



Paradigm of Indonesian Society towards Persons with Disabilities: Literature Review

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Abstrak

Pergeseran paradigma pemahaman disabilitas perlu dilakukan sejalan dengan semangat reformasi dan demokrasi yang bertumpu pada penguatan prinsip-prinsip dasar hak asasi manusia. Penulisan artikel ini menggunakan studi literatur dan studi dokumen. Paradigma dalam menangani atau memberikan pelayanan bagi penyandang disabilitas. Penelitian saat ini menunjukkan hubungan yang erat antara paradigma publik tentang disabilitas dan penyandang disabilitas dengan perilaku diskriminatif yang dialami penyandang disabilitas dalam kehidupan sehari-hari. Pemahaman umum masyarakat dunia, termasuk Indonesia, tentang penyandang disabilitas masih cenderung negatif. Pemahaman negatif ini karena masyarakat umumnya mendefinisikan dan memperlakukan penyandang disabilitas berdasarkan pola pikir yang didominasi oleh konsep normalitas yang berimplikasi pada stigmatisasi dan diskriminasi terhadap penyandang disabilitas. Hal ini disebabkan masih terbatasnya sosialisasi dan edukasi resmi dari pemerintah atau instansi terkait serta minimnya sosialisasi hasil kajian ilmiah tentang disabilitas dan penyandang disabilitas. Artikel ini bertujuan untuk mendeskripsikan tinjauan pustaka terkait pemahaman disabilitas dan penyandang disabilitas. Diharapkan penelitian ini dapat berkontribusi untuk mengatasi kesenjangan informasi dan pendidikan tentang disabilitas dan penyandang disabilitas, serta memberikan pemahaman yang tepat dan perilaku yang lebih baik dalam menghormati hak asasi penyandang disabilitas di Indonesia. Dengan pemahaman dan perilaku yang benar, diharapkan masyarakat dapat berkontribusi dalam perlindungan dan kesejahteraan sosial penyandang disabilitas di Indonesia sejalan dengan semangat reformasi dan demokrasi.

Kata-kata kunci: disabilitas, hak asasi manusia, perubahan paradigma, pelayanan bagi penyandang disabilitas

Abstract

The paradigm shift in understanding disability needs to be carried out in line with the spirit of reform and democracy which is based on strengthening the basic principles of human rights. The writing of this article uses literature and document studies. Paradigm in handling or providing services for persons with disabilities. Current research shows a close relationship between the public paradigm of disability and persons with disabilities and discriminatory behavior experienced by persons with disabilities in their daily lives. The general understanding of people in the world, including Indonesia, about persons with disabilities still tends to be negative. This negative understanding is because society generally defines and treats persons with disabilities based on a mindset that is dominated by the concept of normality which has implications for stigmatization and discrimination against persons with disabilities. This is due to the limited dissemination of information and official education from the government or related authorities and the lack of socialization of the results of scientific studies on disability and persons with disabilities. This article aims to describe a literature review related to the understanding of disability and persons with disabilities. It is hoped that this study can contribute to overcoming the gap in information and education about disability and persons with disabilities, as well as providing proper understanding and better behavior in respecting the human rights of persons with disabilities in Indonesia. With the right understanding and behavior, it is hoped that the community will contribute to the protection and social welfare of persons with disabilities in Indonesia in line with the spirit of reform and democracy.

Keywords: disability, human right, paradigm shift, services for person with disability

A. Introduction

One of the measuring tools of democracy that is being supported by a government is the ability of the state to fulfill and guarantee the rights of its citizens. This means that the state becomes the provider as well as the protector of the rights of all its citizens. Strengthening the basic principles of human rights, people with disabilities are essentially social beings who have potential, so they have the opportunity to contribute and play an optimal role in all aspects of the life of the nation, state and society. This statement was revealed in the Academic Paper on the Draft Law on Persons with Disabilities published by the House of Representatives of the Republic of Indonesia (DPR RI, 2015). Social welfare of persons with disabilities in Indonesia. This shows that there is concern and good will for persons with disabilities to involve them in various sectors and fields of life.

In line with this, the terms used to refer to people with disabilities have changed and shifted from time to time along with the development of public awareness and understanding of the issue of equality in human rights for people with disabilities.

Persons with disabilities are one of the largest minority groups in the world, accounting for 600 million people, two-thirds of whom are in developing countries. Historically, persons with disabilities have been indicated to have been neglected during the first three decades of the UN's existence. The drafters of the International Bill of Human Rights did not include persons with disabilities as a group vulnerable to human rights violations (Degener, 2000: 187).

Thus, one of them, in this context, is the state's obligation to provide public services that can be enjoyed and truly sourced from the needs of its people. For this reason, the accessibility of public facilities is very important, especially for persons with disabilities, because without such accessibility, they will have difficulty in mobility.

Public understanding of disability and persons with disabilities is closely related to the discriminatory behavior they experience in their daily lives has been conveyed by various writings, research and reports in various places in the world. Some of them have documentation that reaches the level of international scientific publications, for example in research in Uganda (Katsui, 2008; Katsui & Kumpuyuori, 2008); in Zambia (Katsui & Koistinen, 2008); in South Africa (Heap, Lorenzo, Thomas, 2009), in Thailand (Naemiratch & Manderson, 2009); in Sweden (Krogh, 2010), in the United States (Schwartz et al., 2010); among Indians who have settled in the United States (Gupta, 2011); in India (Buckingham, 2011), in Ghana, (Naami & Hayashi, 2012). In addition, research or reports submitted to the international academic

community on disability and persons with disabilities in Indonesia (Byrne, J., 2002; Widinarsih 2012; Suharto, S., P. Kuiper, & P. Dorset, 2016; Widinarsih, 2017).

From the various research results referred to in the first paragraph of this article, it is also known that discriminatory behavior towards persons with disabilities is generally caused by a negative understanding/negative awareness of what a disability is and who a person with a disability is. Negative understandings about disability and persons with disabilities are rooted in the mindset of society which is dominated by the concept of normality. History has shown that people whose appearance or body looks or is seen as 'different' from what society considers normative, as normality, will be perceived as not desirable and unacceptable as part of the community (Couser, 2009, p.1; Rothman, 2003, pp. 4-7). Negative labeling as 'different from what is accepted as normality' is a process of stigmatization. Discriminatory attitudes and behavior will arise if the stigmatization/negative labeling continues with further distinctions, among others, in the form of forced and restrictive separation/segregation, or exclusion because they are considered not an integral part and/or equal/social exclusion, or are considered less/not valuable. socially devalued ((Shapiro, 2000, p. 124; Stool, 2011, pp. 36-37; Wolfensberger, 1992).

Discriminatory attitudes and behaviors based on disability are contrary to universally recognized human rights throughout the world (Ollerton & Horsfall, 2013, p.618). It also contradicts the aspirations of human rights and social justice which are the commitments in the discipline of Social Work (International Federation of Social Work, 2000; Zastrow, 2004, p.57).

This study summarizes the development of the paradigm of the Indonesian people towards disability and persons with disabilities by answering the following questionst:

1. How is the paradigm shift of society in interpreting disability?
2. How is public accessibility for persons with disabilities?
3. What is the public paradigm about disability and persons with disabilities with discriminatory behavior experienced by persons with disabilities in everyday life?

B. Research Method

To obtain a broad source of information on this paper, the authors conducted a study of the most relevant journals, namely international publications that have a factor impact with the following sources: Google scholar, Taylor and Fancis online (www.tandfonline.com), <https://garuda.kemdikbud.go.id/journal>, <https://sinta.kemdikbud.go.id/> and journal

<http://jurnalkesos.ui.ac.id>. The author chose internationally published journals as the criteria for searching for journals, which covered relevant topics such as “paradigm of disability, development and definition of disability”

The selection process was traced to 50 journals, and only 40 journals were relevant to the topic. Of the 40 journals, they can be grouped into: 13 journals on the development of disabilities and persons with disabilities in Indonesia, 20 journals on Disability and Accessibility of Public Facilities for Persons with Disabilities 7 journals on the Development of Terms and Definitions of Persons with Disabilities.

C. Result and Discussion

1. Disability Paradigm

None of the equivalence clauses of the Universal Declaration of Human Rights (1948), the International Covenant on Civil and Political Rights (1966), and the International Covenant on Economic, Social and Cultural Rights (1966), explicitly mention disability as a protected category. The word disability, which is referred to as a human rights issue in various documents, only relates to social security and preventive health policies. It was only in the 1970s, with the promulgation of the Declaration on Persons with Mental Disabilities (1971) and the Declaration on the Rights of Persons with Disabilities (1975), that persons with disabilities became the subject of the Declaration on Human Rights. However, these early instruments still reflect the idea of disability as a medical model. The model views persons with disabilities as people with medical problems, whose treatment depends on the social security and welfare provided in each country (Degener, 2000).

This is different from the disability model proposed by the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (WHO, 1980) which suggests that the elements of disability can be distinguished in several parts, namely (1). Impairment on organs - body dimension; (2). impaired function for activities, - individual dimension; (3). Handicap in environment - social dimension. The concept of disability put forward by ICIDH has a wider scope of dimensions by looking not only at the individual, but also the handicap factor from the environment as a social dimension. In its development, in 2011, the view of The International Classification of Functioning, Disability and Health (ICF) (WHO, 2011) regarding disability includes impairment, activity limitations, and participation restrictions. In this context, impairment includes problems with the function or structure of the body; activity limitations are aimed at difficulties in carrying out tasks or taking actions; and barriers to participation,

namely that people with disabilities have problems engaging in society or their life situations. Thus, people with disabilities are no longer seen as problematic people, but the environment is the problem in providing equal access and being inclusive for everyone in their society (Rioux & Carbert, 2003).

Rioux & Carbert (2003) mentions that along with the increasing international attention for persons with disabilities, the international parties have also made more commitments regarding the human rights of persons with disabilities. These commitments are driven by a paradigm shift in the international community. One of them is by being formally mentioned by the Committee on Economic, Social and Cultural Rights (ECOSOC) (1994), considering the International Covenant on Economic, Social and Cultural Rights (ICESCR) mentions:

“... since the Covenant's provisions apply fully to all members of society, persons with disabilities are clearly entitled to the full range of rights recognized in the Covenant. In addition, insofar as special treatment is necessary, States parties are required to take appropriate measures, to the maximum extent of their available resources, to enable such persons to seek to overcome any disadvantages, in terms of the enjoyment of the rights specified in the Covenant, flowing from their disability. Moreover, the requirement contained in article 2 of the Covenant that the rights 'enunciated ¼ will be exercised without discrimination of any kind' based on certain specified grounds 'or other status' clearly applies to discrimination on the grounds of disability” (para. 5).

Other commitments that have been made by countries in the world in the research of Quinn & Degener (2002) found that there are 39 countries that have instituted and spawned non-discriminatory policies or equality of opportunity in the context of disability. Rioux & Carbert (2003) mentions in their research a summary of various international movements that encourage the realization of equal access for persons with disabilities, such as the World Program of Action Concerning Disabled Persons, 1982; The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1994; Resolutions of the United Nations Commission on Human Rights; Regional Agreements and Declarations; Disabled Persons International (DPI) Sapporo Declaration, 2002; International Norms and Standards Relating to Disability.

Persons with disabilities are those who have long-term physical, mental, intellectual or sensory limitations, which due to various barriers may hinder their full participation and effectiveness in society (Convention on the Rights of Persons with Disabilities, 2006). In

addition, facilities in the form of physical and non-physical accessibility for persons with disabilities are relatively very limited, making it difficult for them to be able to carry out their activities independently (PPUA Penca, 2015). In line with this, various kinds of obstacles are experienced by persons with disabilities, including the following obstacles:

1. Inadequate policies & standards: Policies/rules that are made often do not pay attention to the needs of persons with disabilities, for example education, employment policies.
2. Negative attitudes: Negative attitudes and prejudices hinder education, employment, health care and social participation.
3. Lack of provision of services: Especially in health services, rehabilitation, and support & assistance.
4. Problems with service delivery: Due to lack of coordination, insufficient staff, lack of competence.
5. Inadequate funding: Insufficient sources of funds allocated to implement policies.
6. Lack of accessibility: Public buildings, transportation systems and inaccessible information.
7. Lack of consultation & involvement: People with disabilities are often not involved in decision making.
8. Lack of data & evidence: Lack of data on disability and evidence of program effectiveness affects further action programs.

With various kinds of obstacles that are accepted and faced by persons with disabilities, their existence is often marginalized and in a disadvantaged position, so that their condition is increasingly marginalized from social interaction and acceptance in society.

Persons with disabilities are known as vulnerable populations. The World Health Survey found that: (1) The prevalence of disability is higher in low-income countries; (2) The poor, women and the elderly have a higher prevalence of disability; (3) Individuals with low income, not working, low level of education have a higher risk of disability. The Multiple Indicator Cluster Surveys state that children from poor families and ethnic minorities have a higher risk of disability.

Based on this situation, the problems faced by people with disabilities began to shift. At first disability was seen as a problem in the context of the individual and then shifted to a social issue, so that efforts to overcome the problems of people with disabilities also experienced a shift, initially trying to be aimed at eliminating or minimizing the malfunction experienced by

individuals, then it became an effort to eliminate or minimize obstacles in society that people with disabilities may face.

The approach to services provided for people with disabilities has also changed, initially in the form of direct, curative services and aimed at changing the disabled, then shifted to efforts to make social changes in society to make it more conducive for people with disabilities, promotive and preventive efforts as well as other efforts to change society, starting from perception, stigma, treatment and preparing society to be more conducive in accepting and treating people with disabilities.

In terms of the services provided by experts, it also shifted, initially being specialist and carried out by professionals, which is in line with the medical perspective in looking at the problems of people with disabilities, then shifted to being general and specific, carried out by the community and professionals. Likewise, the form of rehabilitation given to people with disabilities has also changed from improving functions to efforts to solve social barriers.

The various shifts and changes in perspective in terms of the treatment of people with disabilities are the basis for a paradigm shift in viewing people with disabilities, which can be summarized in the table below:

Table 1. Paradigm Shift of Society in Interpreting Disability

	Old Paradigm	New Paradigm
Disability issue	Individual issue Malfunction	Social issue Barriers in society
Approach	Direct Service Curative Change Disabled	Social Change Promotive and preventif Change Public
Service	Spesialistic By professional	General dan specific By public and professional
Rehabilitation	Function Corrective	Solving social barriers

Along with the paradigm shift in looking at disability and the ongoing issue of disability in society, this has triggered and encouraged the development of the perspectives of stakeholders who have attention to disability issues in viewing the disability paradigm, thus encouraging efforts to build a new disability paradigm.

Various new paradigms in viewing disability are reflected in the viewpoints that view disability issues: (1) Disability was originally seen as an individual problem into a social problem; (2) Efforts are being made to make changes to individuals with disabilities into

changes to people's behavior; (3) In dealing with disability, initially focused on fulfilling practical needs only to meeting practical and strategic needs; (4) The solution provided was originally a partial solution to become an integrated solution; and (5) Programs created to deal with disability problems were originally in the form of an exclusive program to become an inclusive program.

Historically, the paradigm shifts in handling or providing services for people with disabilities from time to time as revealed by Dewi (2017), started with the Traditional model, with the main activities carried out for people with disabilities being voluntary or charity, then changed to Individual Model – Medical Model, with an emphasis on assistance provided in the form of rehabilitation for people with disabilities. This second model is deemed insufficient to eliminate the obstacles experienced by people with disabilities, so professionals who work with people with disabilities then develop a third paradigm, namely the Social Model, with a focus on services aimed at social change – community change. Until now, the model used in providing services to people with disabilities is the Inclusion Model, namely inclusive development – inclusive society, where by using this model, an inclusive approach is used with the aim of bringing people with disabilities into social life which is felt to be more accommodating human rights of persons with disabilities.

Handling or providing services for people with disabilities, there are several approaches (Dewi, 2017), including the Institutional Based approach, which is characterized by the existence of institutions built with various rehabilitation facilities for people with disabilities, then the professionals in these institutions provide rehabilitation services to persons with disabilities with established programs and persons with disabilities proactively visiting institutions to obtain the necessary services. The next approach is a community-oriented approach, where professionals provide rehabilitation services to people with disabilities not within the institution, but proactively visit the community while bringing established programs such as the Mobile Rehabilitation Unit (MRU), and the Out Reach Program. Another approach is a community-based approach, where professionals play a role in facilitating persons with disabilities and the community to analyze their problems and needs, analyze available local resources, prepare an organized action plan through planning, implementation, monitoring and evaluation. As well as the community managed approach, which believes that people with disabilities and the community are able to organize and implement programs independently after receiving adequate facilitation and assistance from professionals.

The social work profession exists with other professions such as doctors and therapists to provide comprehensive services for people with disabilities. Social workers who are engaged in the fulfillment of rights, ensure that people with disabilities have access to all aspects related to their rights as individuals and citizens, such as the right to life, the right to participate and the right to protection (Apsari, 2016).

One example of the fulfillment of rights that can be advocated by social workers is the right of people with disabilities to get jobs and incomes that can meet their needs. Ali, et al. (2010) in his research stated the reasons for the challenges for people with disabilities to get decent work, including that they may want flexible work considering their health condition and mobility ability; feel that they do not have many choices because they are pressed by the increasing needs, so they choose any job that is important to earn an income; and people with disabilities are at risk of losing their jobs because they do not get support from the people around them, causing people with disabilities to no longer be able to meet their needs.

Many people with disabilities in Indonesia currently live on the basis of the mercy of others, and choose to become beggars, entrepreneurs with limited capital or scavengers. This happens because there is no equal access for people with disabilities. They do not get access to work according to their skills, because employers already view people with disabilities as helpless. With such a perspective, people with disabilities are trapped in a situation.

Even though Law Number 8 of 2016 concerning Persons with Disabilities has stated about equal opportunity (Article 1 paragraph 2), changes in employment policies have not yet been felt by persons with disabilities. The work environment still does not accommodate the special needs needed by people with disabilities, such as ramps, technology devices with braille, hearing aids, etc. Provision of these special needs is still perceived as an expensive additional cost that must be provided by the company or the world of work, which in the end prevents people with disabilities from realizing and developing their potential and proving to the world that they are capable of working like non-disabled people. . This is according to Ali, et al. (2010) related to the perception and culture of the world of work, so it takes strength and encouragement to apply an inclusive model to the world of work in particular and the wider community in general.

Approaching disability problem solving in the employment sector with community development through community awareness activities regarding the capabilities of people with disabilities in their environment, identification and analysis of problems, determining the

employment needs of people with disabilities, identifying resources and potential for absorption of people with disabilities in the field of employment, jointly setting priorities for problems, then planning and implementing the resolution of employment problems for people with disabilities, and finally monitoring and evaluating employment conditions for people with disabilities. All these activities are carried out through two approaches, an approach that focuses on the community to remove barriers that can eliminate equal opportunities for people with disabilities, and an approach that focuses on people with disabilities to continue to build their capacity and support them to participate in all aspects of their lives.

2. Accessibility

Accessibility is an important need for persons with disabilities. Therefore, people with disabilities can carry out their mobility to various places they want. Regulations regarding accessibility actually already exist:

Regulation of the Minister of Public Works Number 30/PRT/M/2006/2006 concerning Technical Guidelines for Facilities and Accessibility in Buildings and the Environment;

1. Minister of Public Works Number 468/KPTS/1998 concerning Technical Requirements for Accessibility in Public Buildings and the Environment.
2. Regional Regulation No. 3 of 2013 East Java regarding the protection of the service rights of persons with disabilities.
3. Decree of the Minister of Transportation No. 71 of 1999 concerning Accessibility for people with disabilities and sick people to transportation facilities and infrastructure.

However, this rule is still far from reality in its implementation. In Indonesia, many public facilities are not yet accessible for persons with disabilities. By using standardization on the rules that have been treated by the government, especially the Regulation of the Minister of Public Works Number 30/PRT/M/2006/2006 concerning Technical Guidelines for Facilities and Accessibility in Buildings and the Environment, it shows that it is difficult to obtain public facilities in Indonesia that are truly really accessible according to the standards applied by the government.

Another thing that is felt by people with disabilities and is the right of people with disabilities is a parking lot. In developed countries, people with disabilities get special parking spaces and if those without disabilities occupy it, they will be punished and it is protected by law. Likewise in Indonesia, regulations regarding special parking and accessibility already exist, but implementation is the biggest problem faced by this nation. Data shows that it is

difficult to obtain facilities in Indonesia that provide special parking for persons with disabilities. Thus, those who bring special cars, special motorbikes such as three-wheeled motorbikes and others cannot place their motorbikes easily, they have to jostle with non-disabled people and often their roads are too small and do not fit their motorbikes which are modified with their bodies and their abilities.

Other data that shows that regulations regarding accessibility have not been implemented also in public facilities in the world of education. In a survey conducted by (Slamet, 2014) found data that in general our educational institutions are not yet accessible, about 84% are not accessible and only 16% are trying to install accessibility and as with other facilities, 0% are for educational facilities that really properly accessible according to applicable standards. In accordance with the community's view, that the priority of facilities that are considered the most important for accessibility according to respondents is transportation, which is 36%. Then followed by educational facilities by 34%, sidewalk facilities by 16%. The rest is occupied by market facilities by 9%, bank facilities by 3% and places of worship with a percentage of 2%. The transportation sector is a priority for facilities that are considered the most important for accessibility by respondents.

3. People's Views on Disabilities

According to Law no. 4 of 1997 concerning Persons with Disabilities, it is stated that disability/disability is any person who has physical and/or mental disorders that can interfere with or are obstacles and obstacles to carrying out life properly. People with disabilities are categorized as follows: 1) People with physical disabilities 2) People with mental disabilities 3) People with physical and mental disabilities. Persons with disabilities as with other people have the same rights, namely Economic, Social and Cultural Rights).

The state has a state obligation to fulfill, respect, and protect every right to education owned by every citizen. Article 28 C of the 1945 Constitution also states that everyone has the right to develop themselves through the fulfillment of their basic needs, the right to education and benefit from science and technology, art and culture, in order to improve the quality of their life and for the welfare of mankind, so that it is clear Here, the generic obligation of the state in fulfilling the right to education is to facilitate, to promote, and to provide. UU no. 4 of 1997 concerning Persons with Disabilities and Law no. 20 of 2003 concerning the National Education System emphasizes the right of every citizen to obtain education in accordance with levels, pathways, units, talents, interests, and abilities without discrimination. In other words,

in the formal education sector there should be no more social barriers that separate people with disabilities from the general public.

Disability is something that a person has so that the problems and difficulties faced by persons with disabilities are caused by that individual. This model approach is called the "medical model". For this approach, naturally, disability is an individual problem caused by functional limitations or physical/mental abnormalities. It is clear that the problem of disability is "a person's deficiency", with the standard of completeness of the body / senses of "normal people" (Darlington, 1981). , so they are referred to as people who have social disorders or social deviants. Disability is an individual problem, and the solution must also be focused on individuals such as rehabilitation, therapy, and individual training and others (Pfeiffer, 1998). The paradigm shifted in the decade of the 70s, which was pioneered by UPIAS (Union of the Psychologically Impaired Against Segregation) which introduced a social model approach (Social Model), in this approach, disability or disability is defined as a social construction and its relation to society and the environment. This means that disability is a product of society that is continuously reproduced until it is difficult to sue and then becomes the truth. The environment, both socially and in terms of infrastructure, is formed by "normal" groups so that it does not provide space and opportunities for persons with disabilities. In the academic world, new developments in looking at disability were promoted by names such as Mike Oliver (1983, 1990, 1996) Barnes (1991) and Vic Finkelstein (1980; 1981) which started from UPIAS. As stated in the UPIAS statement as stated in its manifesto, disability is defined as a result of "social oppression".

D. Conclusion

Based on the various literature studies and documents described above, the paradigm shift in interpreting disability needs to be continuously socialized so that the ideals stated in the Law on Persons with Disabilities can be realized, and cooperation from all parties is needed to start applying an inclusive model in viewing disability, and the human rights of people with disabilities can be fulfilled and they are seen as whole human beings who can also contribute to the nation and state of Indonesia. It is equally important for the government to increase accessibility which is an important requirement for persons with disabilities to carry out their life activities. With accessibility, it is an accessible place, in accordance with the standards that have been treated by the government. Even the majority of government agencies themselves are not accessible, making it difficult for people with disabilities to access.

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