

# The Paradigm of Disability: A Discussion of Participation of Persons with Disability in Development in Indonesia

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## Abstract

This literature study aims to catch up on the inclusive development issues in the conception of disability perspective and participation of persons with disabilities in the development goals. This topic is in line with the global development of which targets seek to accommodate the needs of every citizen, including persons with disability to be involved in development. The researcher uses a qualitative approach to construct the conceptual discussion between disability conception and participation practice. The data were documented and collected from research articles containing Indonesian context and legislation. The discussion is described in 4 (four) important areas of development: education, health, employment, and accessibility.

*Keywords: Paradigm of Disability, Participation, Inclusive Development*

## 1. Research Background

Global development refers to development programs used by UN member states. The Sustainable Development Goals (SDGs) are strategies for achieving global development goals by 2030. The SDGs are planned to improve the quality of development that has an orientation on people, the earth, welfare, peace, and partnership. The principles embedded in achieving the 17 objectives of the 2030 SDGs as development progress are 1) universal development, 2) integration, 3) no one left behind, and 4) inclusive (Brown & Rasmussen, 2019; ICCTF, 2021). These principles encourage policymakers to engage everyone as a development actor, one of whom is a person with a disability. The SDGs sought to improve the previous global development participation approach that had a low impact on achieving the 2015 MDGs because development actors focused on the government. Indonesia has committed to achieving the inclusive and collaborative the 2030 SDGs in Presidential Regulation (PP) No. 59/2017 on the Implementation of the Achievement of sustainable development goals.

The issue of disability is one of the development targets raised nationally in Indonesia after the Ratification of the Convention on the Rights of Persons with Disabilities. The Indonesian Government is quite serious about responding to this international legal instrument by passing Law No. 8/2016 on persons with Disabilities. However, disability issues face various challenges because the attention given tends to come from one sector only, such as focusing on social assistance or security. The Covid-19 pandemic has provided some learning in the development process, one of which is handling disability issues. Based on the results of a rapid review of the pandemic impacts on disability at the beginning of the Covid-19 outbreak in Indonesia, persons with disabilities have more complex risks and this fact is a crucial issue follow-up (Bappenas RI, 2020; SIGAB, 2020). The reality in the field has encouraged the acceleration of government support for the implementation of one of the disability derivative regulations, namely Government Regulation No. 70/2019 on Planning, Implementation, and Evaluation of Respect, Protection, and Fulfillment of the Rights of Persons with Disabilities.

Disability Inclusive Development (DID) is a topic to answer the complex and comprehensive problems on the issues of disability. In 2021, the central government sought to provide space for groups with disabilities through the National Action Plan for Persons with Disabilities (RANPD) which is lowered to regions at the provincial and district/city levels through the Regional Action Plan for Persons with Disabilities (RADPD). However, the question is how prepared are the regions as government representatives to implement RADPD through the provision of accessibility to increase the participation of persons with disabilities in any aspect? How does the government ensure that the implementation of the regulation has fully met the participation rights of persons with disabilities? And finally, how can persons with disabilities advocate their rights of participation in the development?

This article is aimed to discuss the role of government as one of the policymakers to consider changing the disability conception when they perceive persons with disabilities in development. In the medical model, people with disabilities are seen as merely pathological. The predominance of misunderstood medical models leads to misconceptions of perception of the existence and role of people with disabilities in socio-political development. The perspective requires stigma liberation for people with disabilities (Areheart, 2017; Barnes, 2009). Disability emancipation needs to be born as a result of development actors involved in criticizing the dominance and suppression of policies that may occur to control the implementation of regulations, provide protection and fulfill the rights of persons with disabilities (Hosking, 2008). CDT underline that the social model conception is important to break the systemic discrimination of person with disabilities in the development caused by the domination of the medical model perspective (Areheart, 2017; Barnes, 2009; Bunbury, 2019). Thus, the experiences of persons with disabilities and or their families become an important contribution to

changing perspectives and improving the achievement of social inclusion in policies (Wike, 2015).

## **2. The Conception of Disability as a Paradigm Movement**

The context of disability perspectives, especially in developing countries, is known to have 4 (four) conceptions of disability as a disability paradigm that include the charity model, medical model, social model, and rights-based model (Ju'beh, 2017). Philosophically, without regard to the conception of disability that dominates in social construction, Amponsah-Bediako found two philosophical foundations: 1) persons with disabilities depend on society, and 2) persons with disabilities as customers who get offers from the community. Both contexts actualize the consequences for various attitudes and responses to persons with disabilities that can also at the same time provide services as an option for persons with disabilities (Amponsah-Bediako, 2013).

There is empirical evidence of the philosophical base regarding the conception of disability that can be reviewed from several studies. Research in Taiwan found that the charity model can reinforce the description of persons with disabilities; i.e., dependent people who need the emotional bond of family or the surrounding community to provide compassion (Tsai & Ho, 2010). In 1973, learning from developing countries prompted the United Nations to improve health services to develop rehabilitation for persons with disabilities. The medical model pays attention to the recovery of mental and/or physical conditions experienced by persons with disabilities that are considered a solution so that persons with disabilities are empowered not to rely on family or society (Department of Economic and Social Affairs Division for Social Policy and Development, 2003). Charity and medical perspectives are not enough to suppress self-stigma and social stigma and encourage the involvement of persons with disabilities in community life (Reckinger, 2010). External barriers from individuals with disabilities are approved as the main thing that complicates the existence of persons with disabilities in society in politics and other fields so the criticism brings out a perspective from the social model (Barnes, 2000).

The results of the evolution of charity models, medical models, and social models can provide simultaneous changes from rehabilitation systems that concentrate on pathology began to be directed at social models. The social model addresses the concept of disability as barriers and attitudes that come from society's perspective toward persons with disabilities (Ju'beh, 2017). The social perception model also shows oppression and social discrimination against persons with disabilities as a result of the misconceptions of the medical model between impairment and disability (Areheart, 2017; Bunbury, 2019). Disability stereotypes from medical models tend to direct perspectives on medical treatment or social security for people with disabilities (Areheart, 2017). Since 2004, the social model has been a form of development using community-based rehabilitation (CBR) strategies. It was started on a joint position paper by WHO, ILO, and UNESCO. The needs and potentials of persons with disabilities continue to be explored through various criticisms and solutions that continue to grow against diverse conceptions of disability.

These disability concepts were then summarized in the drafting of the Convention on the Rights of Persons with Disabilities (CRPD) which was ratified in 2006 to protect the rights of persons with disabilities while collecting affirmations for the fulfillment of these rights. The obligation to fulfill these rights directs the movement of the disability perspective to the rights-based model. Thus, persons with disabilities are expected to be accepted as part of a society with a role as development actors.

The conception of the social model strongly supports the presence of people with disabilities as actors in development. The social model exists to challenge the form of participation of people with disabilities who are carried away by the misconceptions of the medical model. The value of the social model is to bring about the emancipation of equality of people with disabilities to relieve the tension between pathological conceptions (bio-psycho) and institutional construction (social) (Hosking, 2008). WHO summarizes this value through the objectives of the CBR strategy and updating the definition of disability in the International Classification of Functioning, Disability, and Health (ICF) as a biopsychosocial concept (Hosking, 2008; Madden et al., 2020; Sonpal & Kumar, 2012). The definition states that the participation of people with disabilities is one of the indicators to be included in the achievement of development goals, i.e., social inclusion which is in line with the objectives of the CBR strategy and the 2030 SDGs as a guideline for disability-inclusive development.

### **3. Disability Perspective in Policy Setting**

The concept of disability is an interesting discussion on developing theories of disability. Conception describes how the presence of persons with disabilities is responded to in the community. Perspectives based on the concept of disability will determine the policy process formulated, implemented, monitored, and evaluated from various sectors based on the local context (Thohari, 2011). The dominance of the disability model is often understood from the different perceptions between government and civil society Thohari named it the contestation of conception. Some of the complex findings include the philosophy of life (habitus patterns) of persons with disabilities, their families, and communities, and the movement of the disability paradigm impacts on social construction and working culture's performance of public services as government policy practices (Thohari, 2011). This difference in perspective can become a space for communication or a battle of conflicts of interest between the government and persons with disabilities.

The polemic of mainstreaming disability issues in the development process continues to develop in the practice of implementing policies. Disability-inclusive policies are very clearly campaigned by the SDGs. However, violations of the right to participation of persons with disabilities are often encountered starting from the view that the experience of disability is a sad tragedy and needs to be pitied. Wike (2015) emphasized through her findings that the Indonesian government's commitments as regulation have not been implemented properly and affected the fulfillment of the participation rights of

persons with disabilities. Previous research showed that one of the triggers for discriminatory behavior towards persons with disabilities is segregation. This is not impossible due to a lack of knowledge about disability, which needs to be part of the target of development policies (Tan et al., 2019). According to Ambassador; Lang and Murangria in Lang on international policy analysis, historically it can be proven that there have been exceptions to the participation of persons with disabilities in formulating and implementing disability policies and practices in developing countries (Lang et al., 2018). In other words, the results of this study encourage that all parties, both the government and persons with disabilities, need to be vigilant by monitoring policy topics that are very likely to be tokenistic instead of specializing in policies for persons with disabilities.

#### **4. Participation of Persons with Disabilities in Development in Indonesia**

Development is defined as progress in terms of economic growth. This definition arose from the history of world development which was trying to recover from post-World War II conditions to maintain political stability and the realization of world peace (The World Bank, 2011). The impact of World War II on countries in the Southern hemisphere, one of which is Indonesia, continues to try to catch up as a result of the prolonged expansion of western imperialism. Previous research showed that 80% of persons with disabilities live in developing countries and they are poor with 20% of them in the poorest category (DFID, 2000). This is in line with several findings, stating that there is a close relationship between disability, limited access, and poverty (Bappenas RI, 2020; Dethmers, 2010). According to the 2019 SUSENAS, the poverty rate for persons with disabilities is around 15%, higher than the national poverty rate of 9.2%. In other words, the development process has not yet significantly affected persons with disabilities. It also shows how the development topic has not yet involved persons with disabilities as development actors in a comprehensive manner that is included in the planning, implementation, monitoring, and evaluation processes.

In the development projection, we can observe that persons with disabilities are only involved as beneficiaries of development and often persons with disabilities fail to put their position as part of the development subject. We can observe this in the discussion of 4 (four) areas closely related to the development process which is understood as part of economic progress.

##### **4.1 Education**

Regulation of the Minister of National Education No. 70/2009 on Inclusive Education for Students with Disabilities and Potential Intelligence and/or Special Talents is a legal umbrella that protects the rights of every child in the implementation of education. However, in the choice of diction, the medical concept is very inherent even though the regulation aims to develop inclusive education more broadly. Pathologically, “abnormality” is the identity of a person with a disability. The word abnormal can trigger the perception that children with disabilities cannot follow the learning process as

children are considered normal by the public. In other words, there is a generalization that every child with a disability needs very special treatment and an alibi to ignore their potential as part of society in general. The normal and abnormal discussion contexts lead to children with disabilities experiencing discrimination and as a result, it is difficult for them to access education services (FMPP Brebes, 2019).

Furthermore, the normal and abnormal conception of the medical model provokes social conflicts in society. Parents with children with disabilities face challenges from the surrounding environment more complex than parents with children who grow up “normally” from the surrounding environment. They face judgment from children with disabilities that are often considered strange and can negatively influence on the school environment (Waki, 2017). The stigma that is constantly being reproduced has an impact on the admission of students with disabilities to regular school. Although the average public acceptance of children with disabilities in regular schools is getting better, other surprising findings exist (Hendrowati, 2017; Waki, 2017). The study found about 58% of parents as community representatives refuse their children who are considered “normal” to study and play with children with disabilities in regular schools (Hendrowati, 2017).

The participation of children with disabilities in education as a gateway to development is hampered by various factors. Both internal factors, namely the ability of families and children, as well as external factors from the stigma of educational services regarding the provision of education for children with disabilities (Pratiwi, 2015). Pratiwi explained the empirical findings regarding the limitation of participation. The challenge started from the small number of special schools (SLB), the location of special schools that were far away, and required a lot of time and transportation costs. In addition, the public schools closest to the residence of children with disabilities are reluctant to accept students with disabilities. The research findings explain that inadequate teacher competence and large budget allocations for providing inclusive education are the reasons for general education services to involve children with disabilities (Hendrowati, 2017; Saputra, 2016). The topics that need to be raised are 1) social disability does not talk about disorders but how the community accepts and involves different people, and 2) not all children with disabilities have to choose special schools to be involved in education. In this case, the government has agreed upon Law No. 8/2016 on Persons with Disabilities to strengthen the guarantee that education is an option for persons with disabilities, and the government is obliged to improve the quality of education that can be enjoyed them.

## **4.2 Health**

Medical conceptions tend to lead to the perception that the disability experienced is a curable disease. This can be seen from the definition of Health contained in Law No. 36/2009 on Health, that health is physical, mental, spiritual, and social health allowing everyone to live socially and economically productive lives. Persons with disabilities as patients are often seen as people who should be pitied so they may be considered as parties who cannot independently access health services. This concept of charity greatly influences how the physical and non-physical environment in health services is displayed.

Knowledge of disability conditions, access, and service options for persons with disabilities is also a challenge that reduces their opportunity to be involved as subjects of development from childhood (Wike, 2015).

Based on empirical data from the Japan International Cooperation Agency, the distribution of basic rehabilitation health facilities is uneven, accompanied by a limited number of health workers (Japan International Cooperation Agency (JICA), 2015). This condition makes it more difficult for persons with disabilities to enjoy services according to their needs. Apsari conveyed the findings from her literature study that persons with disabilities in Indonesia are very likely to experience discrimination in accessing health services (Apsari & Raharjo, 2021).

Research in London found that there is discrimination experienced by caregivers or persons with disabilities when accessing health services (Ali et al., 2013). These findings include negative health worker behavior, services unable to make reasonable adjustments, communication challenges, lack of information about health services, lack of caregiver involvement, and language use of ethnic minorities. This is not impossible to challenge the participation of persons with disabilities are accessing health services. The government needs to continue increasing the quantity and quality of inclusive health services, including primary health services that are closest to the community. Some of them are Lingsar Health Center, West Lombok Regency, Lendah 1 Health Center, Kulon Progo Regency, Salam Health Center, Bandung Wetan District, Bandung City (Hasibuan & Ayuningtyas, 2021). One example is the Janti Primary Public Health Services in Malang City which was developed based on the participation of persons with disabilities who need to access health services. The institution gave a fairly positive response to fulfilling the health rights of persons with disabilities. The COVID-19 pandemic or other outbreaks teach that discussions on health topics need to involve persons with disabilities in the government priority response (Gupta et al., 2021). In other words, not only physical accessibility but also accessibility to health information is indispensable for persons with disabilities.

### **4.3 Employment**

Departing from the dominance of charity and medical perceptions, persons with disabilities rarely get proper rights in the formal world of work. Hastuti and his colleagues gathered evidence that the stigma against the work qualifications of persons with disabilities in the formal sector is still quite strong (Hastuti et al., 2020). Research conducted in Malang Raya in 2016 related to the fulfillment of employment rights for persons with disabilities said that 41.57% of respondents to community volunteers admitted that the fulfillment and provision of employment for adults with disabilities was still not good enough. The existence of a compassionate view in the acceptance of persons with disabilities as labor is one of the strong reasons for respondents to express the unkind fulfillment of rights in the field of work, in addition to the limited available employment opportunities, which can be accessed by persons with disabilities (Subasno, 2017). The results of another study conducted in Malang Raya stated that the intense

competition for jobs for persons with disabilities who have physical (and mental) limitations has made it almost impossible for them to get a decent job. This causes the economic condition of persons with disabilities to be far below the poverty line. Even in meeting their daily needs, most of the people with disabilities who participated in the study depended on the help of their families and other kind-hearted persons (Subasno, 2016).

Work is an opportunity for persons with disabilities to participate in the economic sector and improve their well-being. However, persons with disabilities have low economic value due to incompetence based on their physical or mental condition (Salim, 2015). Based on data processed by SMERU researchers from SUSENAS 2018, persons with disabilities in Indonesia mostly work as self-employed (Hastuti et al., 2020). This discriminates against persons with disabilities who find it difficult to get a job in the formal sector compared to people in general. A disability study mentioned that in the economic sector persons with disabilities play the highest economic role in the trade sector with a figure of 23.9%, the industrial sector of 18.6%, and agriculture of 17% (Irwanto et al., 2010).

The things above contribute to the discrepancy between government regulations and the reality in society, namely the company's obligation to provide guarantees for workers with disabilities. Another issue is that the government did not take firm steps toward the implementation of Law No. 8/2016 on Persons with Disabilities in providing sanctions for job providers who are unable to meet the overall quota requirements of 1% of employees with disabilities for the private sector and 2% of persons with disabilities for the government sector.

#### **4.4 Accessibility**

Accessibility is a technical way to provide convenience for its users, one of whom is a person with a disability. Accessibility is one of the needs for communities to be able to facilitate their active role in development. Previous researchers reported public facilities or public spaces in Indonesia are unable to meet the needs. The most basic thing as an accessibility indicator following the Regulation of the Minister of Public Works and Public Housing No. 30/PRT/M/2006 includes 4 (four) principles of accessibility, namely usability, convenience, security, and independence when in a place. Rural areas are rated as areas untouched by development, so the availability of accessibility has not been a concern (Magribi & Suhardjo, 2004). But 10 years later, research in Malang city stated that about 24% of public facilities or public spaces have implemented accessibility since the regulation on disability technical guidelines was published 7 years earlier (Thohari, 2014).

The implementation of accessibility in areas in Indonesia is so slow, abandoned, and not functioning without reason. Indonesia faced changing socio-economic-political conditions, and accessibility has not been able to contribute to the need for stability (Nuraviva et al., 2017). The Indonesian government prioritizes strategic issues that can massively improve the economic development process but forgets accessibility in it



(Komardjaja, 2001). For example, street vendors make sidewalks difficult to access for pedestrians, because the availability of trade land is limited in urban areas (Komardjaja, 2010).

Society can prejudice that accessibility for persons with disabilities is not beneficial. The medical conception that persons with disabilities are those who can do nothing because of their limitations encourages the thought of compassion for their presence in the public sphere. The conception directs that people with disabilities do not need to participate in public spaces because they are sick and need a lot of help from others. Komardjaya said that good communal and collective cultural interaction in Indonesia can thwart the conception of accessibility that supports individual independence (Komardjaja, 2001, 2010). Nevertheless, the government needs to consider the functionality of accessibility for all parties in all public services and facilities to open innovation and collaboration with the community. This is to achieve the objectives of the Regulation of the Minister of Public Works and Public Housing No. 14/PRT/M/2017 on Universal Design that everyone has the right to access and carry out activities in buildings or the environment. Accessibility is not a labeling product only intended for persons with disabilities but can be enjoyed by everyone (Bringolf, 2008). Good accessibility planning, implementation, monitoring, and evaluation involve persons with disabilities. A good plan requires only 7% of the total cost of construction. In addition, accessibility also has high flexibility with local contexts that cost more affordable, because renovations or repairs providing accessibility can cost about 20% more than the entire building (UNICEF, 2013).

## **5. Conception is Dealt the Participation of Persons with Disabilities in the Development**

This discussion finds that the regions should investigate public service to improve the participation of persons with disabilities. It will increase the success of inclusive development (Sonpal & Kumar, 2012). The regulation as complementary policies between budgeting for disability ensures that the policy allows community participation and persons with disabilities can advocate their needs (Tsaputra, 2019). Rights and issues about disability that are well conceptualized by the government and persons with disabilities with similar perceptions will form the grand design of participation (Ju'beh, 2017; Madden et al., 2020). The participation of people with disabilities to control policies will realize the inclusiveness of the development process. This perception will encourage the paradigm of the concept of disability to shift and pay more attention to equality (Carby et al., 2018).

The social model criticizes the policy order to change the social construction that dominates the group of persons with disabilities (Sztobryn-Giercuskiewicz, 2017). Nevertheless, sociological movements encouraging the emancipation of people with disabilities also need to consider projections about exploring the definition of disability through disability conditions (medical model). Disability measurement is important in

monitoring policies because people with disabilities will experience losses that increase along with the level of disability experienced (Crow, 2010; Jones & Saloniki, 2021). It is necessary to see people with disabilities need help with improved accessibility, given their well-being and fulfilled their equality. As is known, the view of charity and medical models is needed as has been facilitated by community donations and social aid from the government for increasing their welfare and accessibility, but not for their role to decide in the development. The use of the term “social” model in Indonesia is not yet fully understood as a form of emancipation of people with disabilities, but rather understood as the embodiment of “inclusion” from a government perspective without including such changes as requiring the participation of people with disabilities in controlling policies (Suhendra, 2017). Another misconception is that the social model is understood as a social aid. The closing statement in this discussion is the conception on the charity, medical, social, and right-based models should be looking at the role of persons with disabilities (participation and inclusion). These conceptions should be understood more proportionately in the mainstreaming of disability issues.

## **6. Conclusion**

Development from an economic perspective has more complicated constructions for people with disabilities, including health cost is higher than people in general, educational experiences that tend to be limited due to segregation systems, and opportunities to work in both the formal and informal sectors are hampered due to ongoing prejudice against people with disabilities. The conception of disability is a trigger for the challenges faced by people with disabilities. Policies can provide appropriate implementation if policymakers listen consistently and persistently to the conditions and situations of persons with disabilities. Accessibility is a key for persons with disability to participate in development.

The concept of disability is very important to be considered in policymaking. The understanding of opposite conceptions between development actors can lead to conflicts. The government administration system needs to consider important things in formulating questions before collecting statistical data on disability. One of them is how the concept of disability reaches consensus among public sector employees and persons with disabilities. This approach is a good example of an in-depth and participatory to providing collective corrections to the questions of statistical need based on the conception of disability. Thus, disability data in government statistics can be appropriately used to measure the achievement of accessibility, participation, and equality of persons with disabilities (Madden et al., 2020).

Disability inclusive development is not just a matter of mainstreaming disability issues in planning or budgeting. The most important thing that needs to be developed is clear priority areas and strategies to ensure the participation of persons with disabilities in it (Tsaputra, 2019). Everyone is the subject of development, so development cannot be achieved because “nothing about us without us”.

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