

# Empowerment Based on Collaborative Governance in Leprosy Patients In Central Java

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## ABSTRACT

Collaborative governance is one of the studies echoed recently in government structures to involve non-government institutions in making collective decisions on problems that exist in society. One of the empowerments is intended to leprosy patients. This article writing aims to see how empowerment is carried out on community / collaborative governance-based leprosy patients in Central Java, especially in Jepara Regency as an area with the highest number of leprosy sufferers. The research method used is a qualitative one in order to obtain comprehensive information. The approach used in writing this article is field studies and hearings at agencies involved in the empowerment process and the leprosy patient community. In principle, there are three aspects in the community empowerment process: creating a climate for community potential development; strengthening community potential, and protecting community rights. The results obtained from this study are, in the process of empowering and the efforts taken by the hospital and other government agencies in the process of increasing community empowerment, especially leprosy patients are to hold various kinds of training and activities that are really beneficial for the community of leprosy patients to interact with the outside community. In addition, at the Donorojo Hospital, there are leprosy patients who are appointed to be state officials indicating their openness to leprosy patients to develop. The agencies involved are, among others, Donorojo Hospital, Jepara District Social Service, Jepara District Bureaucracy and NGOs from abroad such as NLR (Netherland Leprosy Research) and LCC (Leprosy Care Community) from Japan.

**Keywords:** *Negative stigma, leprosy, cross actors, collaborative governance, empowerment.*

## 1. INTRODUCTION

Discussing matters related to empowerment, there are two views regarding empowerment: the developmental and anti-developmental groups. The developmental group views the final estuary highlighting the aspects of helplessness, poverty, limited access that should be obtained by every

member of the community, and improved quality of life and community development itself [1], [2], [3], [4]. Meanwhile, the anti-developmental group believes that empowerment must obtain inclusive democracy, economic growth, gender equality as a form of liberation, and fundamental structural transformation, increase the power of a person, influence the elite and make elite alliances, and create a fair and civilized atmosphere. [5], [6], [7]. From what is stated above, it can be concluded that empowerment is an action taken to enable the

unable and powerless people, so that they have the ability of competing in the economic, political, and social fields.

Leprosy is a disease that has been encountered for a very long time and this can be traced [8]. This disease is a contagious disease by mycobacterium leprae affecting the nerves of the limbs, skin, eyes and respiratory tract [9], [10], [11]. The process of leprosy transmission is by long-term skin contact and improper handling [12], [13]. In the empowerment process, in order to get maximum results, it requires cooperation with various sectors, both government and private. As contained in the WHO program [14] "Global Leprosy Strategy" which states that in dealing with leprosy problems, both in healing the disease and empowering patients, cooperation/collaboration from various parties from government and outside of government is needed.

Based on a report from the Center for Data and Information of the Ministry of Health of the Republic of Indonesia as of April 2018, Central Java is on the third number among the areas with largest leprosy sufferers in Indonesia following West Java and East Java [11]. Donorejo Hospital's report, Kelet, Central Java which specializes in handling leprosy said that the largest distribution of leprosy in Central Java is in Jepara Regency out of 16 districts in Central Java. There were 185 people in 2017, 136 people in 2018 and 113 people were hospitalized in 2019 [15]. The problems faced in this case include inadequate information for the community regarding leprosy for people, officers' poor knowledge on early detection of leprosy, less optimal empowerment of leprosy sufferers which results in a high negative stigma against leprosy patients [16]. One of the main things done in the strategy for handling infectious diseases is to empower people with leprosy [17]. Thus, this article writing aims to see how empowerment is carried out on community / collaborative governance- based leprosy patients in Central Java, especially in Jepara Regency as an area with the highest number of leprosy sufferers.

## **2. LITERATURE REVIEW**

### **2.1 Empowerment**

Community empowerment is the principle of community growth and development that contains social values. This definition represents a new development model, which is "community-centred, participatory, inspiring, and sustainable" [18]. It is broader than simply meeting basic needs or offering a framework for avoiding more cycles of impoverishment (safety nets), and has recently been introduced in an effort to find alternatives to past development principles. This definition arises from the efforts of many experts and practitioners [19] to seek development alternatives that are termed 'including

democracy, sustainable economic growth, gender equality and intergenerational justice'.

The concept above is not against growth and equity, [20] these two things should not be assumed as incompatible or antithesis. This concept seeks to break away from the trap of zero-sum games (win-lose solutions) and trade-offs [21]. This departs from the opinion that through equity, a broader basis will be created to ensure long-term and sustainable growth. The view sees "growth pattern is as important as growth rate" [22]. The right types of growth are broad-based, labour-intensive, and not compartmentalized [23].

Community empowerment can be seen from several aspects [21]: firstly, creating a climate that can develop the potential of the community, where the main basis is to introduce that everyone in a community or society has the potential to develop. In other words, there is no helpless society. Because empowerment is an effort to build that power by encouraging, motivating and building awareness of the potential possessed by each person and trying to develop it.

Secondly, it can be seen from the aspect of strengthening the potential of the community. In this context, positive steps are needed. Apart from just creating a climate and atmosphere, the strengthening (reinforcement) carried out involves concrete actions, input from various stakeholders as well as open access to various opportunities which in turn will make the community more empowered.

In the context of empowering people with leprosy, the efforts made are to increase the standard of living (improving the economy), health status, confidence of each community member in facing the stigma circulating, and access to agriculture and markets. Inputs related to this empowerment include the construction and provision of basic facilities and infrastructure such as irrigation, agricultural fields, road access, electricity, education services without exception for children with leprosy, health services that can be reached by the community, as well as the availability of access to marketable crops and livestock cultivation without any price differences.

Thirdly, empowerment implies protecting. In the empowerment process, one must be able to make the weak people stronger. In that sense, there is a partiality for the weak (leprosy patients) in creating independence for leprosy patients who are unable and are always looked down upon. Taking sides or protecting the weak, in this case, the leprosy patient community is fundamental to the empowerment process. Taking sides or protecting these does not isolate oneself from the existing interactions but in order to prevent exploitation and adverse competition against leprosy patients who have always been looked down on and have limitations.

The empowerment of leprosy patients is not only to create a sustainable dependency and to expose the program that has been launched, but also to be able to compete following the existence of empowerment activities/programs. In other words, the empowerment program can be independent, enable and create competitiveness without any harmful exploitation over leprosy patients so that they have a better and sustainable life.

## 2.2 Collaborative Governance

Collaborative governance is the governance regulating public institutions by involving non-governmental stakeholders in formal, agreement-oriented decision making and aiming to implement Policies and/or collective asset management [24]. Six essential requirements are emphasized on in this definition:

- (1) the forum shall be sponsored by a public agency,
- (2) to involve non-state actors in the forum;
- (3) members are interested actively in decision-making and are merely "consulted" by governmental bodies;
- (4) the forum is professionally organized and will meet together,
- (5) The purpose of forum is to make decisions by consensus (even if there is no consensus in practice), and
- (6) The partnership shall concentrate on public policy or public administration.

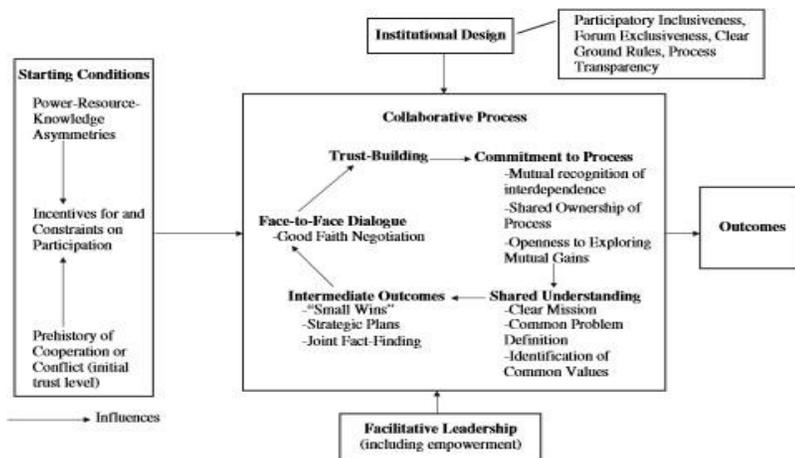


Figure 1. Model of CG by Ansel and Gash, 2008.

Ansell and Gash (2008) present a collaborative governance model with four main variables: initial conditions, institutional design, facilitative leadership, and collaborative processes. Collaborative process is concerned with face-to-face dialogue, commitment to the process, building trust, mutual understanding, and results. Any collaborative governance is implemented through a face-to-face dialogue process among stakeholders. As a consensus-defined process, the dialogue is urgently needed by stakeholders to identify consensus. The institutional design establishes the ground rules by which collaboration occurs.

The focus on collaborative governance is on collective decision making, meaning that governance is not about one person but about groups of individuals or organizations make decisions [25]. Collaborative governance is a form of governance regulating public institutions by involving stakeholders and holding the principle of equality of relations between stakeholders in public, private and community sectors based on mutual agreement (consensus) [24], [26], [27].

Emerson, et al [28] presented an integrative framework for collaborative governance. This framework provides a

broad conceptual map in-depth of all components of cross-border governance systems concerning collaborative policies. The integrative framework involves system control, collaborative governance regimes and collaborative

dynamics. The third dimension consists of three elements: principled involvement, mutual motivation and capacity to take collective action. The following is a picture of the framework.

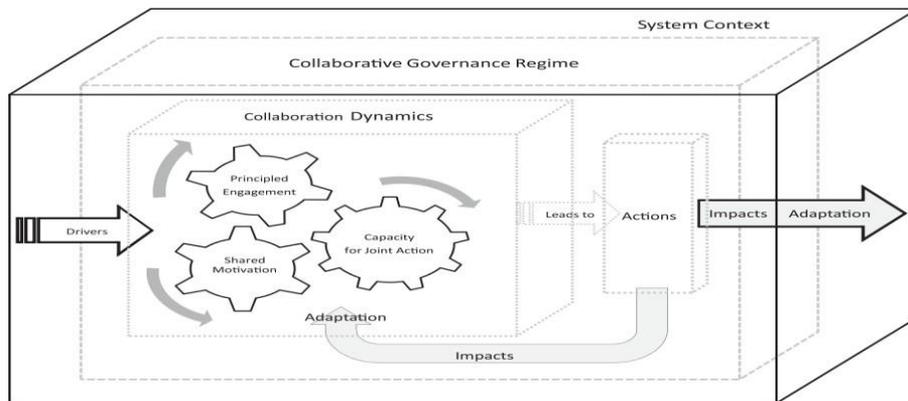


Figure 2. Framework of CG by Emerson, et al (2011).

Collaborative governance regimes (GCR's) are described as dotted boxes containing collaborative dynamics and collaborative action. Collaboration dynamics consist of three interactive components: principled engagement, shared motivation and the capacity to take collective action. In its development, Emerson (2015b) refined the indicators used to improve performance. There are three indicators to improve performance: action/output, outcome and adaptation. Meanwhile the unit of analysis includes organizational participation, collaborative regime and target objectives.

and data sources [32]. The purpose of triangulation technique use is to determine convergent, contradictory and inconsistent data. Therefore, it is hoped that through using this triangulation technique, the results will be consistent, sure and thorough. So, the stages carried out in this process include:

### 3. METHODS

The focus of this paper is on collaborative governance-based empowerment for leprosy patients in Central Java. It started with the government agency in the health sector, i.e. the Donorejo Hospital of Leprosy, Central Java, as an agency that deals with leprosy problems in Central Java. The author used qualitative methods in order to obtain comprehensive information. Qualitative research [30] is the one resulting in findings that cannot be obtained using statistical procedures or by means of other means of quantification (measurement). A qualitative approach is a research approach based on phenomenology and the constructivism paradigm in developing science [31]. Technique of collecting data used was triangulation. Triangulation technique is interpreted as a form of combining several existing data collection techniques

### 3.1. Observation

The purpose of observations is to observe directly the object of research and problems occurring in the field. This observation was carried out when first entering into the object of research related to the empowerment of leprosy in Central Java, especially in Jepara Regency, that is, the area with the highest leprosy sufferers in Central Java. Furthermore, recording is made on every incident that occurring while in the location becoming the object of research. This aims to ensure that the problem occurring is in accordance with the events in the field, or in other words as comparative data between expectations and reality.

### 3.2. Interview

In the interview process, there are three models, including:

#### 3.2.1 Structured interview

Researchers have already known exactly what will be discussed and questioned by informants. In other words, what will be asked is in accordance with predetermined procedures. Thus, the interviews are more focused.

#### 3.2.2 Semi-structured interview

This system is included in the in-depth interview, where the researcher has the stages of questions to informants, but not as detailed as the one in structured interviews. Researchers can question many things from each informant's answer they consider that what is conveyed still requires a more in-depth explanation. Thus, the information to be obtained is more in-depth and comprehensive.

#### 3.2.3 Unstructured interview

This interview was conducted independently by the researcher, where the researcher did not use an interview guide, was not systematic in the process of obtaining data.

### 3.3. Documentation

In the process of research, the documentation used is a recording of events occurring during this research and is related to the locus of research in the form of images, monumental works or images.

## 4. RESULT AND DISCUSSIONS

### 4.1 Leprosy Patients Empowerment

Community empowerment is the principle of community growth and development containing social values. This definition represents a new development model, which is "community-centred, participatory, inspiring, and sustainable" [18]. If we look at the community empowerment program for leprosy patients in Jepara, Central Java, there will be various programs in the community empowerment process. In principle, the community empowerment program has three aspects: Creating a climate for community potential development; strengthening community potential; and protecting community rights.

A more in-depth explanation will be discussed in accordance with the empowerment program carried out by the government through the existing network for community empowerment programs for leprosy patients in Central Java, especially in Jepara Regency.

#### 4.1.1 Creating a climate that can develop the potential of the community.

The main basis is to introduce that everyone in a community or society has its own potential to be developed. In other words, there is no helpless society. Because empowerment is an effort to build that power by encouraging, motivating and building awareness of the potential possessed by each person and trying to develop it.



**Figure 4. Empowerment Program**

Figure 4 shows that the Donorojo hospital programs in the community empowerment process for patients with leprosy are, among others, in the fields of agriculture, agricultural plantations and crafts. The empowerment of leprosy patients is expected to raise a fighting spirit from a downturn which has been seen as having disability/helplessness in all fields.



**Figure 5. Leprosy Patient Empowerment to make a bird cage**

In figure 5, it can be seen that the empowerment program for leprosy patients in the field of handicrafts produces bird cages with a quality that can compete with other craftsmen who are not leprosy patients. This is a process initiated by the Donorojo Hospital, so that the negative stigma developing for leprosy patients can be put aside and even eliminated.



**Figure 6. Leprosy Patient Empowerment, Art of Carving.**

Figure 6 shows that the process of empowering leprosy patients in terms of crafting in sculpting was carried out by the Donorojo Hospital in collaboration with the social service, bureaucracy of Jepara district.

#### 4.1.2 By strengthening the potential of the community.

In order to strengthen the potential of the community, positive steps are needed. Apart from just creating a climate and atmosphere, Strengthening carried out involves concrete actions, input from various stakeholders as well as open access to various opportunities which in turn will make the community more empowered. Efforts made are to improve the standard of living (improving the economy) and health status, to increase the confidence of each member of the community is facing the stigma that is circulating, and to increase access to agriculture and markets. Inputs related to this empowerment include the construction and provision of basic facilities and infrastructure such as irrigation, agricultural fields, road access, electricity, education services without exception for children with leprosy, health services that can be reached by the community, as well as the availability of access to marketable crops and livestock cultivation without any price differences. For this reason, we can see the figure below dealing with strengthening community potential in the empowerment process



**Figure 7. Leprosy Patient Empowerment (Wasis People).**

From Figure 7, it can be seen an attempt has been taken by the hospital to empower the leprosy patient community, by means of a program called "wasis people ". This meaning is intended to provide understanding in the fields they are in, or in other words, to create superior Human Resources in their respective fields. For example, providing skills and understanding in the fields of fisheries, animal husbandry increased creativity which will later be utilized by leprosy patients in improving their standard of living.



Figure 8. Entrepreneurial Community Empowerment.

Figure 8 shows that there is an empowerment program carried out to improve skills in implementing entrepreneurship without having to think about and be ashamed of the status as a leprosy patient, and to grow assumption that the degree to every human being is the same if you want to try.

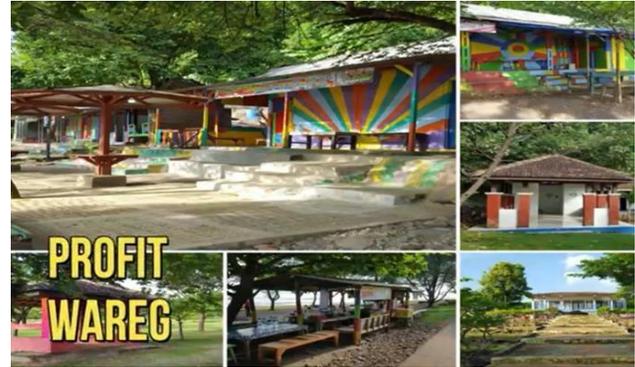


Figure 10. Stalls along with the Goamanik Tourism Center.

The empowerment program related to "profit ware" is the provision of tourist sites for the trading community. However, the traders are the general public whose raw materials are provided by the leprosy patient community. Thus, there is a bond of interdependence among the community.



Figure 9. LIPOSOS PACA in Donorojo Village, Jepara District.

Here is a leprosy village, which is indeed provided by the government through the Donorojo Hospital for leprosy patient settlements so that they can interact with each other and encourage one another. In this location, there is also a post called the Social Lodge for Ex-Disabled Leprosy Patients. This place is a location for activists and social institutions that will contribute their ability and energy to providing counselling and empowerment for people with leprosy patients to be able to rise, to compete and to empower their lives so as to get rid of the bad stigma that is given to them.

#### 4.1.3 Empowerment means protecting.

In the empowerment process, one must be able to make the weak people stronger. In that sense, there is a partiality for the weak (leprosy patients) in creating independence for leprosy patients who are unable and are always looked down upon. Taking sides or protecting the weak, in this case, the leprosy patient community is fundamental to the empowerment process. Taking sides or protecting these does not isolate oneself from the existing interactions but in order to prevent exploitation and adverse competition against leprosy patients who have always been looked down on and have limitations. The empowerment of leprosy patients is not only to create a sustainable dependency and expose the program that has been launched, but also to be able to compete after the empowerment activities/programs exist. In other words, the empowerment program can be independent, enable and create competitiveness without any harmful exploitation for leprosy patients, so that they have a better and sustainable life.

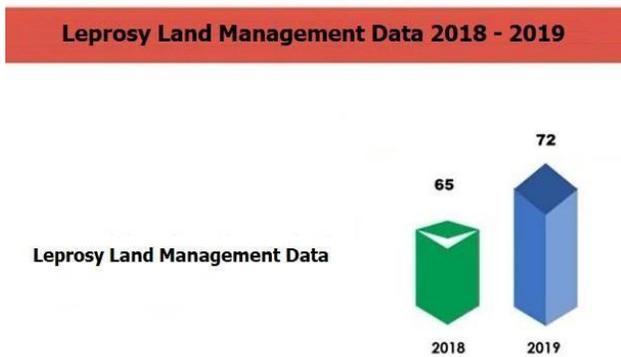


Figure 11. Leprosy Land Management

If seen from the data above, there is an increase in the number of leprosy patients involved in land management. Which is 2018 there were 65 people, while in 2019 there was an increase to 72 people. In the sense, the empowerment of leprosy patients will always be implemented and prioritized in order to strengthen their position as community members who must obtain equal rights in the life of a state.



Figure 12. Data on Cooperation Cultivators of Plantation Land

Whereas, the data in figure 12 shows that the cooperation in managing agricultural land between the general public and leprosy patients has increased, in which there were only 24 people in 2018, increasing to 60 people in 2019. So, from the data above, it can be concluded that there has been a negative paradigm shift or stigma against leprosy patients.

*Collaborative Governance the Process of Empowering Leprosy Patients*

If we discuss collaborative governance in the process of empowering leprosy patients, of course, there will be governance regulating public institutions by involving non-governmental stakeholders in formal, agreement-oriented decision making and aiming to implement policies or manage public assets [24]. Thus, there are six important criteria that become benchmarks, especially in the process of community empowerment for leprosy patients in Donorojo Village, Jepara Regency, Central Java:

1. forum initiated by a public institution or institution,
2. forum participants including non-state actors,
3. participants directly involved in decision making and not only "consulted" by public bodies,
4. the forum formally organized and meeting collectively,
5. the forum aiming to make decisions by consensus (even if consensus is not reached in practice), and
6. the collaboration focusing on public policy or public management.

In the collaborative governance process, the initiators of the empowerment program come from government agencies Donorojo Leprosy Hospital, Jepara Regency Social Service, Jepara Regency People's Welfare Bureau and NGOs from abroad, namely Netherland Leprosy Research (NLR) and Leprosy Care Community (LCC) from the State Japan.

**5. CONCLUSION**

In principle, there are three aspects in the community empowerment process: creating a climate for community potential development; strengthening community potential, and protecting community rights. The results obtained from this study are, in the process of empowering many things and efforts have been taken by the hospital and other government agencies in the process of increasing community empowerment, especially leprosy patients with various kinds of training and activities that are really beneficial for the community of leprosy patients to interact with the outside community. In addition, at the Donorojo Hospital, there are leprosy patients who are appointed to be state officials indicating their openness to leprosy patients to develop. Some of the agencies involved include Donorojo Hospital, Jepara District Social Service, Jepara District Bureaucracy and NGOs from abroad such as Netherland Leprosy Research (NLR) and Leprosy Care Community (LCC) from Japan.

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