coordination with several hospitals in Indonesia. LAS has been networking with Surakarta City Regional Hospital (*Rumah Sakit Daerah Kota Surakarta*) while LAP's medical support came from Cipto Mangunkusumo Hospital Jakarta or known as RSCM.

Lentera Anak Surakarta and Lentera Anak Pelangi Jakarta Advocacy Model Comparison

Non-governmental organizations in advocacy studies have a vital role in the policy change. Besides its ability to trigger public opinion through its programs, the real actions from those NGOs are the ones that were seen to be positively impactful toward the vulnerable spectrum of actors within the system. LAS and LAP, as an NGO that concentrate on CLWH right assurance issues, have been able to deliver its maneuvers in creating policy change through multichannel and various sectors policy advocacy. This subchapter aims to elaborate and compare the advocacy model of LAS and LAP as formal and informal non-professional advocacy network.

As written on the conceptual framework, there is three channel of advocacy to excel the advocate interest to the policymaker; (1) legalization/jurisdiction process, (2) bureaucratic/political process and (3) socialization/mobilization process. These three would be the parameter of advocacy comparison of LAS and LAP.

1. Legalization/Jurisdiction Process Comparison

An in involvement in legal drafting was not initially one of the programs when LAS was established by Puger in 2017. Living within and representing the marginalized community, the circumstances led him to focus more on the survival of the CLWH than spending his resource to lobby the policy maker. Not to mention the severe background of the CLWH in the Shelter would require him to pay more attention to their survival. Puger (2017) explained, mostly the CLWH living under his supervision was utterly abandoned by their family, to the extent of being dumped in the river. Seeing the urgency, indeed the main program of LAS was to recover the physical and mental condition of the CLWH before anything else. Therefore, the legal drafting came second after the survival of CLWH.

However, Lentera Anak Surakarta was able to be involved in the legal drafting. For LAS, Perda No.12 Th.2014 concerning the HIV/AIDS Prevention and Treatment was the major trophy of their direct involvement in the constitutional preparation. That Regional Government Bill of Law (Perda) was the first legislation bill that recognizes the term “Children With HIV/AIDS” within the constitution. Toto (2017) from Social Office for Surakarta City added that this legal drafting process also involved the Surakarta Government along with Regional Service Unit (UPD), multi-sector Regional Employment Working Units (SKPD), parliament members and Sebelas Maret University academician.

It is an exceptional case when a marginalized based advocacy movement able to be directly involved in one of the most decisive legal draftings for the CLWH right assurance. LAS involvement in the constitutional drafting was brought by the ability of Puger in conducting political lobbying with Surakarta Social Bureau as would be explained in the next part of the subchapter.

Meanwhile, LAP saw the government differently than LAS did. This far, LAP had conducted its maneuvers independently without government aid so LAP personnel put its involvement in the decision making as a lower priority than CLWH survival. Its independence also caused LAP as an NGO not to expect the government aid that much. This research found out that LAP, at the opposite of LAS, shown a pessimistic gesture toward the government view of HIV/AIDS. Natasya (2017) as the LAP head of advocacy stated that indeed LAP had been trying to be involved in the decision making like other HIV/AIDS NGOs. However, LAP did not continue its approach to the decision making as its involvement was seen not to be significant, as the main focus of the society was the critical population instead of CLWH.

Despite the fact that LAP did not put significant concern on the direct involvement in the decision making, as an academia-based advocacy LAP did provide several policy recommendations for the sake of CLWH rights assurance. LAP saw that the legal framework in Indonesia regarding CLWH was already firm. It was proven by LAP advocacy attempts that succeeded in changing several policies utilizing the existing legal framework. Therefore, LAP direct involvement in the legal drafting was minimum compared to LAS, but it had a more significant role in changing the policies through its academic recommendation. LAP could be seen to be passive in the legal drafting involvement as it would be involved if only the government decided to involve LAP.

2. Bureaucratic/Political Process Comparison

In the political lobbying, Lentera Anak Surakarta has a close bond with Surakarta Social Bureau. This connection was established after LAS, and Puger reputation rose for building CLWH Shelter.

Through its wide personal networking and reputation, Puger had been able to be connected with Toto that represented Surakarta Social Bureau. The LAS lobby toward Surakarta Social Bureau had granted LAS an easier access toward health, education and civil registration access for the CLWH. As the Surakarta Governmental Personnel, Toto also reflects a positive gesture in the attempt to nurture the marginalized society, as written in Indonesian Bill of Law UUD 1945 verse 34 point (1) (Interview with Toto, 2017).

The LAS lobby toward Surakarta Social Bureau was also developed well as the urgency of LAS role in the CLWH right assurance escalates. The society increasing awareness toward HIV/AIDS had pushed the government to create sufficient legislation and policy in accommodating CLWH and Adults with HIV/AIDS. This increasing awareness was caused by the growing number of death due to HIV/AIDS in Surakarta, in which it was also a spotlighted concern of Surakarta Government at that time. In fulfilling society demand and tackling down the issue, Toto (2017) admitted that Puger position was very vital in achieving so. Besides LAS was able to build a first sustaining CLWH Shelter in Southeast Asia, Puger reputation and track record as an influential actor was needed in conducting such advocacy to fulfill society demand of better policies concerning HIV/AIDS. Therefore, since there is a constructive and mutual relationship among both actors, LAS lobby toward Surakarta Government worked progressively. At the same time, as an organization that concerns on HIV, LAP also held a vital role in the attempt to channel the interest of CLWH. In several occasions, LAP had been involved in the lobbying process toward the government. LAP also showed a high commitment when it was included in government agenda to take care of CLWH. It established a strong trust from the government toward the LAP, to the extent LAP was the one contacted by the government if it People Living with HIV/AIDS (PLWH) related issue.

Despite the excellent image, LAP also spotlighted several main obstacles in conducting the lobby toward the government. The government gesture in avoiding critics was one of the troubling constraints in LAP advocacy process. Natasya (2017) emphasized that the advocacy strategy toward the government could not be done under the strategy of "Bad Cops and Good Cops". According to LAP, by criticizing the government or taking the blame on it would otherwise worsen the situation as it changed the government gesture regressively. The government would turn out to be defensive and not cooperative when it felt that it was accused as the Bad Cops. Therefore, it was imperative for LAP to maintain a stable and cooperative relationship with the government by adapting and triggering a more constructive government gesture.

Along with its development, LAP had been able to establish a partnership with Indonesian Education Bureau that was helping LAP in channeling its education-based interest to the government. Bullying and rejection toward CLWH, also CLWH discrimination in education environment was the primary focus of the partnership with the Bureau. From this partnership also, it resulted in the Kartu Jakarta Pintar (KJP) revoking as the punishment model toward the students that discriminates CLWH (Interview with Ministry of Education, 2017). This KJP was a card used by elementary school students to the senior high school ones as identification to access the education facility provided by the government; therefore it was a significant deterrent for the students.

3. Socialization/Mobilization Process Comparison

The primary purpose of the socialization process of Lentera Anak Surakarta is to protect the CLWH from the severe social stigma toward HIV/AIDS. The means of achieving the CLWH right assurance free from stigma is to socialize and mobilize society in eradicating that stigma by establishing the Shelter and involving in HIV/AIDS education cluster. This socialization and mobilization process toward the marginalized CLWH was seen to be one of the most vital means in the advocacy.

Not only it aims to eradicate social stigma, but it also targets to revive CLWH mentality after being discriminated against and excluded by society. The self-esteem and stable mental state of CLWH were vital since it was highly contingent upon their body immune (Alifatin 2015). Halik Sidik (2017) from the National Aids Commission agreed that stigma had been the most common problem in the HIV/AIDS issue. This stigma problem is urgent in regards to CLWH because not only those external parties will discriminate them, but it may lead to self-stigmatization for CLWH to agree that they are devalued in society (Deacon and Stephey 2007). This research mitigated that the source of this stigma had been varied, depending on its social variable of the community where the CLWH was living and stigmatized. For the more significant number of Indonesians, inaccurate education and misinformation regarding HIV/AIDS have been judged as the mainstream that creates the stigma. This far, the HIV/AIDS education socialized in the various institution such as governmental, education and private ones was unrepresentative toward the more detailed HIV/AIDS image. With the portrayal of disturbing pictures, HIV/AIDS socialization was pictured to be highly associated with the narcotics usage(Interview with Education Office of Surakarta, 2017). This portrayal escalates the negative stigma of society toward HIV/AIDS.

The other form of portrayal of HIV/AIDS was the association of HIV/AIDS with the cursed and immoral disease that pushed a stronger label toward a person living with HIV/AIDS (Liamputtong 2016). The generalization and narrative that pictured a person with HIV/AIDS as a "sinful person that deserved it” was unavoidable. Even though not all people with HIV/AIDS were directly connected to the vital population, this stigma grew anyway. As an example, the infection of HIV/AIDS could occur toward the medical personnel that handles patients with HIV/AIDS, even though the number of cases was very small. However, the ones becoming the victim of such stigma would be still CLWH and Adults with HIV/AIDS anyway.

In protecting CLWH from stigma and providing a secure living, the Shelter was established. Despite its offered exclusivity, the establishment of the Shelter was not the end of the abandoned CLWH problems. The new obstacle emerged as CLWH living in the Shelter was exposed to the neighborhood as a group of people who might spread their disease off toward their surroundings. And the effort that is taken to resolve this problem is by building the shelter that far enough from community residents. *"With the new shelter plan that located far away from the residential area, we can finally live in peace without any rejection.",* Puger (2018) explained. However, this solution does not truly resolve the core problems as moving the shelter would not give any impact on the mindset of society. The insufficient society understanding of HIV/AIDS was believed to push the society to stigmatize the HIV/AIDS communities, including CLWH in the Shelter. Besides their obstacle in accessing their basic rights, CLWH under Puger Shelter was also faced with social stigma at a very early age.

This stigma problem was the grand vision of Lentera Anak Surakarta advocacy in socialization and mobilization process. The consequence of stigmatization of CLWH was very significant for them. As seen, stigma had separated them from the society while at the same time the normal social relations with other people is important to enhance their survival (Kamya 2010). This issue was also seen to be the biggest obstacle in CLWH right assurance, one of the most vital one was education since stigma had caused the exclusion of CLWH in school, a place at which CLWH learned to socialize with other people. Due to stigma, CLWH had to move from school to school since the stigma was manifested in the parent's community rejection. LAS had done several maneuvers and strategy in minimizing the denial, such as choosing another school with a fewer number of students, underground advocacy toward the principal and also convincing the parent’s community to be more sympathetic toward CLWH (Interview with Puger, 2017). Even though all of above was done behind the stage, those maneuvers reflect a true commitment of LAS in guaranteeing CLWH rights, especially in access to education.

In its attempt, LAS was gradually able to gain the sympathy of a part of society spectrum. LAS could sway the students' parent to understand the CLWH under Puger supervision and also increase the support of the religious group in Surakarta that offered another house to be CLWH shelter. Besides that, the marginalized community as the biggest supporting base of LAS was getting stronger despite the numerous rejection and stigma toward HIV/AIDS. Argyo Demartoto (2017) community observer and academician from Universitas Sebelas Maret Surakarta explained that Sexual Worker Community, LGBTQ, and Adult with HIV/AIDS was also joined in protecting and participating in the attempt of LAS to guarantee CLWH rights. On the other hand, LAP model in mobilization and socialization was more formal and systematic compared to LAS. In tackling stigma, LAP recognizes its mobilization and socialization channel of advocacy must lie to educate the society, as it is urgent in eradicating stigma (Interview with Natasya, 2017). As elaborated, stigma had been the most significant obstacles both for PLWH and CLWH right assurance. Therefore the shifting perspective of society was urgently necessary to guarantee CLWH and PLWH rights. This research found that LAP had conducted its socialization toward two communities; a community of people who directly engage with CLWH and the ones who did not. By this strategy, it was expected to identify more efficient the approach pattern in socialization and mobilization process. This is similar like what happened in the Western World such as the United Kingdom and the United States, where the institutional care (such as LAS Shelter) role is starting to be replaced by family-based alternatives (like what LAP did) (Phiri and Tolfree 2006).

In the first spectrum, socialization was indeed essential to educate the people who directly engage with CLWH. Natasya Sitorus (2017) Chief Advocate of Lentera Anak Pelangi emphasize that the ones with high intensity of interaction with CLWH such as family members should be prioritized. Despite the fact that they lived in the same house along with CLWH, their education regarding CLWH condition was essential to be improved to assure the better treatment for CLWH.

As an example, the psychosocial education was LAP program in guaranteeing the healthy psychological development for CLWH and their families. *"What we do (in Character and Morality School) is Character Building, ...by introducing the children with emotions"* CLWH were classified according to their age to be later given an appropriate education to support their development. Through this program, it was expected that CLWH could better recognize their emotions and surroundings and how to react toward it. This kind of education could decrease the depression rate, the suicidal thoughts and the losing appetite in medical consuming for CLWH. For the CLWH caretaker community, the support group was also initiated by LAP to provide a sharing platform for CLWH parents, family members, and caretakers. This was instituted after seeing the various problems in taking care of CLWH daily; therefore the exchange of experiences and suggestion was vital. By those programs, LAP socialization toward this group was expected to create a more conducive environment for CLWH.

In the other category, LAP was committed to change the condition and perspective of general society toward HIV/AIDS. General society socialization, for LAP, was aimed at tackling the stigma related issues. The main agendas such as a seminar for education institution by conducting school roadshow had been done by LAP. The school community was undeniably an environment where the members of it were engaging with CLWH, conscious or unconsciously. As the status of CLWH in schools was mainly kept in secret, this socialization was expected to prepare the school community to accept CLWH better when the identity of the CLWH was leaked. In general, socialization procedures done by LAP were systematic and schematic. The entire program released went through a comprehensive study and consideration for the success of educating society. Outside of the two categories, LAP was also socializing and advocating CLWH rights when violation case occurred. Such as when the status of CLWH in one of the private school in Jakarta leaked, LAP promptly involved in the socialization toward the parents' community in that school to provide a better view in accepting CLWH.

Even though not all parents changed their perspective significantly, LAP attempt was the representation of its high commitment to CLWH right assurance.

Lesson Learned from the Comparison

The comparisons of LAP and LAS raised several critical analyses to be taken into account. There are 3 points this subchapter would deliver: (1) how the similarities/differences came up, (2) what the consequences of the difference/similarities and (3) the reason behind the aftermaths. To compare the 2 NGOs, this article utilized Ugyel Network Types that consists of 4 classifications. Lentera Anak Surakarta and Lentera Anak Pelangi Jakarta as seen are classified into informal—non-professional and formal—non-professional. By this metric, we can see that LAS and LAP are similarly placed in the non-professional cluster. This similarity came up since both LAS and LAP were not initiated by health professionals but parking attendant in Surakarta and academician in Jakarta consecutively.

Those two NGOs are bolder in differences. Seen by the metric, LAS and LAP are different since LAS is placed in the informal cluster and LAP is classified as the formal one. This difference was not by choice but rather by the dictation of structure limitation. As seen from the previous chapter comparison, by structure LAP was established by academicians from Atma Jaya University, in which could be judged as an upper spectrum of society. By this position, LAP has more access to exposure and access to the support of NGO establishment, namely United Nations funding and mentorship, as they applied for it (Natasya, 2017). This access and initial breakthrough of LAP indeed makes them formal since to get funding and supervision; they need to establish a systemic organization and vision in their proposal. Lentera Anak Surakarta, by the information given in the previous subchapter, could be interpreted that LAS was initiated informally since structurally they are marginalized. LAS was initially by Puger's personal community in his environment of thugs, parking attendant, sexual worker and anything around them.

CONCLUSION

The issue in Indonesia until the moment still needs a better spotlight in tackling down the constraint for CLWH in accessing their fundamental rights. The major obstacles in doing so were society stigma and inaccurate portrayal of HIV/AIDS in the institutions within the society. These two things had created numbers of rejection and discrimination toward CLWH in Indonesia. In tackling down the issue, several actors of advocacy emerged namely Lentera Anak Surakarta from Surakarta and Lentera Anak Pelangi from Jakarta. Despite its similarity in advocating CLWH issues, both had differently unique nature of advocacy. Due to that, this research aimed to compare both advocacy models.

This research classified LAS as informal—non-professional type of network as it was established by some personal communities of marginalized society in 2012. Despite its development into an organization, later on, the informal characteristic of lobbying and networking was still highly reflected by LAS. While LAP was included in formal—non-professional cluster since LAP operated under academia personnel. The type of network and programs developed by LAP was also systematic as the representation of its formality.

The research findings stated that LAS informal—non professional advocacy model had shown a more significant utilization of legislation and political process compared to LAP, seen by the fact that LAS was directly involved in the legal drafting of Perda No.12 Th.2014 concerning the HIV/AIDS Prevention & Treatment and having a strong lobby toward Surakarta Social Bureau. This was because LAS was formed as the initiation of marginalized society; therefore a strong connection with the authority through legal drafting and political lobbying was essential.

In comparison, this research presented that LAP had reflected a more schematic movement and programs on socialization and mobilization process of advocacy. This systematic maneuver was caused by the fact that LAP was an academia-based body, in which establishing a theoretical and study-based program was within their skill sets.

Due to the ability to progress independently as an academia-based NGO, the engagement with the government through direct legal drafting was less urgent compared to developing its program in tackling down CLWH right assurance issues. However, LAP still could engage in indirect lobbying by providing policy recommendation to the government despite its minimum involvement in government engagement.

From that findings, we can learn from this research that it is possible of all spectrum of society, either upper or marginalized, can do significant advocacy in regards to CLWH. This research has extended the analysis to a broader context, namely the advocacy from a non -professional group in engaging with CLWH support. We can understand that to support CLWH; we don't have to possess a professional medical capability to begin with. Even, this article presented the marginalized spectrum of society that was able to establish and develop an HIV shelter for children, Lentera Anak Surakarta. In the aftermath, this research suggests that every actor in society could support the CLWH right advocacy with their way.

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