Influencing Disability Rights: The Role of FKDK in the 2021 Kudus Regency Law

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Abstract. This study examines the involvement of people with disabilities in the policymaking process of the Disability Regional Regulation in Kudus Regency, which was passed in November 2021. The Forum Komunikasi Disabilitas Kudus (FKDK) played a crucial role in initiating and supporting the regulation's ratification. Using a descriptive qualitative approach, primary data were collected through in-depth interviews with the head of FKDK and a member of parliament, while secondary data were gathered from FKDK's social media, news articles, journals, and other relevant sources. The findings reveal FKDK's involvement through three key approaches: the positional approach as the initiator of the regulation, the reputational approach involving networking and lobbying with decision-makers, and the decisional approach ensuring the inclusion of key issues in the regulation's final draft. This study highlights the significant role of disability groups in shaping local policies to protect and fulfill the rights of persons with disabilities.

 $\textbf{Keywords:} \ disability, FKDK, policy making, policy analysis, regional \ regulation$

1 Introduction

People with disabilities are the largest minority group in the world. The number of people with disabilities is estimated to be 15 percent of the world's population of more than one billion people. 82 percent of people with disabilities live in developing countries. They often experience discrimination and access difficulties in various fields, including economics, politics, education, health services, as well as social and cultural life [1]. This difficult access results in them living below the poverty line. The Central Bureau of Statistics (BPS) reported that there are 22.5 million of people with disabilities in Indonesia which is amounted to five percent of the total population of Indonesia [2].

People with disabilities in Indonesia are mostly having low levels of education, health, less access to public services, and less access to economy opportunities [3]. These obstacles are the results of negative stigma, attitudes and inaccessible law which failed to give the protection and fulfillment of disability rights [4].

Accessibility is then required to ensure the full participation of people with disabilities in various aspects of social life including socio-economic, health, education, employment, and self-development facilitation. Among others, the socio-economic aspect is one of the crucial aspect as it is related to the level of welfare as well as public awareness and openness to the people with disabilities' right [5].

Addressing the challenges to protect and to fulfill disability rights, the Indonesian Government passed Law Number 4 of 1997. This law ensures equal rights and opportunities for individuals to achieve a decent standard of living, access employment, education, and participate fully in national development. Additionally, the government ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) on March 30, 2007. To formalize this commitment, the government enacted Law Number 19 of 2011, which ratified the UNCRPD. This law was later updated and replaced by Law Number 8 of 2016.[6].

This law defines person with disabilities as those experiencing physical, intellectual, mental and/or sensory limitations for a long period of time which challenge them to participate fully as the citizen to actively engage in social endeavors. [7]. In the new policy there has been a paradigm shift and a new approach. Previously, the approach developed in support was a social welfare paradigm which viewed people with disabilities as objects of development. The stigma that has been growing in society often sees people with disabilities as someone who is medically incapacitated. Meanwhile, the paradigm of conservative groups believes that the condition of disability is God's will, so that people with disabilities are seen as people who are unlucky and have social disabilities. [8].

In the new approach, people with disabilities must be seen as development subjects who are able to contribute and participate actively. As a result, both central and regional governments are required to implement the provisions outlined in the law, including the development of necessary facilities and infrastructure. To date, approximately 112 districts and cities have established Regional Regulations aimed at protecting and fulfilling the rights of persons with disabilities [9]. The Regional Government of Kudus Regency passed regulations related to disabilities through Law 10 Year 2021 Regarding Protection and Fulfillment of The Rights of Persons with Disabilities.

Based on SUPAS BPS Central Java data, the number of people with disabilities in Kudus Regency over the age of 10 years is: 23,716 people with functional visual difficulties; 13,916 people had functional hearing difficulties; 19,750 people have functional difficulty walking or climbing stairs; 5,888 people have functional difficulty using their hands or fingers; 15,761 functional memory difficulties; 5,415 behavioral or emotional functional difficulties; 7,184 people have functional difficulties speaking, and 5,891 people have functional difficulties taking care of themselves [10].

With the large number of people with disabilities as above, there is an articulation of the interests of groups of people with disabilities, one of which is the Kudus Disability Communication Forum (FKDK). The founder of this community, Rismawan Yulianto, stated that there are still many people with disabilities whose rights have not been fulfilled, especially in the fields of education and employment. For this reason, FKDK encourages legal protection at the regional level to protect and fulfill the rights of persons with disabilities. Forum Komunikasi Disabilitas Kudus (FKDK) is a forum for people with disabilities to organize themselves. Through this community, people with disabilities support each other and encourage the realization of an inclusive Kudus Regency.

This research focuses on The Role of Forum Komunikasi Disabilitas Kudus (FKDK) in The Policymaking of Regional Regulation of Kudus Regency Law 10 Year 2021 Regarding Protection and Fulfillment of The Rights of Persons with Disabilities. To address the research

focus, research question is formulated as follow: What is the role of the Kudus Disability Communication Forum to encourage the ratification of regional regulations regarding the protection and fulfillment of the rights of persons with disabilities in Kudus Regency. With a qualitative methodology, this study collected the data through interview with the head of Forum Komunikasi Disabilitas Kudus (FKDK), Disability Activist, and the member of DPRD Kudus regency. In addition, secondary data were employed to support the primary data in form of documentary analysis from reputable journals, books, the internet, other written sources relevant to the research topic. Further, data was analyzed following the qualitative data analysis consisting several steps including data familiarization, data coding, thematic clustering, and drawing themes. Forum Komunikasi Disabilitas Kudus (FKDK)

2 Forum Komunikasi Disabilitas Kudus (FKDK)

The Kudus Disability Communication Forum (FKDK) is a forum for people with disabilities to organize themselves. People with disabilities often face significant challenges, including lower levels of education, poor health, inadequate public services, and limited economic opportunities. Additionally, they encounter psychological barriers stemming from negative societal stigma, which often portrays them as helpless or incapable. Unfortunately, this stigma can also extend to their families, who should ideally serve as a source of support, helping to build self-confidence and empowerment. As a result of these societal attitudes, people with disabilities may experience feelings of inferiority, leading them to withdraw from social interactions and isolate themselves. These persistent challenges have motivated individuals with disabilities to create support forums where they can come together to seek solutions and advocate for their rights. FKDK was founded on November 20, 2014. Initially FKDK was a three-wheeled community called the Kudus Disabled Motorcycle Community (KMDK). KMDK has been running for 2 years but has not been able to provide benefits for other people with disabilities. FKDK had the initial goal of fighting for the rights of people with disabilities. FKDK wants to realize the welfare of people with disabilities in the inclusiveness of Indonesian society. By requesting the legality of the notary's deed and the Kudus Government in 2016, the FKDK was officially recognized by the government [11].

FKDK has the spirit to aid and advocacy to its members so that a generation with disabilities is formed that is independent and not dependent on other people, so that people with disabilities are no longer pitied but are able to be useful to society according to their capacities. People with disabilities also can be skilled in their respective fields and meet their daily needs. The aim of empowerment in groups of people with disabilities is to increase participation of people with disabilities in social life. And as a form of participation in groups of people with disabilities for productive activities to encourage economic growth by people with disabilities.

FKDK has a vision to realize an inclusive society that upholds the honor and dignity of disabled people to live with equality and justice in the economic, social, cultural, political, legal, as well as technology and public service fields. Meanwhile, FKDK's missions include: a) research and updating data and information regarding disabilities; b) carrying out inclusive education campaigns and education; c) advocating for public policies that are friendly and accommodate the rights of people with disabilities in Kudus Regency; d) Helping to increase the abilities and self-confidence of people with disabilities in Kudus; e) carry out massive collective action [11].

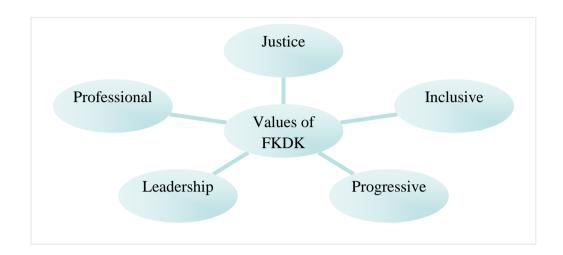


Figure 1. Values of Forum Komunikasi Disabilitas Kudus (FKDK)

FKDK highly upholds the values of justice and equality, especially for people with disabilities. Structural and cultural marginalization of people with disabilities is a concern for the disability community. In this way, FKDK states that it will fully side with the disabled community. FKDK also propose to create an inclusive climate in the social life of the disabled community. Inclusive means that there is no marginalization of people with disabilities in social life, education, health, employment, accessibility and so on. Disabled people also have the right to be given the same rights as the general public and to be given special disabled facilities so that disabled people can more easily access public facilities [11].

In carrying out the empowerment movement, disabled people are not only beneficiaries of the programs that have been implemented but are also leadership figures played by disabled people in realizing change for disabled people. The FKDK community intend to create transformation that affect the lives of people with disabilities, thus FKDK always requires progressiveness in carrying out various programs on the agenda and also prove their professionalism through real action to fight for the rights of people with disabilities, especially in Kudus [12].

Regarding data collection on people with disabilities in Kudus Regency, Rismawan as the head of FKDK stated that there is no definite data regarding the number of people with disabilities in Kudus Regency. It has been guided by data from the Kudus Regency Regional General Election Commission (KPUD), which is the permanent voter data collection mechanism (DPT). However, not all people with disabilities are registered as DPT due to various inhibiting factors. Rismawan hopes in the future that data collection on people with disabilities can start from the village level. Therefore, disability empowerment reaches more targets. In the 2018 Kudus Regency Regional Head Election (Pilkada), the number of DPTs with disabilities was obtained as follows:

Table 1.

Number of Persons with Disabilities in Kudus Regency Based on Calculation of the Permanent Voter
List in the Kudus Regional Election in 2018

Disability as DPT	Sex	Number
Persons with Disabilities who are registered as DPT	Male Female Total	420 423 843
Persons with Disabilities who are registered as DPT and using voting rights	Male Female Total	127 110 237

Source: Kudus Regency General Election Commission

Political participation of person with disability in general or regional election often suffers various obstacles. Several significant obstacles negatively impact engagement people with disabilities in political life include lack of access to parliament and information about political issues, inadequate support, stereotypes applicable regarding persons with disabilities and their possible contribution on political processes and decision making. Exclusivity in the policy-making process increasingly marginalized people with disabilities. For this reason, efforts are needed to ensure that people with disabilities can play an active role in social and political life, and a policy framework is needed that can accommodate this group so that a society that respects each other is created. [13].

3 The Policymaking of Regional Regulation

Policymaking is a cyclical process that begins with the agenda-setting stage, where a significant public issue is recognized and defined, prompting a call for government action. It can be understood as a step-by-step sequence, where policies are developed and implemented through a series of stages.

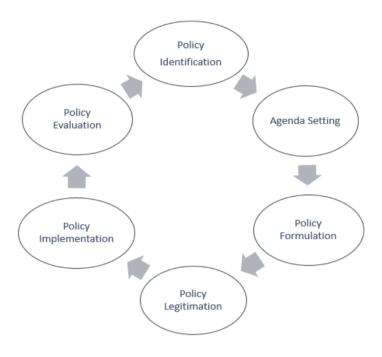


Figure 2. Policymaking Cycle by Thomas R. Dye

3.1 Policy Identification

In the policy identification stage, the focus is on raising awareness of societal issues and advocating for government action. Key participants in this process include the mass media, interest groups, citizen initiatives, and public opinion. To formulate Regional Regulations aimed at protecting and fulfilling the rights of people with disabilities, the Kudus Disability Communication Forum (FKDK) plays a crucial role as an interest group. FKDK actively advocates for the rights and protection of people with disabilities in Kudus, ensuring their voices are heard and their needs addressed.

Rismawan Yulianto as chairman of the FKDK identified various forms of discrimination and access difficulties faced by people with disabilities in Kudus Regency, both in the fields of education, economics, health and social culture. In society, people with disabilities still receive a negative stigma, giving rise to a feeling of lack of confidence in being involved and participating in society. Especially for those who experience disabilities in adulthood. In addition, not all families have awareness of self-development with disabilities and not all have sufficient financial capacity to support self-development. Children with disabilities also often experience bullying from their friends at school and in their home environment. This can affect the child's mental state [11].

In the field of work, Rismawan identified that some FKDK administrators and members work as entrepreneurs, this is because it is difficult to find agencies in Kudus, both public and private, that provide opportunities for people with disabilities to work. Several disabled people

who have vehicles are looking for work in factories in Jepara Regency. Jepara Regency already had a Disability Regional Regulation. However, the number of people involved in employment is still minimal because not many people with disabilities have studied up to Senior High School, most only reach Junior High School or Elementary School [11].

In the health sector, families of people with disabilities, especially those with low economic levels, do not have knowledge regarding health facilities that can be accessed by disabled family members. During a visit to a charity event, Rismawan found a child who was having difficulty walking but his parents did not know if the child could receive therapy. Rismawan and the team then aided access health services at the hospital so that the child could receive therapy services. Another thing that Rismawan highlighted was that public facilities were not yet friendly to people with disabilities, making them difficult to access. Such as public spaces, sidewalks, and places of worship that are not yet accessible. Regarding places of worship, Rismawan once published an article in local print media about the difficulties of people with disabilities in carrying out worship in places of worship because the buildings often have stairs. Even though worship is a basic need in everyday life [11].

In overseeing disability issues, Rismawan carries out internal and external consolidation. In internal consolidation, Rismawan strengthens organizational development and management of disabled human resources who are members of it. Rismawan encouraged FKDK members to upskill and improve their education level through the package pursuit program. Education and skills are important capital for people with disabilities to grow into independent and independent humans. Rismawan always emphasizes that it is good for FKDK members not to get used to being dependent on other people, but that everyone has an obligation to develop themselves to achieve a better quality of life. Meanwhile, in external consolidation, FKDK establishes networking with decision makers, stakeholders, media, academics, as well as activists or volunteers. FKDK also continues to carry out massive outreach to the community both directly and through social media, with the aim of fighting society's negative stigma towards people with disabilities. Forms of outreach to the public include the Republic of Indonesia Independence Day ceremony, commemoration of international disability day, and three-wheeled motorbike convoys.

3.2 Agenda Setting

Preparing the agenda is a phase and a very strategic process in policy reality public. In this process there is room for meaning what are called public issues and agendas the public needs to be considered. If an issue has become public issues, and get priority on the agenda public, then the issue is entitled to receive allocation more public resources than any other issue.

The activities in agenda setting are deciding what issues will be decided, what problems will be addressed by government. Participants consist of Elites, including regional heads, house of representative's members, mass media. In fighting for the protection and fulfillment of the rights of persons with disabilities, FKDK articulates interests to decision makers. FKDK built intensive communication and lobbying with several members of the Kudus Regency DPRD. One of them was Yusuf Roni who was chairman of the Kudus DPRD at that time. Yusuf stated that the problems of people with disabilities must be resolved through the umbrella of law. Yusuf sees that there are still many people with disabilities in Kudus Regency who

experience discrimination and have difficulty gaining access in various fields, especially education, health, and social and economic welfare [14].

In 2019, a draft regional regulation regarding the protection and fulfillment of disability rights began to be proposed for discussion at the parliament of Kudus Regency. This regional regulation is an initiative of the parliament of Kudus Regency considering the urgency of this Regional Regulation for people with disabilities, where there are still many rights of people with disabilities in Kudus Regency that have not been accommodated. However, the obstacle at that time was the Covid-19 pandemic, therefore discussions at the DPRD had to be postponed because the focus of program at that time was handling the pandemic. After the pandemic, discussions on the draft regional regulation began again in 2021. Input from people with disabilities was taken into consideration in preparing the draft regional regulation. The parliament of Kudus Regency carried out public hearing activities which presented several disabled communities in Kudus Regency. [14].

3.3 Policy Formulation

Policy Formulation is the most crucial stage, because implementation and evaluation can be carried out at stage policy formulation has been completed, besides failure a policy or program in achieving something Most goals stem from imperfection management at the formulation stage. Policy formulation is development policy alternatives in dealing with problems that have entered the public agenda.

The activity in the policy formulation stage is developing policy proposals to resolve issues and ameliorate problems. The participants of the stage are academics, regional head and executive office, congressional committees and interest groups. Before drafting regional regulations, a planning process for drafting regional regulations is carried out in a Regional Legislation Program (*Prolegda*). *Prolegda* is a planning instrument for the law formation program which is prepared in a planned, integrated and systematic manner. Planning for the preparation of regional regulations is carried out in the regional regulation formation program (*Propemperda*). The preparation of *Propemperda* is carried out by the parliament and the Regent/Mayor. *Propemperda* is determined for a period of a year based on the priority scale for the formation of local regulation draft. The preparation and stipulation of the *Propemperda* is carried out every year before the stipulation of the draft Regional Regulation on the Regency/City APBD [15].

In the policy formulation process, the local parliament involved academics as drafters of regional regulations. The Draft Regional Regulation was then discussed through the Special Committee (*Pansus*) of the parliament. This special committee involves members of parliament, related agencies, companies, as well as representatives of disability groups. This Special Committee meeting was held more than five times. In the special committee, the substance of the articles of the draft regional regulations is discussed article by article.

3.4 Policy legitimation

Legitimacy is a form of public acceptance and recognition regarding the authority, decisions or policies taken by a leader. The activity in the policy legitimation is selecting a proposal, developing political support for it, enacting it into law, deciding on its constitutionality. The

source of legitimacy has changed from the perspective of physical and military strength to massive support from society.

3.5 Policy Implementation

Policy legitimation is one of the important stages and momentum in the formulation/manufacturing process the next policy, because of whether something is successful or not policies in achieving its objectives are determined in its implementation. Success or failure of an implementation policies can be evaluated in terms of their merits in continuing and operationalizing it government programs that have been designed previously. Seen from the perspective of a political approach, success and failure public policy is ultimately influenced by willingness and the capabilities of various interest groups dominant which may consist of various coalitions interests that impose will. In certain conditions the distribution of power can also causing bottlenecks during implementation policy, even though it is public policy has been formally directed.

Regional Regulation of Kudus Regency Law 10 Year 2021 Regarding Protection and Fulfillment of The Rights of Persons with Disabilities cannot yet be implemented because there are no technical regulations that regulate the implementation of this regional regulation in detail, namely the Regent's Regulation. Since it was passed in November 2021, this Perda a is still waiting for the Regent's Regulation to be ratified. This Regent's Regulation is closely related to the readiness of relevant agencies or stakeholders in providing an adequate environment or infrastructure for people with disabilities if the regent's regulation has been ratified. For example, in the education sector, the district education office must provide inclusive schools for people with disabilities, where to make this happen, the education office also needs to prepare infrastructure and ready human resources for educators.

3.6 Policy Evaluation

Policy evaluation is assessing the success/failure of policies based on predetermined indicators. And if the policy is declared to have failed to address public problems, then a new policy will be created and learning from previous experiences. Public policy evaluation seeks to assess the effectiveness of a policy in achieving its intended goals. It also provides recommendations and feedback for improving existing policies. Additionally, evaluation can contribute to the development of new or revised policy alternatives by demonstrating that a different policy option may be more effective.

4 Conclusion

The Kudus Disability Communication Forum (FKDK), one of the most active disability organizations in Kudus Regency, plays a crucial role in the drafting of the Regional Regulations on the Protection and Fulfillment of Disability Rights. FKDK's involvement can be categorized into three main approaches: 1) Positional Approach: FKDK serves as the primary initiator of the disability regional regulation; 2) Reputational Approach: FKDK contributes to the drafting process by building networks, lobbying decision-makers, and participating in discussions surrounding the regulation; and 3) Decisional Approach: FKDK ensures that key issues related to the rights and needs of people with disabilities are maintained in the draft regulation. FKDK's advocacy efforts must remain sustained and

consistent, particularly in encouraging the regent to adopt regulations that fulfill the rights of individuals with disabilities.

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