

# Collaborative Governance Based Protection for HIV/AIDS (ADHA) Infected Kids in Surakarta

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Keywords: Children, HIV/AIDS, Protection, Collaborative.

Abstract: HIV/AIDS disease is not only occurs in adults, but also affected with children. In generally children who affected by it be orphan, they lost their parents because this disease and welfare less. Children who affected by it has discrimination treatment from education and health services. To improve quality of children and family's welfare can be done by collaborative and coordination with another sector. This article will discuss Children HIV/AIDS's Protection Based on Collaborative Governance in Surakarta. This research was conducted with method qualitative analysis. Data obtained through interviews, observation, and document. This research choose Yayasan Lentera Surakarta as the subject, because itself non governments (LSM) in Surakarta whom take care children with HIV/AIDS's unattached. Children's who live in Yayasan Lentera Surakarta still get discrimination treatment from education and health services. The existence of Yayasan Lentera has rejection from society because negative stigamation of this disease does exist. Yayasan Lentera has lack of resources (economy and human) to take care children HIV/AIDS's protection. Regulation of Perda Surakarta about children's protection has no responsive to Children with HIV/AIDS. The collaboration exists to provide protection for the children in Lentera Foundation is not effective yet because there are succeeding elements which are not fulfilled.

## 1 INTRODUCTION

One third from the total amount of our citizens is children. Children are an inseparable part of the human's and country's life line (Rosalin, 2015). Currently there are still some children getting discriminated from their own family and surrounding, for example the discrimination received by the children suffering from HIV/AIDS (ADHA). Their access to education and health services becomes limited due to that discrimination (Unicef, 2012). The nature of discrimination is the unfair and imbalance treatment done to differentiate someone or a certain group which is usually categorical or based on specified attributes, such as race, ethnicity, religion, or membership of social classes.

Children suffering from HIV are kids and teenagers under 18 years old who live with HIV (infected by HIV), have lost one or both of their parents due to AIDS and are prone to welfare and development because of HIV (Unicef, 2007)

Most of our people still perceive that people suffering from HIV/AIDS are the people who suffer a disgusting disease; these negative perceptions tend

to be close to them. In other words, their existence is not wanted in the social environment, even those people often get discriminated (Niko, 2014). Human Immunodeficiency Virus (HIV) has infected millions of people in the world. This virus lowers the immunity of the infected person. When one's immunity decreases, that person will be prone to be infected by other diseases (opportunistic infection), this condition is called as AIDS (*Acquired Immuno Deficiency Syndrome*) phase (WHO, 2013).

Surakarta government has seriously worked hard in response to the issues of children protection, but there are still many obstacles to be taken care in the future, which is the existence of Non-Governance Lentera Foundation Surakarta taking care of 11 ADHA that must strive because it gets rejection from the surrounding environment (Unicef, 2017). Lentera Foundation has many assisting programs toward ODH; one of them is the care and support for the children suffering from HIV/AIDS (ADHA). Lentera Foundation was used to be located in Kartosuro, Sukoharjo, but must be moved to Bhumi Laweyan because the people there did not want to welcome the ADHA (Susanto, 2016). The vice mayor of Solo had

given assistance in the search of shelter location, but it always ended with the rejection from the local residents. Besides getting rejections from the people, ADHA also had ever gotten rejection from the health services and education access. There was an ADHA who also had to be expelled from the school because he / she suffered from HIV and there was an ADHA who got rejected by the hospital because of the reason that there were no medical staffs that could handle HIV/AIDS issues (Oktaviani, 2017).

Surakarta government has local regulation of Solo No.12 in 2014 about the prevention and treatment of HIV/AIDS, in that regulation it is explained that the people must accept the existence of ADHA (People with HIV/AIDS) and not to do discriminations and also must create a conducive environment for ODHA, ADHA, and their families. The local government is also obligated to provide health service access for ADHA according to their needs. In providing the health services to ADHA there has to be no stigmatizations nor discriminations, besides that ADHA have the right to receive comprehensive health services, the grant of children's right, and basic life needs support.

Besides health services, ADHA also have the right to receive equal education and tutor without any discriminations. Through major rules No. 28-D in 2014 about Children-Friendly School, ADHA have the right to education and tutor according to their own intelligence, talent, and interest without being discriminated. In the management of children-friendly school organization, it must also give special protections to the children with HIV/AIDS.

The Intermediate Phase of Local Construction Plan (RPJMD) of Surakarta in the year of 2016-2021 it is explained that in order to improve the life quality of children and family welfare, cross-sectoral collaboration and coordination are needed to be involved. It is not impossible that the government has limits in providing the protection rights to the ADHA, so in order to optimize their performance, collaborative governance might be done.

The importances of commencing this collaboration are: (1) the failure in implementing the regulations at the field, (2) the groups' inability especially in separating the powerful regimes to use the other institution arenas to slow down the decision, (3) the mobilization of importance groups, and (4) the high cost and regulation politicization (Ansell, 2009). This research is important to be carried out in order to investigate the form of collaborative governance in giving protections to the ADHA. That is why the writer is interested in making the title "The

Collaborative Governance-based Protection of Children with HIV/AIDS (ADHA) in Surakarta".

## 2 LITERATURE REVIEW

According to De Seve in (Sudarmo, 2009) there are 8 elements contributing to the success of collaborative governance, they are:

1. *Networked structure*  
The network must not form authorization hierarchy, domination, and monopoly because it will not be effective. Everything must be in balance whether in right, obligation, responsibility, authority, and chance.
2. *Commitment to common purpose*  
The reason why a network must be exist is because the attention and commitment to achieve the positive objectives. It is usually articulated in the common mission of a governmental organization.
3. *Trust among the participants*  
The belief that the participants trust to the informations from the other stakeholders in a network to achieve the goal
4. *Governance*
  - a. *Boundary and exclusivity*, emphasizing who the members are
  - b. *Rules*, the limitation of the members' behavior there is a clear rule about what have to be done.
  - c. *Self-determination*, freedom to anyone who is allowed to operate.
  - d. *Network management*, in relation to the rejection resolution, resources allocation, quality control, and organization maintenance.
5. *Access to authority*  
It is about the availability of the clear procedural term standards which are widely accepted.
6. *Distributive accountability*  
Sharing in terms of structuring, execution, and management together with the other stakeholders and sharing some decision makings to the whole members of the network so that the responsibility sharing in order to achieve the expected results.
7. *Information sharing*  
It is about the easy access which includes system, software, and the convenient and secure procedure to access the information for the members.

8. *Access to resources*

It is the availability of the financial, technical, human, and other resources which are needed for the network goals.

### 3 METHODS

This research is a descriptive qualitative research. The data were gathered through interview with Mr. Puger Mulyono (the founder of Lentera Foundation), Mr. Yudi (the caretaker of lentera foundation), the chairman of Solo social department, and local residents; and documentation study. The data analysis was done by collecting data, reducing, serving, and inferring conclusion. The data validity was done by using the triangulation technique which is checking the data gathered through the interview, and then checking it by using observation and documentation.

Lentera Foundation Surakarta was chosen with the consideration that the foundation is a non-governance institution in Surakarta that takes care of children with HIV/AIDS and also the pilot project in Indonesia and an independent one (it does not rely on the government and already has a law protection).

### 4 DISCUSSION

#### 4.1 Lentera Foundation

Lentera Foundation was built by Mr. Puger because of his humanity feelings that made him want to help the people in need, especially the children suffering HIV/AIDS who are abandoned by their parents / families. Currently the number of HIV infected children in Lentera Foundation is 12, with the ages ranging from 2 months – 14 years old, accompanied with 4 nursemaids. Up to now only the Surakarta Social Department that builds a relationship with the Lentera Foundation. The protections given to the children with HIV/AIDS (ADHA) in Lentera Foundation are.

##### 4.1.1 Social Sector

Lentera Foundation has owned a shelter even though the building status is still renting with a small size, so that the children cannot play freely. Actually the children are given freedom to socialize with the other, but they play and socialize more with their friends in the Lentera Foundation. The local residents have understood about the HIV/AIDS theoretically because they have been accustomed to the

socialization program from the government, but if they meet or interact directly with the people infected with HIV/AIDS still feel disgusted. In giving the protections to the HIV infected children in Lentera Foundation, the social department has the main contribution which is giving the shelter to the Lentera Foundation and giving reference to the ADHA who will visit the hospital. However, up to this point the social department has not given the shelter yet. That is not yet realized because there is still a rejection conflict from the local residents and also it is not possible to build a shelter because the free land in Solo is limited.

##### 4.1.2 Education Sector

Children with HIV/AIDS in Lentera Foundation Surakarta get the education access in the form of going to school formally, but the status of that child must be hidden because if the school side or the parents finds out, that child will be discriminated even there will be a rejection that causes the child dropped out from the school. The regulation product possessed by the Education Department is Major Rule No. 28-D in 2014. Every time there is a problem about ADHA education in Lentera Foundation is taken care by Mr. Puger himself. There is no response from the education department to take care about the education problem undergone by ADHA. Whenever there is an ADHA dropped out from his/her school, Mr. Puger himself takes care of it and looks for the substitute school. Every child with HIV has a Smart Indonesia card, that card is useful for giving dispensation of education fee.

##### 4.1.3 Health Sector

Children suffering from HIV are prone to other diseases because their immunity is decreased. Due to the limited money, the medical treatments to the ADHA are done traditionally, if the situation has become severe so that they have to be referred to the hospital through the social department. There are also some medical staffs who are inexperienced in handling ADHA. There are also some doctors/medical staffs who feel disgusted with those children. There is no supports from the health department in the form of neither supplements nor vitamins. The health department conceives that it should be the responsibility from the social department, because it concerns about the children welfare. The health department of Surakarta has a regulation product which is the Local Regulation of Surakarta No.12 in 2014 about the Prevention and Treatment of HIV/AIDS. In that regulation, it is not mentioned specifically about the treatment, medication, and rehabilitation for ADHA.

Succeeding elements of collaborative governance done between the social department and Lentera Foundation:

### 1. Networked structure

According to Jones (in Sudarmo, 2011), network must not form hierarchy because it will not be effective and the network structure must be organized and as even as possible which is there is no authority hierarchy, domination, and monopoly, everything must be equivalent in terms of obligation, responsibility, authority, and chance for the sake of the main goals. Between the Lentera Foundation and Social Department, there is no hierarchy formed. There is no stages that identifies Social Department is higher than Lentera Foundation and vice versa. Each of them has its own responsibility and chance to make decision.

Theoretically the requirements of the successful collaboration between the Social Department and Lentera Foundation according to the Networked Structure have been fulfilled. However, the problem is that there is still a lack of commitment from the members proven in Table 1. More discussions will be continued in the following element.

### 2. Commitment to common purpose

The commitment of each institution is different from one stakeholder and the others. The form of the commitment of Surakarta Government is giving protection to the children which is listed in RPJMD and the regulation products existed. In the Intermediate Phase of Local Construction Plan of Surakarta in the year of 2016-2021 "to improve the family welfare it is needed to involve the cross-sectoral collaboration and coordination". One of the regulation products is the Local Regulation of Surakarta No 4 2012 about Children Protection.

There is still a lack of commitment of the Social Department members in searching for shelter for Lentera Foundation. The shelter issue has not been realized because there is a rejection from the local residents who disagree if there are ADHA in their environment. It causes the Lentera Foundation do not believe the enticements from the Social Department in relation to the shelter issue.

The most crucial department that has to give protection to the children is the PP PA and PM Department. The children protection department has the responsibility in arranging the policy about the children protection and welfare, however up to this point the policy product of the

Local Regulation of Surakarta No 4 2012 about Children Protection made by Surakarta Children Protection Department has not responded the needs of the HIV/AIDS infected children.

From the facts above, it can be concluded that the commitment toward the shelter provision to the children with HIV/AIDS (ADHA) really varies, even there is a party who only contributes in the form of regulation. Statements from the Lentera Foundation that disbelieved the Social Department promise in providing shelter will be discussed in the following section.

### 3. Trust among participants

It is the belief that the participants entrusted to the information or efforts from the other stakeholders in a network to achieve the union's goals (Sudarmo, 2011). It means that each stakeholder in a network must trust each other. Surakarta Government has promised to provide shelter for Lentera Foundation, however that it has not been granted up to this point, if in the end of 2017 Surakarta Government has not granted the shelter facilities, Lentera Foundation will demand back Surakarta Government's promise.

According to Mr. Puger's statement, that issue is just Surakarta Government's gimmick, because at that time there was an evaluation of Children-Friendly City, so that many political elements put in order to make Surakarta look good in handling children protection. That thing causes Lentera Foundation distrust Surakarta Government. If there is no more trusts between work partners, it is proven that in the matter of collaboration is already in the edge of ending point. (Huxham, 1996) states that trust and respect is important if collaboration is to be successful and enjoyable and communication and trust very important are typical and indicate that the existence of trust between the parties involved is seen as an important success factor.

### 4. Governance

In the boundary point of view, there is no clarity about who the members of the collaboration are. In the rules point of view, there are no rules or MoU that regulates the collaboration between the Social Department and Lentera Foundation. Both of them collaborate because it is based on their responsibility in carrying out their job. Surakarta Social Department has the responsibility to guarantee PMKS welfare, while Lentera Foundation has the responsibility to take care of ADHA. This collaboration is free and flexible. In the matter of network management, this collaboration is still having conflict which is the

department's responsibility that is handing over about the AIDS issues. One day Lentera Foundation was asked to take care of an AIDS infected woman from the Social Department, but Lentera Foundation rejected the request because they only take care of children infected with HIV/AIDS, their financial resources were also low.

#### 5. Access to authority

Access to authority is the availability of the clear procedural term standards which are widely accepted, but the collaboration made between the network currently does not have any clear regulations (SOP).

#### 6. Distributive accountability

If the members do not want to be involved in the network / collaboration goal making and do not want to bring their resources or authority into the network, there will be a probability that the network will fail to achieve its goals (Sudarmo, 2011). That is why collaboration is needed between institutions to make it come true. Each of the department has a different responsibility. The responsibility upon the protection of the children with HIV/AIDS (ADHA) in Lentera Foundation is an important thing to be done. However, the fact that the Health Department who is in charge in giving health services has not given the resources possessed. It is proven that the supplements and vitamins logistics are still Lentera Foundation's burden.

Lentera Foundation has several human resources but they are not involved enough in policy/regulation making. The impact is that the current regulation/policy still does not respond the ADHA needs. In the end, every policy made affects the future of the children with HIV.

#### 7. Information sharing

Lentera Foundation has a difficulty in accessing information about children. For example Lentera Foundation does not get the explanation from the Social Department about the reason why they still do not get promised shelter, whereas the social department previously stated that Lentera Foundation will get a shelter in an ex local government clinic in Setabelan. That thing was stated when there was a visit from the Indonesian PP PA Ministry to Solo. However, after the visit was over, the shelter was not given to Lentera Foundation. From the statement above, it is emphasized that it is still hard to access information between Social Department and Lentera Foundation.

#### 8. Access to resources

Every form of treatment and medication of ADHA is paid by using personal money of Mr. Puger that is obtained through the result of his work as a park man in Indosat Purwosari. Besides that, there is also a grant from the Vice Major of Surakarta for each ADHA 2.000 rupiahs every day. That money is just enough for eating, while it is not enough to pay the treatment fee. To increase the living money for the ADHA, Mr. Puger has already tried to submit a request proposal in Solo Peduli, but it was rejected without any reasons. Surakarta Lentera Foundation also does not get any supports from the Surakarta APBD estimation for the treatment fee of ADHA. So that in this case, Lentera Foundation needs an abundant financial resource, because the needs of HIV infected children are different from the normal ones. They need supplements, ARV medicines, and therapy. The availability of the economic resources become the collaboration problem in providing protection for ADHA.

## 5 CONCLUSIONS

The collaboration exists to provide protection for the children with HIV/AIDS (ADHA) in Lentera Foundation is not effective yet because there are succeeding elements which are not fulfilled which is commitment implementation, the lack of trust between networks, the unfulfilled governance factor, no procedure in collaboration implementation, no responsibility division between networks, a difficulty in accessing information, and also limited economic resources especially finance to pay the treatment and medication for ADHA.

Children with HIV/AIDS (ADHA) have received their protection rights in matter of health sector which is treatment and medication; education sector which is attending formal school even though their status is hidden; social sector which is protected from discrimination and freedom of socializing with other people; regulation sector which is proven with major rules No. 28-D in 2014 about Children-Friendly School and local regulation of Solo No.12 in 2014 about the prevention and treatment of HIV/AIDS, but there is still a lack in Surakarta local regulation of children protection which has not explained the special protections for ADHA.

## REFERENCES

- Ansell, C. a. 2009. Collaborative Governance in Theory and Practice. *University of California Berkeley*.
- Huxham, C. a. 1996. Working Together : Key Themes In The Management Relationship Between Public And Non Profit Organization. *Journal Of Public Sector Management, Public and Voluntary Organization*.
- Niko, N. 2014. Peranan Komisi Penanggulangan AIDS (KPA) Dalam Upaya Mengurangi Stigma Sosial Bagi Orang Dengan HIV Dan AIDS (ODHA) di Kota Pontianak. *Jurnal S-1 Progam Studi Sosiologi* , 1 - 8.
- Oktaviani, A. N. 2017. *Diusir Warga, Dilarang Sekolah, Ditolak RS*. Surakarta: Jawa Pos.
- Rosalin, L. 2015. *Kabupaten/Kota Layak Anak*. Jakarta: Deputi Tumbuh Kembang Anak Kementerian PP PA Republik Indonesia.
- Sudarmo. 2009. Elemen - Elemen Collaborative Leadership dan Hambatan - Hambatan Bagi Pencapaian Efektivitas Collaborative Governance. *Jurnal Spirit Publik*.
- Sudarmo. 2011. *Isu - Isu Administrasi Publik Perspektif Good Governance*. Surakarta: Smart Media.
- Susanto, A. 2016, 11 18. *Juru Parkir Selamatkan Anak - Anak Yang Hidup Dengan HIV/AIDS*. Retrieved from Rappler.com: [www.rappler.com/indonesia/143499-juru-parkir-selamatkan-anak-anak-dengan-hiv-aids-yang-terbuang](http://www.rappler.com/indonesia/143499-juru-parkir-selamatkan-anak-anak-dengan-hiv-aids-yang-terbuang).
- Unicef. 2007. Enhanced protection for children affected by AIDS. A companion paper to the framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS. New York [http://www.unicef.org/publications/files/Enhanced\\_Protection\\_for\\_Children\\_Affected\\_by\\_AIDS.pdf](http://www.unicef.org/publications/files/Enhanced_Protection_for_Children_Affected_by_AIDS.pdf).
- Unicef. 2012. State of the world's children. New York. In Mann, Gillian, Sian Long, Emily Delap, and Lucy Conneli. 2012. Children living with and affected by HIV in residential care. [http://www.crin.org/docs/HIVandResCare\\_FinalWeb%20%28%29.pdf](http://www.crin.org/docs/HIVandResCare_FinalWeb%20%28%29.pdf).
- Unicef. 2017. A City Belongs To Children: How Surakarta Establishes Its Trademark As A Child-Friendly City, 10/03/2017.
- WHO 2013. HIV/AIDS. [http://www.who.int/topics/hiv\\_aids/en/](http://www.who.int/topics/hiv_aids/en/).
- Undang-Undang No. 35 Tahun 2014 tentang Perlindungan Anak.
- Perda Kota Surakarta No. 4 Tahun 2012 tentang Perlindungan Anak.
- Perda Kota Surakarta No. 12 Tahun 2014 tentang Pencegahan Penanggulangan HIV/AIDS.
- Perwali Surakarta No.28-D Tahun 2014 tentang Sekolah Ramah Anak.
- RPJMD Kota Surakarta Tahun 2016 – 2021.