Disability Identity: 
Perspective for Policy Formulation

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Abstract
Policies regarding people with disabilities (PWDs) often ruled out disability identity as decision making factors, resulting in multiple issues about PWDs empowerment and livelihood. This research aims to analyze factors that shapes disability identity to understand identity aspects of PWDs that needed to be considered in policy formulation. Researcher interviewed seven PWDs to gain understanding about factors that influence PWDs to formulate their identity, which analyzed further on how disability identity could be implemented in public policy formulation. This research shows that policy formulation needs to established solid categorization of disability, prepare the environment and support system to treat PWDs in equal and inclusive way, increase PWDs adaptability to interact with larger society, and focus more on how PWDs are being empowered during their participation in organization, specifically aim for enable PWDs to contribute and be treated fairly within organization. Furthermore, some program such as inclusivity audits, government-based training for organization, to extra-benefits for organizations with high rate of inclusivity could be added to policies as well.

Keywords: Disability Identity, Disability Policy, Policy Formulation

1. Research Background
World Health Organization (2018) elaborated that more than 15% of the world population is part of people with disabilities (PWDs), which puts them in a minority group with higher risk of unfairness and discrimination (WHO, 2011; Heymann et al., 2014; Luo and Wang, 2017). Disability conditions experienced by PWDs resulted in lower education access, lower opportunity for employment, and limited access to primary needs (Loeb et al., 2008; Mitra et al., 2011). More than 80% of PWDs live in developing countries with low-level of disability empowerment, resulting on limited choices aside of survival in such inequality (Ndzwayi & Ned, 2017). Those conditions provide new challenges for PWDs to participate in efforts to reduce poverty, which directly increase PWDs empowerment (Maini and Heera, 2019), increase social inclusion (Naranie and Lindsay, 2011, Heera an Devi, 2016), as well as economic inclusion (Mansour, 2009).

Primary challenges for PWDs could be traced into the social empowerment model of PWDs which often see disability as medical condition that need specific treatment to assimilate with general society (Kayess and French, 2008, Symeonidou, 2009). During the processes, PWDs often form groups and organizations to pursue equal accessibility
Specifically, Vanhala (2011) explains that equal rights approach is the correct approach to change the conventional view on PWDs. PWDs efforts finally resulted in global adoption of “Convention of on the Rights of Persons with Disabilities” (CRPD) in 2006, which often referred as new era of PWDs activism in transform approaches of disability to integration between medical and social approaches (Megret, 2008). CRPD provide fundamental understanding that provision of accommodation is a standard of non-discriminative practice, and increase opportunity for PWDs to pursue for disability rights in larger international context.

How PWDs are able to stand up for their rights by forming groups based on their identity indicates that disability identity should be seen as the main focus to view the disability phenomenon. Generally, Hahn in Dirth and Barnscombe (2018) explain that collective treatment on PWDs is an important factor in understanding the correlation between political, structural and cultural aspect of PWDs experience and also indicate that interaction between PWDs and their social environment influences how PWDs acts and behaves. Lejzerowicz (2016) also explains that individual role in communities and social environments also define their identity. Specifically, Forber-Pratt et al. (2017) propose that PWDs perception of themselves, PWDs interaction with the social environment, as well as their adaptation mechanisms to adapt with their conditions are unique phenomena shaped by their disability identity.

Disability identity development is a unique process since identity itself is a personal and intrinsic concept, yet could be viewed as a communal concept since an individual still depends on interaction with another individual to form and develop their identity (Forber-Pratt and Zape, 2017). Structurally, disability identity also shaped by ecological, race, gender, history and politic surrounding PWDs existence (Forber-Pratt and Zape, 2017; Dirth and Branscombe, 2018). Other factors such as poverty and economic inequality also contribute as factors that reduce PWDs opportunity to access their primary needs and contribute further on society (Banks et al., 2018).

In practice, there are discrepancies on the policy design of disability rights and its implementation (Kulkarni and Lengnick-Hall, 2014; Vornholt et al., 2018), where this phenomenon is occurring in both developing countries (Mizunoya and Mitra, 2013) and developed countries with strict anti-discrimination policies (Khan et al., 2018). In policy perspective, policy formulation usually is not based on PWDs perception about disability itself (Santuzzi and Waltz, 2016). Serrat et al. (2016) elaborate that policies are often formulated based on assumption that collective voice could be represented through single individuals, lead into urgency to put diverse representation as policy maker. Based on those explanation, policy formulation often ruled out multiple perspective of PWDs and their identity, which might be crucial to form accurate policies to increase disability rights and empowerment.

Furthermore, PWDs empowerment in structural approach usually addressed by the implementation of multiple programs and policies to solve issues from marginalized
communities (Datta and Singh, 2018). Furthermore, these methods of affirmative policies are often criticized since they could perpetuate the discrimination cycle (Velazquez, 2012) and are unable to solve societal problems which are the main roots of unfairness experienced by minority group (Fisher et al., 2013). Affirmative policies also might lower people supports for policies for a minority group (Rose, 2019), where lower supports might place PWDs as the first group to receive impacts from social disappointments. Society might express their disappointment with several form of discrimination within their daily interaction with other individuals, especially those who belongs to minority group who benefited from affirmative policies (Lindsay, 2018). In results, PWDs as a large part of minority groups often exclude themselves from their environment and try to compensate for their low perception of themselves by several actions in hopes their actions might hinder their perceived weaknesses (Mc Gonagle and Hamblin in Bonaccio et al., 2019).

Exploration about disability identity is often overlooked in academic research with some notable exceptions. First, Gibson (2006) classified disability identity with clinical approaches which focus on researcher experience during interaction with PWDs directly. Second, few researchers such as Hahn and Belt (2004), Dunn and Burcaw (2013), also Forber-Pratt and Zape (2017) conducted research on disability identity formulation based on the empirical investigation based on factual phenomenon of PWDs and their identity. Although these researches provide specific understandings of disability identity, there is needs to analyze how disability identity adds depth on public policy formulation. Policies about PWDs influence disability empowerment as well as PWDs life quality, hence it is important for those policies to provide room for disability identity as fundamental aspect within formulation processes.

Furthermore, academic researchers have explored about the correlation between identity and policy formulation. First, Cassan and Vandewalle (2018) explained that individual identity could be associated with various social categories, which intersection between each category (in example: gender and caste) might alters the distribution of the benefits of this policy. Second, Hornung et al. (2019) addressed that policy actors act in accordance with their salient social identity, which raise the importance to understand how identities might explain underlying dynamics of policy formulation and decision making. Third, research from Bell and Lui (2023) elaborated that identity complexity such as gender, income and race shaped public support for affirmative action policies. These researches successfully explained how identity could influence various dimensions of policy formulation, from the underlying decision making, public support, as well as distribution of the benefits. However, these researches focus more on intersectionality of large social identity (in example: gender, race, caste, and economic status) in which some social identity has solid representations within policy makers and political power to influence policy formulation process. Researches generally ruled out disability identity, which indicates that disability is still unrecognized as a part of social identity.
This research aims to analyze factors that shape disability identity to understand identity aspects of PWDs that needed to be considered in policy formulation. According to Yanow (2000), policy formulation should portray the stories behind groups represented within the policy itself. This explanation correlated with further elaboration from Béland (2018), who explains that understanding identity provides new approaches to explain political phenomenon and future advice on public policy. Specifically, Howlett et al. (2009) elaborate that identity could be represented in policy through the policy formulation cycle: agenda setting, formulation, implementation and evaluation. Direct correlation between identity and policy creates urgencies to understand how identity itself is formed, especially in PWDs.

2. Method

This research interviewed seven PWDs with different kinds of disabilities with at least one year of experience contributing for an organization. Organizational experience is added as criteria since it is also important to address how disability identity is formed within the organizational setting. Furthermore, one year experience requirement is adopted from Zhu et al. (2019) which explains that members need at least one year of experience to process the experience during their participation within the organization. Research also implemented semi-structured interview, which is defined as interview technique adopted specific points to guide the interview process, where researchers are able to adapt and develop the interview based on the interview processes (Copper and Schiendler, 2014). Semi-structured interview is not strictly controlled the relation between interviewer and informant, hence enable interviewer to adjust interview dynamics based on the situation during the process (Yin, 2011). Informant general information is shown in Table 1:

<table>
<thead>
<tr>
<th>Code</th>
<th>Age</th>
<th>Profession</th>
<th>Length of Experience</th>
<th>Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>N1</td>
<td>24</td>
<td>Researcher and Journalist</td>
<td>4 years</td>
<td>Blind</td>
</tr>
<tr>
<td>N2</td>
<td>23</td>
<td>Content Writer</td>
<td>2 years</td>
<td>Autoimmune</td>
</tr>
<tr>
<td>N3</td>
<td>25</td>
<td>Copywriter</td>
<td>2 years</td>
<td>Cerebral Palsy</td>
</tr>
<tr>
<td>N4</td>
<td>28</td>
<td>HR Supervisor</td>
<td>3 years</td>
<td>Physical Disability</td>
</tr>
<tr>
<td>N5</td>
<td>32</td>
<td>Social Media Strategist</td>
<td>3 years</td>
<td>Hard-of-hearing – Hearing Aid</td>
</tr>
<tr>
<td>N6</td>
<td>25</td>
<td>Administrative</td>
<td>2 years</td>
<td>Deaf – Sign Language</td>
</tr>
<tr>
<td>N7</td>
<td>30</td>
<td>Illustrator and Photographer</td>
<td>3 years</td>
<td>Cerebral Palsy</td>
</tr>
</tbody>
</table>

Table 1. Informant General Information
Interview was conducted from January to March 2021 through Zoom Meeting and focuses on how informants shape their identity and how their identity influences their perspective. Interview process also included participation of a sign language interpreter for an informant, which informant chose the interpreter themselves. The connection between sign-language interpreter and Deaf people is needed due to the linguistic richness of sign language. For example, informant often chooses signs that also represents his dialects and emotion, where these kinds of preferences are better understood by interpreter that usually communicates with them. Each interview was conducted for 30-80 minutes, and transcribed into paper documents.

Multiple informants with different backgrounds are needed to provide validity of this researches, which Yin (2011) elaborated that multiple informants increases the richness of data gained from the interview. In addition, this research adopts triangulation methods from Creswell (2017) who suggests to conduct data triangulation through interviews, observations, and document analysis. Each document gained from interview with informant is treated as independent document, where the interpretation will be compiled to find generalizable findings.

3. Results

3.1 Structural Factor and Disability Identity Development

Generally, structural factors consisted of three main aspects: legal, medical and cultural. In legal aspect, policies to ensure disability employment actually plays a significant role to increase more opportunity for PWDs to improve their quality of life. However, how policy maker view disability also influences how organizations view PWDs, which also influences how PWDs view themselves as a person. Lacks of solid disability categorization from the policy maker provides organizations with PWDs members with unclear information about disability, resulting in different interpretation and meanings by the organization which potentially harms the implementation of disability right and reduce the benefits received by PWDs.

According to the reports from Gunawan and Rizki (2022), it could be concluded that government still does not have solid categorization of disability. This is represented on the data collection methods by the government, where they used three different measurements of disability in Village Potential Survey (Pendataan Potensi Desa), National Survey of Working Forces (Survei Angkatan Kerja Nasional), and National Survey of Social and Economics (Survei Sosial Ekonomi Nasional). As expected, collected data has significant differences in both numbers and categorization. For PWDs with invisible disabilities, these differences directly harm them since: 1) it is possible that they will find it hard to get government support since they might be included in one data but not in the others; 2) organizations will have no solid standards to define disability, which led them to choose the definition they see fit; and 3) they might not be included in the categorization at all since their condition is harder to grasp than visible disabilities.
Culturally, PWDs form their own cultural identity as efforts to create togetherness that unites PWDs under the same identity. As an example, Deaf people now established Deaf as a part of their cultural identity, which are linguistic minority whom uses sign language as their communication method. An informant explained below:

“Deaf people has our own language and culture. Sign-language is also a language, a solid language. The differences it has from others language is only on visual modality.” – N6

However, this cultural identity formulation also has several issues which potentially lead to another layer of discrimination for PWDs from their own community. Based on informant explanation, there are also internal conflicts in Deaf community where individual whom are technically still able to hear sounds through the help of hearing aid (hard-of-hearing) are “not categorized as true Deaf people and Deaf community often exclude us from the group” (N6). At the opposite, one of the informants belong to the Deaf community explained that exclusion of hard-of-hearing individuals might happen because the community “feel unsafe and find it hard to communicate because they (hard-of-hearing individuals) usually are not fluent in sign language” (N5). This different perspective shows that disability communities were formed to create a safe space between PWDs, which they are unable to get from the structural mechanism.

3.2 Personal Experience, Social Interaction and Disability Identity Development

Personal experience explains how individuals view and interpret their experience and condition to shape their identity. PWDs might have different view of their disability, which could be formed by different experience that influence trajectory of their identity development. Hence, it might be important to dwell deeper into the detailed experience of PWDs to understand the reasons behind those different trajectories.

There are several personal experiences that potentially influence disability identity development. First, there are differences between PWDs whom experienced disability since they were born and PWDs whom experienced disability because certain events happened during their life. The latest category often feels less motivated and harder to accept their experience, resulted from drastic changes they experienced. Second, PWDs often have tendencies to normalize their condition, especially those with invisible disabilities. This normalization indicates that PWDs, especially those with invisible disabilities often view themselves as unfit for disability categorization, resulting in normalization behavior to avoid risks of discrimination.

Furthermore, interaction between PWDs and their environment also plays a role in how they will form their identity. Conversations with some informants revealed that different interaction patterns between PWDs and their environment were caused from several factors. First, different interaction patterns constructed from different levels of interaction PWDs have when it comes to interacting with non-PWDs. An informant explained:
“I was never attended school for PWDs. Those time (school phases) might be the most thrilling phase in my life. In the end, I could say that it shapes me to be more confident about myself.” - N5

Daily interaction with non-PWDs might be able to train PWDs to be more used to larger social interaction. Experiences with environmental backgrounds, such as background diversity and attendance on educational institutions might influence how PWDs interact with non-PWDs, which PWDs with more exposure of diverse society are generally more adaptive. Characteristics of public school, which in general filled with students from various backgrounds, enable PWDs to interact more with non-PWDs people, resulting in higher adaptability.

Second factor is support from family and closest environment. Interestingly, informant whom explained that their family believes that they “could achieve anything I want” (N3) and informant who explained that their family “often see them as a burden” (N7) explained further that they both felt difficult to process bad things which they thought it happened because of their disability conditions. This phenomenon shows that both approaches, either taught PWDs that their conditions do not matter at all or their conditions matters a lot until it becomes a burden, could be considered as failure to see disability issue in comprehensive matters, which includes understanding about PWDs needs for adjustments and supports.

Third, how social environment views PWDs also stands as contributing factor for PWDs to think that it will be hard for them to be accepted in larger society. This perception leads into different actions from PWDs to keep their position within their environment, which PWDs often opt to do nothing when they receive discrimination or not raise their opinion about specific invitations because they fear to be ignored in the future. Interestingly, these actions occur even in PWDs who claimed they have high confidence about themselves and their disability. It shows that aside from the trajectory of disability identity development experienced by PWDs, generally PWDs have constant insecurity as a result of the perception about discrimination and stigma they might receive from society.

However, their insecurity also led to their reaction to cope and overcome. PWDs often develop certain methods to change negative perception they often thought about themselves. Their coping mechanism could be categorized in three main actions, which are: sense of achievement, willingness to contribute to disability community, and establishment of safe space to express their identity. These actions prove that although PWDs have their own insecurity about their conditions, they have strong will to address the insecurity which indicate strong determination to improve their condition.

3.3 Organizational Practice and Disability Identity Development

Organizations where PWDs participated or worked could change or reshape disability identity formed before PWDs contribute as a member of these organizations. In organizational participation context, some informant explained that they often feel
unsafe about their future at works, whether their rights will be granted to them, and how organization view them as members. In order to address those issue, it is important for organization to empower PWDs through the right approaches. PWDs whom feel that they are empowered within the organization often want to contribute more, since they are willing to return the favors. Organizational support, especially from the fellow organization members and leaders would encourage PWDs to embrace different opportunities to increase their capabilities as well as feel secure about their position.

Furthermore, organization that always tries its best efforts to empower PWDs will gain positive perception from PWDs. This positive perception makes PWDs to be able to view organizations with more positive point of view, more than practical accommodation these organizations provide for PWDs. An informant explained:

“Organization treats me like I am important and it makes me feel maybe this is actually where I belong. Although there are many things to improve, I could feel kindness and good gestures made by the organization” (N3).

Organization with good performance management often provide positive feedback for talent development, including PWDs within the organization. In general, PWDs in organization wants to be treated as equal and provides an opportunity for each member to raise their opinion make PWDs feel that they are not forced to comply. Moreover, PWDs could utilize space to have discussion with their leader about their performance, issues, and improvements expected by their leader.

3.4 Disability Identity and Policy Formulation

Results about factors that influences disability identity development bring new approach that PWDs is not entity with limitations caused by their conditions, but they are individuals with their own unique identity. Moreover, identity also influence on how individuals see different phenomenon and issues in their world, and this is not different with PWDs. Forber-Pratt et al. (2017) explained that although PWDs formed their identity with disability as one of main factor, is important to understand that disability is not the only thing that define PWDs identity, and they have various and diverse characteristics aside of their disability condition.

Fundamental issue about policy formulation regarding PWDs is how policy-maker actually view disability as barrier in everyday life, hence the policies often focus on ‘help’ rather than focus to ‘providing equal opportunity’ for PWDs to contribute more to society. Understanding about disability identity could help policy-maker to view disability as a part of diversity, and avoid to think that disability is an absolute inadequacy that makes PWDs unable to be empowered.

First, policy maker needs to establish solid categorization of disability. This categorization should not only determine by the conditions of the individual, but it needs to also consider how interaction between disability and its surrounding environment could limit actions and opportunities of PWDs. In the disability identity context, establishment of solid categorization might avoid PWDs from question their own
disability status, and provide legal guarantees suitable with their conditions and surroundings. In example, disability categorization might need to includes how individual gained the disability itself. This research shows that there are differences in disability identity development between inborn disability and acquired disability. Lejzerowicz (2016) explained that PWDs with inborn disability create their identity of a disabled person from the beginning. Adler et al. (2021) added that people with acquired disability experience a drastic change in their identity as wholly transformed by the experience of acquiring a disability. These two differences provide an urgency for policy-maker to address source of disability in categorization, since it plays a significant role on how people develop their identity and adapt with their disability.

Furthermore, policy-maker also needs to understand invisible disability and includes this condition into disability categorization. This research shows that PWDs with invisible disability often normalized their conditions, regardless about issues they experienced from their disability. According to Norstedt (2019) who conducted their research at developed country with well-regulated working conditions, PWDs with invisible disabilities are still often not disclose their disability situation to their employer or future employer to avoid stigma and stereotypes about their identity and working ability. Furthermore, individual with tendencies to normalize their situation often unable to gain access for policies that aim to help their daily life since they are not included in formal categorization of PWDs. Hendry et al. (2022) explained that since invisible disabilities often unable to clearly seen and perceived by people, PWDs often refuse to asks for adjustment and accommodations since they fear people would not believe in their explanation.

Second, policy-maker needs to understand how identity could be shaped from social interaction of PWDs and their environment. According to Liu et al. (2018), different social patterns between PWDs and non-PWDs provide barriers for integration of PWDs in social environment. These barriers consist of stigma and discrimination received by PWDs from their environment, which influenced how PWDs will behave in larger social context (Quinn and Earnshaw, 2013). Policies need to not only address PWDs as policy target, but policies need to also focus on the environment and support system needed by PWDs. Policy should aim to increase preparation of environment and support system to treat PWDs in equal and inclusive way. Furthermore, closest environment needs policy intervention which focus on increase on their knowledge about disability conditions and treatments based on disability characteristics. Policies which increase community preparedness to accept and treat PWDs are needed since treatments from environment, both family and community, will influence on how PWDs perceive their identity, which lead into how PWDs will behave in larger social structure. Improvement on community will lead into better access of equal basis to non-PWDs to community living, as well as ability to participate in meaningful and necessary activities (Hunt et al., 2022).

Policies need to also address PWDs readiness to interact with society through programs and curriculum at public schools. At the same time, policies should also aim for
improvement in inclusion practice within public school, hence PWDs still be able to attend public school and receive equal treatments. Moreover, disability-focused school to focus on increase PWDs adaptability in social environment. Policies needs to also aim for the closest environment of PWDs within scope of educative approach, where policies are implemented to raise awareness about inclusivity and equal treatment for PWDs.

Third, policies about PWDs involvement within organization or working environment needs to be addressed further than policies that oblige organization to hire PWDs, but also address about how PWDs are being empowered within organization. These policies are needed to protect PWDs from unequal treatments from organization nor members of the organization and being recruited only as a token or symbol of organization’s image. In practice, Bonaccio et al. (2019) reported that PWDs still experiencing issues during their participation within the organization, such as hidden discrimination, barriers to access information, unfairness in performance evaluation, and often blamed for unrelated incidents within the organization.

Specifically, policies need to move further from instruction of specific actions, but rather designed to indirectly create spaces for enabling PWDs to contribute and be treated fairly within organization. Kaletta et al. (2012) explained that there is no significant difference between PWDs and non-PWDs in terms of average productivity, indicates that when PWDs are placed in right position and job, they are able to perform as well as non-PWDs people. However, Vornholt et al. (2018) explained that although organization already recruited PWDs as its members, PWDs still be seen as burden and receive less assignment due to lack of faith in PWDs working capability. Based on Bonaccio et al. (2019) policy maker might need to address about how PWDs are introduced with organizational knowledge, ensure of equal treatments at works, including communication and information access, as well as equal performance evaluation and feedbacks to increase PWDs participation. In addition, some implementation controls, such as inclusivity audits, government-based training for organization, to extra-benefits for organizations with high rate of inclusivity could be added to policies as well. Although policies are generally unable to intervene in organizational practice, yet policies could be designed to increase organizational practices that empower PWDs.

4. Conclusion

This research aims to analyze about disability identity and how disability identity could provide new approach and knowledge for policy formulation about PWDs. This research finds that disability identity is shaped from three main factors: structural, personal experience and social interaction, as well as organizational practice. First, structural factor highlights the importance of solid disability categorization as well as cultural identity formed by PWDs to create togetherness that unites PWDs under the same identity. Second, personal experience and social interaction highlight differences between inborn and acquired disability, exposure of interaction with non-PWDs, as well as family and community support. Lastly, organizational practice highlights the
importance of equal treatments and evaluation for PWDs to form sense of security and increase their participation at work, which in the process add positive value for their identity development.

There are some notable understandings about disability identity that needs to be considered in future policy formulation. First, policy maker needs to established solid disability categorization that also includes cause of disability as well as invisible disabilities. Second, policy maker also needs to increase preparation of environment and support system to treat PWDs in equal and inclusive way. This suggestion also includes improvement of inclusivity in both public school and increase on PWDs social interaction preparedness in disability-focused school. Third, policy formulation also needs to design policies that create spaces for enabling PWDs to contribute and be treated fairly within organization. In addition, some implementation control also needs to be implemented in order to evaluate policies results and benefit distributions.

This research’s findings add more depth into policy formulation, especially in considering minority group collective identity in policy making process. Methodologically, this research provides perspective from PWDs to uncover important factors from disability identity needed to be addressed in policy formulation. Policy formulated by non-PWDs might not be able to fully capture disability identity within the policies, hence perspective from PWDs is needed to provide detailed information about identity and PWDs experiences. Furthermore, this research provides suggestions to be considered in three important aspects of PWDs well-being: structural aspect, personal and social interaction aspect, and organizational aspect. These findings could be used for policy maker to form comprehensive policies, which could address important factors in PWDs livelihood.

Future researcher needs to consider about extension of informant to gain more views about disability identity and condition within social and working environment. This extension could be conducted through larger numbers of informant in each category of disability, or even focuses on some specific category to analyze how disability type could influence identity formulation. Furthermore, since the data gained from personal stories of marginalized community, future researcher is able to consider direct involvement with PWDs daily life through ethnographic research to gain deeper and larger data based on their observation and daily interaction with PWDs in a large number. Moreover, if future researcher is willing to conduct quantitative research, they need to also consider several communication or perception barriers that might occur and interfere with informant understanding about the questionnaire, such as: different uses of language, communication issues, or questionnaire comprehension ability. In general, future researcher might need to simplify the sentences within questionnaire to be easily understood by all PWDs. In addition, future researcher should be ready to prepare and accommodate adjustments for PWDs. Lastly, future researcher needs to consider to use intersectional approach to gain better understanding of specific context shaped the social reality perceived by PWDs.
Bibliography


