

ARGUING FOR THE NEO-BIOPSYCHOSOCIAL AGENDA: HOW DOES HUMAN RIGHTS FIT IN AND WHICH POLITICAL PARADIGM TO USE?

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ABSTRACT

The extent of human rights fulfillment in a country is shaped by the way the government and its citizens perceive the notion and definition of human rights concept in various circumstances. The government with its political paradigm which is the product of its episteme may carry out certain approaches and use certain tools in defending the rights of its citizens and non-citizens. Therefore, the two concepts, human rights and political paradigm are interwoven. We write this paper to try to contextualize the neo-biopsychosocial model of disability in the realm of human rights and political philosophy. This paper problematizes the vagueness of human rights definition, both for philosophical argument and practical implications. We first discuss the principles, application, and limitations of the human rights concept as argued by various scholars in the field, including the nexus of disability and human rights. We also explore the political paradigms of disability in relation to the protection of human rights of persons with impairment and/or chronic illness. We find there is a need to extend the basic values of human rights by inserting the values of individualized-communal adjustment, shared responsibilities, and multidimensionality. We support transformative equality principles and the adoption of transformative egalitarian politics. To facilitate the translation of the two, we propose our version of 'whole system mapping approach' which comprises of the following matrix: (1) Internal environment; (2) Human factors; (3) Tool application; (4) Lived process cycle; and, (5) External environment. The formulation of the whole system mapping approach is based on the integration of the neo-biopsychosocial model of disability and the disability emancipation climate framework. We firmly believe the discussion in this paper can facilitate better translation of transformative egalitarian politics in Malaysia besides comprehensively frame an issue relating to persons with impairment and/or chronic illness and other marginalized groups. We strongly advocate further research to validate our 'whole system mapping approach' as well as reflect on other keywords that have effects on or produced from living with an impairment or a chronic illness across the historical and cultural spectrum.

Keywords: Human rights, political paradigm, transformative equality, transformative egalitarian politics, whole system mapping approach.

INTRODUCTION

The phrase 'human rights' is relatively new in modern human discourse. The international movement of human rights begins more than 70 years ago with the adoption of the Universal Declaration of Human Rights by the United Nations in 1948. Following that declaration, various human rights-related declarations, conventions, and covenants were introduced. Today, we can hear the discussion about human rights almost every day regardless of the issues, especially when it involves the marginalized groups. Even in Malaysia, we can witness the rising of human rights discourse. To some extent, we are happy to see this new development in Malaysia. The community of persons with impairment and/or chronic illness in this country certainly has fought and continue to fight for their issues, rights, and interests.

However, the discussion about human rights can be challenging and sometimes obscured due to misconception and misunderstanding. The word 'human rights' is somewhat vague and abstract without clear operationalization. The most materialized form and easiest example of human rights are laws and international human rights documents. We feel these examples oversimplify the word 'human rights'. For instance, we find the rights of disabled people to higher education not only refers to equal access for them, but also links to different forms of capacity, national policies and strategies, reasonable accommodation, human capital development, state funding, the question of meritocracy, and educational support mechanisms (Nasir & Efendi, 2019).

Certain political paradigm such as conservative, libertarian, utilitarian, and egalitarian may also affect the government's policymaking process in protecting its citizens' rights. Each of these political paradigms has its own criticisms toward human rights. As a result, the human rights-based policies and programs are produced through constant contention between the government and interest groups which can be unstable or easily dismantled due to the decline of democracy and the weakening of civil society movement (Koehler, 2017). In developing the neo-biopsychosocial model of disability, we felt inspired and encouraged to reflect on many of the issues and terminologies, including the term 'human rights'. As we argued in our paper before:

"The neo-biopsychosocial model of disability encourages us to investigate a conflict from a broader perspective, but at the same time do not neglect the different smaller aspects. This new arrangement of consciousness calls for reengagement with the subject of human rights, disabled people's identity, normalization and may also produce a new political paradigm for governance and policymaking." (Nasir & Efendi, 2018, p. 31)

Hence, this paper explores the conceptualization and boundaries in human rights philosophy and its political implication. We start by discussing different arguments made by previous scholars with regard to the human rights concept. Then, we explore the nexus of human rights and disability. Afterward, we review current discussion with respect to political paradigms of disability. Subsequently, we assert the need to extend the basic values of the term 'human rights' and propose our version of 'whole system mapping approach'. Though this paper is developed from the perspective of two researchers in the disability-related field, we hope the discussion may encourage critical reflection and can be applied to different domains (e.g. race, gender, age, and sexual orientation).

HUMAN RIGHTS DISCUSSION

For most people, human rights are understood and felt like something natural which they are born with like the color of their eyes or the color of their skin. In fact, *hak*, which is the Malay word for rights is synonymous with the word truth, power, and ownership. This mirrors the possibility of a connection between human rights and human nature. However, Brown (2013) argues it is problematic when connecting human rights to human nature since earliest philosophical construction of human nature tends to see differences in human beings (physically or culturally) as inferiority, thus proposing rigid criteria of what is meant to be a human. Instead, he suggests the conceptualization of the nexus of human rights and human nature should recognize and value the plurality in human nature while at the same time identify the common generality between the two dimensions.

This also begs the question of whether human rights are universal or otherwise. Martin (2013) lists five major criticisms against the universality of human rights which are: (1) There is no one acceptable universal ground for human rights; (2) Some rights are strictly between individuals in the society which may not require state intervention; (3) Not everyone can obtain all social and economic rights as enshrined in the human rights instruments pertaining to those rights; (4) Not all states can protect and ensure all social and economic rights of their citizens due to different social and economic factors; and, (5) Some rights are perceived as specific rights to a group of person due to their physical and social characteristics. In his opinion, a right can be recognized as a universal right when it has mutual and general benefits to a vast number of people and there is an overlapping consensus from various cultural standpoints that can strengthen its justification.

From another angle, Walker (2013) postulates potential aspects to reconcile the relationships between universalism and particularism viewpoint towards human rights through normative flexibility, the trans-cultural attractiveness, and the structural reconfigurability of human rights claims. For this to happen, we must recognize the relations and implications of cultural diversity to human rights conception and vice versa (Corradetti, 2013; Gregg, 2012; Renteln, 2013). This also entails the interrogation of individuals' personal ownership and standpoint, the interaction between individuals in a group, and the interaction of different groups in a society. This process is important, especially all countries in the world today are becoming increasingly multi-racial and multi-cultural nations.

In the global context, it affects the interaction and relationships between countries in various economic and political dimensions (e.g. international trade, human migration, and sovereignty) as well as interaction and relationships between citizens of different countries (e.g. cultural goods consumption, trans-national marriage, and even stereotyping). The way the governments and its citizens conceptualize the nature of human rights will influence the way human rights are being safeguarded or otherwise. The governments will adopt certain approaches based on their political stands in regulating and managing the citizens' and non-citizens' rights. In the era of globalization and trans-nationalism, Fraser (2009) proposes a three-dimensional model of justice which centers on the political dimension of representation, the economic dimension of distribution, and the cultural dimension of recognition.

The third hot button issue in human rights discussion is regarding duty-bearers of rights fulfillment. Human rights do not exist only as moral or political concepts but also represent obligations to achieve those rights. Someone must take responsibilities to promote, ensure, and protect those rights. Some scholars discuss who should take responsibilities in safeguarding those rights (Barilan, 2012; Boot, 2017; Karp, 2014). For liberals, they argue that human rights discussion is only meaningful when the duty-bearers are clearly identified because there is an opposing opinion whether the duty-bearers should be the individuals, the community or the government (Evans, 2002). In his book, Boot (2017) discusses the growing attention to the duties of non-state actors (individuals and private groups) in human rights discussion which he explains two forms of human duties; negative duties (referring to duties of forbearance and duties to exercise one's rights responsibly) and positive duties. However, he concludes negative duties are not defined sufficiently in the international human rights instruments (Boot, 2017, p. 7).

As argued by Martin (2013) and Boot (2017; see also Osiatynski, 2009), some cases of human rights violation can also cause by individuals and non-state organizations such as private businesses. Among individuals, the example can be in the form of forced labor or invasion of privacy. In the context of business, the examples can be in the form of work-related discrimination or refusing services to a certain group of persons. Therefore, human rights not only comprise of what one should have but also what one should refrain from doing. The entanglement of duties across different level of actors is more complex and apparent when discussing the fulfillment of social and economic rights. For example, in the case of providing employment or in providing health insurance. These two examples require not only proactive measures from the government but also involve the private sector. One possible solution in reconciling this dilemma is to encourage voluntary collaboration between government and private entities (Goodman, 2005).

The fourth issue of human rights is the intersection between different rights, especially the connection of social and economic rights to one another (Degener, 2016; Efendi, 2019; Efendi, Fadzil, & Khoo, 2018; Heymann, Cassola, Raub, & Mishra, 2013; Toebe, 2015). However, some scholars argue that there is no substantial moral or sociological explanation that all forms of

human rights should be seen as interconnected (Walker, 2013) in addition to different capabilities of countries to practically translate the fulfillment of a complex intersection of their citizens' rights.

The problem of multi- and intersectionality encourages us to revisit the basic values of human rights (dignity, autonomy, equality, and solidarity) and other relating aspects such as capacity, duties, the policymaking process, and citizenship. On top of that, human rights discussion should reflect and support different identities (e.g. age, ethnicity, impairment, nationality, race, sex, and sexual orientation). The following section shall briefly discuss the nexus of human rights and disability issues.

THE NEXUS OF DISABILITY AND HUMAN RIGHTS

The adoption of the Convention on the Rights of Persons with Disabilities in 2006 does not mean persons with impairment and/or chronic illness have different and new rights compared to others. Instead, the convention reaffirms that these persons also share and should enjoy the same rights as enshrined in other United Nations' human rights documents. Each of the international human rights instruments can be applied in the context of persons with impairment and/or chronic illness (Quinn, Degener, Bruce, Burke, Castellino, Kenna, Kilkelly, & Quinlivan, 2002). The four basic values which are dignity, autonomy, equality, and solidarity are imperative in both general human rights discussion and in the context of persons with impairment and/or chronic illness, however the problems occur when typical construction and conceptualization of these basic values are imposed on persons with impairment and/or chronic illness (Quinn et al., 2002, p. 14).

In comparing disability in political theories and international practices, Arneil (2016) unveil that political theories still very far behind in reconceptualizing disability. She stresses the need to redefine equality and freedom to be more inclusive of persons with impairment and/or chronic illness based on the principle of universal interdependence. By incorporating the principle of universal interdependence, we can bring about the ontological reform in many aspects of private and public lives, such as care and ethics of care, social protection for all and the fulfillment of other social and economic rights, the implication of regionalism for disabled people's inclusion, and so forth.

However, Degener (2016) argues that the Convention on the Rights of Persons with Disabilities moves beyond the social model of disability, therefore establishing the human rights model of disability which is built on the following underlying statements:

1. The human rights model of disability provides a set of values for the policymaking process to ensure the protection of dignity and fundamental rights of persons with impairment and/or chronic illness;
2. The human rights model of disability moves beyond the fight for anti-discrimination legislation, instead the model highlights the interdependence and interrelatedness between civil, political, economic, social, and cultural rights of persons with impairment and/or chronic illness;
3. The human rights model of disability recognizes impairment as part of human variations;
4. The human rights model of disability acknowledges and centers on multiple forms of discrimination and layers of identity among persons with impairment and/or chronic illness;
5. The human rights model of disability supplies a basis for assessment to determine whether impairment and/or chronic illness prevention policies can be claimed to safeguard human rights protection of persons with impairment and/or chronic illness; and,
6. The human rights model of disability offers a roadmap to elevate the situation of persons with impairment and/or chronic illness from poverty.

Degener (2016, pp. 17-18) also argues that the human rights model of disability promotes transformative equality paradigm which aims to change the structure and system through a variety of positive measures to protect the rights of persons with impairment and/or chronic illness. At the center of transformative equality, there must be democratic participation which goes beyond mere engagement and consultation as well as ensuring accountability of the actors and the process during the planning and implementation stages (Hepple, 2013). To change the structure and system, we must challenge the social and cultural roots to discrimination (Biholar, 2014), thus reinventing the collective ontological standing towards the nature of human variations (e.g. age, ethnicity, impairment, race, sex, and sexual orientation).

The discussion about the nexus of human rights and disability has been conducted by many scholars in different topics and themes. In Malaysia, such discussion can be seen in legal discourse (Tah & Mokhtar, 2017), the relations of national and international human rights-related documents (Efendi, Fadzil, & Khoo, 2018; Tah & Mokhtar, 2018a), socio-legal analysis (Efendi, 2019; Jaafar, Wahab, & Yaacob, 2017; Nasir & Efendi, 2019; Tah & Mokhtar, 2018b), legislative improvement (Tah, 2013; Yaqin, 1996), citizenship (Jayasooria, 1999), and social awareness through media (Rosli, Mahmud, & Mahbob, 2016). Though this positive trend seems promising, there are plenty of other topics relating to the rights of persons with impairment and/or chronic illness in Malaysia across civil, political, social, cultural, economic, and technological dimensions have yet to be explored.

POLITICAL PARADIGMS AND DISABLED PEOPLE

The introduction of the social model of disability pushes us to question about the wider power relations between persons with impairment and/or chronic illness in their society and reflect on the government's duties in enforcing barrier-free environment for this group, thus trigger discussion on citizenship, freedom, equality, and human rights from political theory perspective (Arneil & Hirschmann, 2016). Devlin and Pothier (2006, p. 1) argue that persons with impairment and/or chronic illness are being forced to become, what they term as "dis-citizens" because this group of persons cannot enjoy the substantive form of participation in political, social, and cultural life in their society. In this section, we shall explore political paradigms in relations to disability. At the end of this section, we shall make a supporting case for transformative egalitarian politics to ensure substantive participation and quality of life among persons with impairment and/or chronic illness.

In the case of disabled people in central and eastern Europe, Mladenov (2018, p. 100) finds negative conditions of the disabled community in that region exist in the form of economic maldistribution, cultural misrecognition, and political misrepresentation. He argues such predicament is inherited from the state socialism and some emerge from the “postsocial neoliberalization era”. In his book, he elaborates on the effect of overvaluation of the self-sufficiency, stigma associated with receiving government assistance schemes, and tokenistic participation to name a few. Some of these findings can also be found in recent work by Karen Soldatic.

Taking the case in Australia, Soldatic (2019) presents the effects of neoliberalism on the lives of persons with impairment and/or chronic illness. From her research, she uncovers that neoliberalism in Australia has produced stratified groups of persons with impairment and/or chronic illness through various forms of support and benefits, resulting in the deeply stigmatized categorization of persons who are deemed as ‘truly disabled’ and those who are not eligible for such labels. Individuals who are deemed as truly disabled despite these government aids as well as for individuals who are not eligible to be identified as disabled still have to face with socioeconomic oppression. The former is shoved to least wanted market and chained to a highly regulated system, while the latter simply cannot compete with others due to the absence of an equal plane field.

It is not surprising when few scholars reject liberalism or other forms of liberalism when it comes to the protection of the rights of persons with impairment and/or chronic illness (Beckett, 2006; Devlin & Pothier, 2006). Mitchell and Snyder (2015, p. 4) coin out the term ‘inclusionism’ which refers to superficial intention to make an environment to look inclusive with the so-called existence of diverse membership, but the implementation becomes distorted. The neoliberal inclusionism measures cause further marginalization of people with impairment and/or chronic illness when:

- “1) deinstitutionalization efforts undermined by austerity cuts to key services such as in-home personal assistance care;
 - 2) liberal leftist backlash against the homogenizing aesthetics and ecological unfriendliness of universal design as a principle of accessibility to public spaces;
 - 3) international disability-based claims of American exceptionalism that operate by shaming developing countries with respect to their neglectful treatment of disabled people; and
 - 4) nationalist-inflected media portrayals of celebrity cyborgs who are provided as false evidence of the rehabilitation-military postindustrial state’s inclusion commitments to providing hyper-compensatory supports for disabled people.”
- (Mitchell & Snyder, 2015, p. 35)

Mitchell and Snyder (2015, pp. 35-36) also argue neoliberalism produces two modes of disability management. The first mode is what they refer as ‘ablenationalism’, which means the use of disability by the government and multinational corporates or charity sector as a basis to advertise the country’s exceptionalism. The second mode is called as ‘the able-disabled’ where one’s impairment or chronic illness is highly sensationalized as a sign of completion and transcendence from one’s limitations due to living with that particular impairment or chronic illness. So, what are the possible alternative political paradigms in advancing the disabled people’s rights and best translate real inclusivity for them?

Stein (2006) advocates for a utilitarian approach to distributive justice for persons with impairment and/or chronic illness. In his book, he argues that utilitarian approach is sensitive to relative benefits where additional support is given to those who need it and to increase their welfare, hence avoiding inadequate support among those who rely on it and prevent excessive redistribution. On the other hand, egalitarian approach in Stein’s opinion is insensitive to relative benefits because of its incapacities to provide appropriate support to those who greatly need it, instead, overly support those who do not need such support.

Due to different forms of inequalities, either in material, relational or abstract form, we strongly believe transformative egalitarian politics can offer a profound solution in ensuring emancipation and inclusivity for persons with impairment and/or chronic illness. We strongly advocate for transformative egalitarian politics because:

1. Everyone has rights and needs which must be recognized, respected, and fulfilled regardless of their biological, social, cultural, economic, and geographical characteristics;
2. Everyone is interdependent, which include the relationships between humans and non-humans resulting in the establishment of a network of care;
3. Positive and proactive measures must be taken in order to abolish political, economic, social, cultural, and technological oppression to enable everyone enjoys a meaningful life.

Unlike formal egalitarian or resource egalitarian, transformative egalitarian politics can be adopted as an overarching political force or as a basis of assessment to safeguard the individuals’ rights and wellbeing. Transformative egalitarian politics can exist within capitalist society or mixed-economic nations. Instead of power relations, transformative egalitarian politics shift the focus to support relations among individuals and organizations without rejecting the use of organizational structure or labor division. Transformative egalitarian politics which based on transformative equality paradigm can fulfill each basic value of human rights, including the new values which we will propose in the next section.

EXTENDING THE BASIC VALUES OF HUMAN RIGHTS

In researching this topic, we feel there is a strong need to extend the basic values of human rights philosophy. We propose three new values; individualized-communal adjustments, shared responsibilities, and multidimensionality. The following paragraphs will confer on these new values. Through this new extension, we hope that the governments and the public population will have a better understanding of what constitutes as human rights and how to practically embrace it.

The first new value is individualized-communal adjustments. Before we go further, we must recognize that in the process of human rights discussion, we will inevitably discuss human needs in parallel. Human rights are partially derived from human needs, although it is not narrowly determined by this dimension. When we situate the human rights discussion in the public

domain and ordinary people lives, it will initiate (at least in the beginning) the discussion on individuals' needs to have something in order for them to achieve something either immediate goals or gradual outcomes.

Of course. Human needs may be different from one individual to another, from one group to another. This is because human needs can be influenced by biological, social, cultural, economic, and psychological characteristics that one has. For example, women have specific reproductive health needs. So, the healthcare sector must be adjusted to also include their needs for good reproductive healthcare services. Another simplest example is providing food options for those who have dietary restrictions, either due to one's health reasons or religious practice.

This calls for adjustments, both by other individuals and the community as a whole. Some scholar proposes normative flexibility (Walker 2013), while others suppose non-normative positivism (Mitchell & Snyder, 2015). What important here is there must be a negotiated space which encourages respectful and dignified adjustments in the interpersonal and communal relationships. Individualized-communal adjustments are also extended to human needs which are built on indivisible human and non-human relations – or what we call as 'intrapersonal needs'. Intrapersonal needs have been a part of needs among persons with impairment and/or chronic illness. These intrapersonal needs include the universal design application on the infrastructure (e.g. traffic lights with audio signals and announcement boards with speech synthesizer), assistive device (e.g. white cane, wheelchair, and hearing aids), and the usage of service animals.

Intrapersonal needs reflect one's right to use and receive related support to use different forms of assistive tool. The society and the government must adjust their perception and actions to be inclusive and respectful of these intrapersonal needs. When the society and the government restrict or deny these intrapersonal needs, such actions are blatant violations of these people's needs which directly nullify or compromise their rights. These violations implicate one's right to life, right to mobility, and the right to live in the community. The inclusion of different human needs, including intrapersonal needs, must go beyond just mere respect. It must embody universal co-existence.

As co-existing beings, everyone in society, including the non-governmental organizations, private businesses, and the government share responsibilities to promote, protect, and ensure human rights fulfillment. Human beings are not only right-holder but must also be the 'right actors'. People tend to overlook the other 'R' word when they discuss rights – the other 'R' word is responsibilities. Of course. We are not suggesting ordinary individuals hijack and take over the responsibilities of private business and the government. Instead, we emphasize that everyone fulfill their responsibilities to the extent of their capacity. At the same time, we are not proposing that the government or private business interrupt individuals' autonomy. Shared responsibilities do not mean to abolish individual autonomy. The same goes for individuals' dignity and their freedom.

Finally, human rights philosophy and discussion must explicitly embrace the multidimensionality. As many scholars have argued before, there is a connection between civil, political, social, cultural, and economic rights. Human beings, as proved by the long tradition of research and theorization, possess multiple identities and live through their living process across these dimensions. This is true, at least from our observation in disability issues, for persons with impairment and/or chronic illness. As such, disability-related theorization inherently encompasses the theme of interrelatedness and intersectionality (Nasir & Efendi, 2018, p. 29).

EXTENDING THE TRANSFORMATIVE EQUALITY PARADIGM FOR NEO-BIOPSYCHOSOCIAL AGENDA

Here, we would like to propose our version of 'whole system mapping approach'. Many scholars have come up, discuss, and apply a different version of the whole system approach or whole system thinking. Our version of whole system mapping approach is based on the neo-biopsychosocial model of disability (Nasir & Efendi, 2018) and disability emancipation climate framework (Nasir & Efendi, 2019, p. 11). To start, we shall present the key statements of both theoretical frameworks.

The neo-biopsychosocial model of disability emphasizes on the trilateral relationships between components within and between the domain of self, society, and environment which is driven and conceptualized by episteme (Nasir & Efendi, 2018, p. 30). To recap, self composes of one's biological, social, cultural, psychological, economic, and political ownership as well as their emotions. This shows that there exists a parallel of body planes in oneself – biological body, social body, cultural body, political body, economic body, and psychological body. Each of these body planes reflects that particular person's functioning and capabilities. Borrowing the term from Amartya Sen, functioning refers to what a person can do and can be.

All of these body planes and their functioning interact and influence the society and the environment in one way or another. Just like in the domain of self, the domains of society and environment also comprise of different constantly interacting components. In a society, there are many institutions such as family institutions, social institutions (e.g. education sector and healthcare sector), cultural institutions (e.g. arts, media, and religious institutions), political institutions (e.g. the different branches of the government and political parties), and labor market (e.g. international trade and local industries). Each institution regulates its actors and structure using various tools, thus pointing towards the power relationships that exist among its actors and between different institutions.

A person with impairment and/or chronic illness belongs and has a different position in all of these institutions. Obviously, such affiliation in some ways affects and develops one's parallel of body planes through socialization, formal and informal education, and other instruments of enforcement and enculturation. Simultaneously, actors in these institutions also act in some ways according to the person's dominant body planes. As we argued before, components in self are constantly interacting and asserting dominance on oneself in different contexts which then produce one's visible characteristics in certain time and place. However, such interaction can also be influenced by external factors – the society and the environment.

Similar to persons who at risks of being restricted or denied of their rights, actors in different institutions also possess their parallel of body planes resulting in their functioning and capabilities. This also points us to their level of capacity. We need to be mindful of the structure and hierarchy of actors in each institution. As such, different actors have different power. These actors collectively (combined with the tool they created and used) establish an ecosystem which provides us with the information of their overall institutional capacity. As we discussed elsewhere (Nasir & Efendi, 2019, p. 14), capacity does not only refer to monetary and human resource capabilities but also include:

“(a) the capabilities to collect, collate and utilize data for institutional improvement; (b) the capabilities to utilize, improve and innovate technological usage to ensure and increase the quality and effectiveness; and, (c) the capabilities to enact change or adapt to changes especially with regards to institutional system, structure and procedures to meet complex and ever-changing needs and unforeseen conflicts.”

The neo-biopsychosocial model of disability also consciously create a clear separation of the environment as one of the domains that shape one's barriers and risks of barriers. The environment consists of various tools created and utilized by both individuals and institutions for certain goals and purposes. For example, in cultural institutions, such tools can be in the form of media, films, stories, heritage places, and cultural norms. For political institutions, such tools can be in the form of laws, policies, national annual budgets, government aids, newspapers, and taxes. Institutions create and use these tools to regulate actors within and establish the way of interaction between actors and other individuals outside their circle. Besides that, individuals and institutions conceptualize and embrace a certain form of relationships toward these tools resulting in the production of symbols and also extend some form of power.

Persons who at risk of being restricted or being denied of their rights also create and use tools to shape their interaction and relationships with institutions. The tools are also being used either to strengthen, diminish or reconceptualize their parallel of body planes which then affects the way they see, feel, and use their functioning as well. These tools include social media platforms, essays and arts, assistive devices, and even service animals. Despite many possible good things that can be produced from these tools, it can also bring harm. All of these relationships are based on one fundamental root, which is episteme.

Episteme is the central and overarching force that constructs the relationships between the domain of self, society, and environment as well as facilitates individuals' actions. Inaccurate episteme will create negative relationships within and between these three domains, while accurate episteme brings about positive relationships. However, our lives proceed in continuum with both negative and positive relationships may occur simultaneously or interchangeably, thus:

“Disability is a lifelong process of having to face or not to face barriers and risks of barriers by persons with impairment and/or chronic illness, caused by negative relationships between the dimension of self, society, and environment based on inaccurate episteme which then leads to material and abstract inequalities in their lives.” (Nasir & Efendi, 2018, p. 29)

Secondly, we develop a set of principles which becomes the basis of the disability emancipation climate framework. Those principles are:

1. Recognition: All stakeholders in the government and targeted institutions, especially those who hold the power and/or provide the services must recognize and prioritize disability emancipation efforts as human rights agenda in all of their planning and programs.
2. Orientation: All stakeholders in the government and the targeted institutions must have an accurate conceptualization of disability and carry out appropriate measures to remove all forms of discrimination and barriers faced by persons with impairment and/or chronic illness. Such measures must take into account the needs and capabilities of persons with impairment and/or chronic illness and other relevant stakeholders.
3. Mutual accountability: Each actor in the government and the targeted institutions, including persons with impairment and/or chronic illness share the responsibility to contribute and achieve the disability emancipation agenda.
4. Coordination: Every part and level in the government structure and the targeted institutions must have effective coordination, hence they must operate harmoniously.
5. Cooperation: Everyone has the obligation to cooperate and support other actors and/or institutions in order to achieve the disability emancipation climate.
6. Communication: Government and targeted institutions must engage persons with impairment and/or chronic illness in all policymaking processes, including ensuring an open and accessible space of communication for persons with impairment and/or chronic illness.
7. Participation: Government and leaders of targeted institutions must ensure direct and active involvement of the community of persons with impairment and/or chronic illness at all stages of planning, implementation, monitoring, and evaluation of a policy or a program.

In developing the disability emancipation climate framework, we also note the questions of group consciousness, group capacity, good interpersonal relationships, networking resources, politics of interests, and power of difference. Consideration of these elements gives us additional input in planning and implementing a policy or a strategy. From the combination of the two aforementioned theoretical frameworks, we identify five indicators for a mapping process:

1. Internal environment: This part has two objectives. First is to identify subcategories of a wider theme which we are targeting. For instance, with respect to the employment issue, we can categorize it into three main subcategories; employment in the public sector, employment in the private sector, and self-employment. Second is to identify the components that build or produce a whole system. This includes level or hierarchy of structure and physical environment. The common components are governance, infrastructure, technology, and social relationships. Different themes and institutions may have different and unique components.

2. Human factors: After we identify the components, we then identify relevant actors in each component, from the lowest to highest hierarchy. With this information, we can zoom in to assess their capacity and episteme which will also provide us with the overall institutional capacity and organizational climate. At this stage, we must also identify the group of persons who at risk of being restricted or denied, their needs, their positions in each component, relationships to other actors in the institution, and their level of capacity.
3. Tool application: The next area is tools which exist in each component. Each component may have a different set of tools. We must also identify the connections between tools used in different components. Some of the questions that we can consider are for example “how university regulation (governance) affects the process of infrastructural renovation (infrastructure)?” or “how impairment disclosure procedures (governance) facilitate the provision of support and relationships between a client and a service provider?”.
4. Lived process cycle: We must also conceptualize the lived process cycle of each group of actors in an institution. This will provide a better framework in relations to the flow of the process and the interaction between different components in the institution. For example, an employee will begin with a job application, job interview, in-house training, working, career development, and retirement. With this information, we can simultaneously identify relevant actors and tools in each phase of the lived process cycle.
5. External environment: Finally, in order to have a comprehensive system mapping, we must also recognize and identify external institutions and external tools which affect the internal environment. This is also to identify and establish an external support mechanism when needed.

CONCLUSION

Besides the four basic values of human rights (dignity, autonomy, equality, and solidarity), we assert the need to incorporate new values which are individualized-communal adjustments, shared responsibilities, and multidimensionality. Furthermore, we support Theresia Degener’s proposal for transformative equality paradigm which we then advocate for transformative egalitarian politics practice. To facilitate these two concepts, we propose our version of whole system mapping approach which consists of the internal environment, human factors, tool application, lived process cycle, and external environment. We consider the whole system mapping approach as the second phase of development of the neo-biopsychosocial agenda for disability emancipation.

Furthermore, there is a stronger need for an intensification of human rights education for all citizens, particularly among marginalized groups such as persons with impairment and/or chronic illness. We argue that human rights education should be a part of the nation-building agenda in Malaysia. Local disabled people’s organizations must also take initiative to organize related seminars and training workshops for their members and clients. One possible opportunity is to make human rights education as a part of all capacity building programs. As insiders in our own community, we feel that we really need a disabled people’s organization that fully stands on human rights advocacy and acts as a watchdog in this country.

In writing this paper, we are excited about the vast new realm for reflection, re-examination, and critical discussion. We firmly believe the discussion here not only contribute to the theoretical debate, but also provide a better framing of solutions and strategies to emancipate the marginalized groups, including persons with impairment and/or chronic illness of their life struggles. We encourage local scholars to continue to investigate the issues relating to the rights of persons with impairment and/or chronic illness and its location in the wider sociopolitical and socioeconomic environment. We also welcome fellow scholars, policymakers, and students to test the practicality of our whole system mapping approach which then leads to the appropriation of the whole system mapping approach in the domestic and regional context.

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