

# The Disability Rights Movements in the EU and Europe



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จุฬาลงกรณ์มหาวิทยาลัย  
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ลักษณะและวิวัฒนาการสิทธิผู้พิการในสหภาพยุโรปและชาติอื่น ๆ ในยุโรป



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Field of Study	European Studies
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จุฬาลงกรณ์มหาวิทยาลัย  
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ธีรวุฒิ ธีรรัตนพงษ์ : ลักษณะและวิวัฒนาการสิทธิผู้พิการในสหภาพยุโรปและชาติอื่น ๆ ในยุโรป. ( The Disability Rights Movements in the EU and Europe) อ.ที่ปรึกษาหลัก : รศ. ดร. ภาววรรณ เรืองศิลป์, อ.ที่ปรึกษาร่วม : ศ. ดร.มาติน ฮอลแลนด์

การวิจัยชิ้นนี้มีวัตถุประสงค์เพื่อศึกษาการจรรโลงซึ่งสิทธิของผู้พิการภายในสหภาพยุโรปด้วยกลไกหลักนิติธรรม และเพื่อศึกษาประสิทธิภาพของนโยบาย ซึ่งผู้วิจัยมีความตระหนักในความสัมพันธ์ของการศึกษาเกี่ยวกับสิทธิของกลุ่มชายขอบในบริบทของความตื่นตัวและการเคลื่อนไหวเพื่อสิทธิและเสรีภาพของผู้คนหรือชนกลุ่มน้อยในศตวรรษที่ 21 จึงได้จัดทำการศึกษาวิจัยชิ้นนี้

การวิจัยได้มีการนำมาใช้ซึ่งหลากหลายวิธีการตั้งแต่การวิเคราะห์หลักฐานขั้นต้น เช่น ข้อกฎหมาย บทบังคับ สนธิสัญญา หรือนโยบายขององค์กรที่มีผลบังคับใช้ภายในสหภาพยุโรปในขณะนี้ และหลักฐานชั้นรอง เช่น บทความวิจัย บทความวิชาการ หรือข่าวสาร นอกจากนี้ ยังมีการใช้แบบสอบถามออนไลน์เพื่อสอบถามความพึงพอใจและตั้งคำถามปลายเปิดให้กับกลุ่มตัวอย่างคือ ผู้พิการที่เป็นพลเมืองหรือพำนักอาศัยในสหภาพยุโรป ซึ่งมีผู้ตอบแบบสอบถามจำนวนทั้งสิ้น 13 คน ซึ่งผู้วิจัยได้แนบต้นฉบับของแบบสอบถามไว้ ณ ผนวกหมู่ภาคผนวก (Appendix) ภายในงานวิจัยเพื่อให้ผู้อ่านได้เห็นภาพอย่างชัดเจนมากยิ่งขึ้น

ผลการวิจัยพบว่า ความขาดแคลนวรรณกรรม เอกสาร หรืองานวิจัยในอดีตนั้นมีที่มาจากความล้มเหลวในการคำนึงถึงลักษณะที่หลากหลายของความพิการ การเน้นย้ำความเฉพาะทางมิติใดมิติหนึ่ง ภาวะไร้ซึ่งการวิจัยในภูมิภาคต่าง ๆ และความล้มเหลวในการคำนึงถึงมีส่วนร่วมของกลุ่มเป้าหมาย ส่วนแล้วทำให้เกิดช่องว่างการวิจัยที่ผู้วิจัยมีความประสงค์ที่จะมีส่วนร่วมด้วยการทำการวิจัยเกี่ยวกับวิวัฒนาการและการธำรงไว้ซึ่งสิทธิของผู้พิการในสหภาพยุโรปทั้งสิ้น เพราะผู้วิจัยมีความคิดเห็นว่ากระบวนการของสหภาพยุโรปมีลักษณะโดดเด่นเป็นเอกลักษณ์ในการจรรโลงและให้สิทธิแก่กลุ่มด้วยการดำเนินการผ่านกลไกทางการเมืองและหลักนิติธรรมภายในขอบเขตอำนาจของสหภาพ งานวิจัยใช้หลักฐานขั้นต้นและชั้นรองเพื่อศึกษาการอำนวยความสะดวกให้แก่ผู้พิการ นอกจากนี้ ผู้วิจัยได้จัดทำแบบสอบถามบนแพลตฟอร์มออนไลน์เพื่อวิเคราะห์ข้อมูลเพิ่มเติมและประเมินความพึงพอใจและประสิทธิภาพของนโยบายของภาครัฐในสายตาของผู้พิการที่ได้รับผลกระทบจากนโยบาย ซึ่งพบว่าเป็นไปได้ในทางตรงกันข้ามกับข้อสันนิษฐานจากมติมหาชนและการประเมินภายในหน่วยงาน เพราะนโยบายต่าง ๆ ที่ดำเนินการโดยสถาบันและองค์กรภายในสหภาพยุโรปส่วนแล้วแต่ไม่เพียงพอต่อความต้องการที่จำเป็นและใช้เวลานานเกินไปสำหรับการร่างและบังคับใช้ อย่างไรก็ตาม ผลการวิจัยยังพบว่าคำตอบของผู้พิการในสหภาพยุโรปที่ตอบแบบสอบถามมีภาพรวมที่ไม่พึงพอใจและไม่รู้สึกถึงความเปลี่ยนแปลงที่เกิดขึ้นจากนโยบายเกี่ยวกับสิทธิผู้พิการในปัจจุบัน ซึ่งอาจจะทวีความรุนแรงจนเป็นปัญหาสิทธิมนุษยชนภายในสหภาพยุโรป การประเมินและทบทวนนโยบายที่เกี่ยวข้องจึงเป็นสิ่งที่จะต้องกระทำในบริบทนี้

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Theerawut Rirattanapong : The Disability Rights Movements in the EU  
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The study of the social movement, specifically on the marginalized or minority group is an important tool to gain insight into the social and cultural evolution of any given society or culture. A study on the disability rights movement is a growing field in social science, especially in the backdrop of the ever-growing awareness of social and cultural change of the 21<sup>st</sup> Century. Generally speaking, there are a wide gap in the prior research as it failed in one way or the another, ranging from inability to account for the multifaceted nature of disability, overemphasis on a specific aspect at the expense of the demographic group, lack of literature in a specific region, and failure to engage with the targeted population themselves in a meaningful manner and thus has ironically removed the input from the actual persons with disability (PWD). Therefore, this research's aim is to scrutinize the relatively "unique" nature of disability rights movement in the European Union from its background to the current characteristics, which is arguably unique in a sense that it is a supranational union which utilized legal and political mechanisms to function as an organization. The research utilized a wide array of primary and secondary sources, legal documents, and official policies to analyze the facilitation of disability rights via the rule-of-law mode of governance. Furthermore, an online survey is also utilized to gauge the reception of the policy among the people with disabilities themselves. In contrast to what the public and the state have often assumed, the initiatives undertaken by the EU and its institutions are still in their infancy and the measures are often deemed inadequate and long overdue by the PWDs and disability rights NGOs. The findings also indicated that PWDs in the EU are quite dissatisfied and felt unaffected by the current policies or a lack thereof, which could have become a major concern for the EU particularly about human rights issues. A policy review might be necessary should the EU wish to celebrate itself as a champion of human rights and social liberation.

Field of Study: European Studies

Student's Signature

Academic 2022

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Advisor's Signature

Year:

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Co-advisor's Signature

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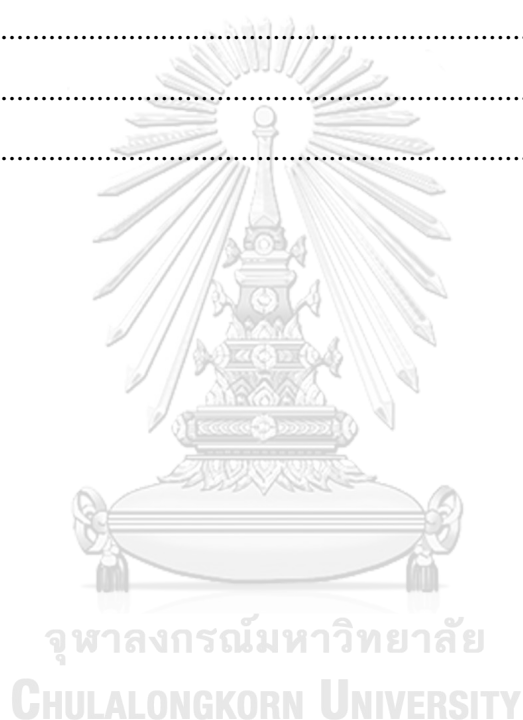
Finally, I would like to also extend my heartfelt thanks to my parents and close friends I have made throughout my lifetime for the moral support they have immensely dispensed to me throughout the researching process.

Theerawut Rirattanapong

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## Introduction

“Injustice anywhere is the threat to justice everywhere” wrote Martin Luther King Jr. (2018) from his confinement in the Birmingham Jail in 1963 to explain himself his intolerance toward all notions of injustice whether it is directed to skin colours, ideology, ethnicity as well as other criteria, reminding that one has a moral responsibility to take a stand against such a trend prevalent in his lifetime. Nevertheless, it is sufficient to say that such struggle for rights and justice never ends even well into the 21<sup>st</sup> Century, in fact, it is burning with passion greater than ever.

Many social movements for civil rights, each of which are tackling different or related issues, arise, evolve, and engage in their own striving for rights or equalities throughout the different periods of human history up until today. In Europe, the cause and the struggle of the feminist movements from the first to the current wave, the decolonization and anti-racism movement such as the ongoing re-evaluation of the consequence of colonialism and white supremacy in the Northern Hemisphere, the LGBT movements for equal rights or same-sex marriage, are well-documented among academics and laypeople alike. Regardless, some social movements will be inevitably overlooked by their smaller scale or complexity and sensitivity to approach the topics. The disability rights movements fell into the latter category.

“Disability rights movement” referred to the loosely global social movement which advocated for equal opportunities and equal rights for people with disabilities (PWD), as well as the end of discrimination in an institutional or personal level toward the group. The movements’ origin can be traced back to the First and the Second World War from the affected citizens in various nations whether they were veterans or civilians alike, as the former event brought the public attention to the concept of “shell shock” and disability caused from the gratuitous usage of chemical weapons, while the latter event brought forth a wanton destruction of human life on a scale no man has ever seen through the horrors such as the Holocaust or terror bombings in continental Europe. Later, the movement’s campaign expanded and gained awareness from the public and the state, who would later concede to their requests and promised to progressively improve their quality of life up until the present day. However, the movement has otherwise gone unnoticed or been overshadowed by the larger concurring movements in the scholarly circle, in large part due to the inherent inaccessibility or incapability to participate in politics and mass mobilizations per the able-bodied people by disabled people themselves. A study on the disability rights movement in Europe will be an important body of knowledge in addition to the pre-existing studies on other social movements for we the laypeople, the policymakers, and the general public to understand the root causes of the struggle for equality and join hands to strive for a better society for ourselves and our offspring. Furthermore, the discussion of the plights of the vulnerable groups and their struggles, as well as the measures taken by the states and the EU might be applicable in the context of other cultures and society.

## Research Objectives

The study will explore the social movements on disability rights in selected nations which are also Member States of the European Union. A thorough scrutinization of the origins, the characteristics, and the methodology of the disability rights movement will be conducted in accordance with the following criteria.

1. To familiarize the context and the origins of the disability rights movement in Europe and relating the movement back into the global trend of activism
2. To assess the strategy undertaken by the member of the demographic, disability rights activists, and other advocates such as public information, demonstration, or protests to advance the cause of disability rights and normalization of disability in the general society, this is in order to determine the effectiveness of the movement as an agent to enforce a social or political change in the policymaking process.
3. To observe the formation of discourse surrounding disabilities in the aftermath of the movement, as well as the normalization of disabilities in the wake of other ongoing social movements in Europe, namely the LGBTQ, environmentalist, or feminist movements in 21<sup>st</sup> Century Europe.
4. To examine the methodology and the effect of the lobbying effort from the activist, political, and the European NGOs sectors in the advancement of disability rights.
5. Lastly, to scrutinize the political and legal dimensions of the handling and implementation of disability rights through the highly unique rule-of-law mechanism of the EU, in a sense of an observation of the laws, amendments, and socio-economic initiatives undertaken by the European Union or national government(s) to improve the conditions under the auspices of the rule-of-law governance of the organization, as well as its effects on the life of the PWDs.

## Literature Review

The characteristics and impact of various social movements and mass mobilization of demographic groups in the contemporary period are a comprehensively researched topic. Prior research findings based on the struggle for social status and egalitarianism in Europe such as the LGBTQ group or the feminist movement are well-researched, although research on some sections of the society is not as widely known as the others. The disability rights movement is an important social movement and thus, it should not be overlooked.

The pre-existing studies relied on the framing theory and Karl Deutsch's Social Mobilization theory (1961), the former is used to gauge how each individual perceived reality and the latter are used to approach the engagement of a specific group in the local and national politics. However, the model encountered slight difficulty when it was utilized to study the disability civil rights movement, for many from the demographic are having difficulty mobilizing themselves in the first place and thus the pre-existing studies are sparse. Subsequently, the study on the social movement on disability rights movement in Europe, particularly within the scope of the European Union's Member States are admittedly scarce in contrast to research on the more well-known and publicized groups such as those from the group.

Regardless, there is still some prior research that is sufficient to serve as a foundation for later research whether as a source for the historical perspective on disabilities, which will be briefly addressed in this paper to provide the reader an insight into the evolution of the concept. For example, Jackson (1993) illustrated the historical shift in attitude and public policies in Central Europe, particularly within Germany, Austria, and other German-speaking regions in the aftermath of the First World War and before the Second World War, in which returning disabled veterans challenged the widespread perception that persons with disabilities (hitherto abbreviated to PWDs from this point if applicable) are a "burden" to society for the first time in European history. A brief, cursory exploration into the differing conceptualization of disability in the various phase of European history ranging as far back as the Middle Ages per Scarborough (2015), or other notable events which shaped or reshaped the paradigm on disability in the like of the First World War (Reznick, 2011; see also Bonfiglioli-Stagni, 2015), or eugenics (Social Sciences and Humanities Research Council of Canada, n.d.) will also be included in this research for the aforementioned reason.

Prior research on the superseded and otherwise obsolete policies or European models toward persons with disabilities will also be explored for a similar reason. For instance, a study suggested that integration of the population with disability must be carried out via legislation of anti-discrimination laws that should not be only restricted to employment, but also to include equal accessibility to benefits the able-bodied citizens are already enjoying such as housing, education, or public transport (Lawson, 2005). Nevertheless, the legal analysis prevalent in this field shall not serve as a main component of the paper per se, but rather it shall be illustrated to outline the practical effect of the disability rights movement on politics and culture in the EU's Member States.

Those notions are also a recurring theme in the subsequent study after the publication of the United Nations' Convention on the Rights of Person with Disability

in 2007. The entry into force of the CRPD constituted a paradigm shift in the policy-making aspects toward disability as it has moved on from the medical to a social model of disability, as well as the adoption of the language of liberation (2006). The EU's adoption of the convention within the same year, which also interestingly raised the point of the contradiction between the national and supranational nature of the EU in which the differing conceptualization of rights clashed (Priestley, 2007). In addition, primary sources such as the UN Convention on the Rights of Persons with Disabilities (CRPD) or the European Disability Strategy as well as other initiatives or plans devised by the apparatuses of the EU, such as the European Commission, the European Parliament, or the Council of the EU will also be examined in the paper accordingly. The UN's Convention is to be subjected to a thorough inspection to discern how the global trends perceive disabilities and human rights changed overtime from the medical model to the social model of disabilities, whereas it is intended to support social development and affirm all persons with disability what rights and freedom they are entitled to in an equal manner with other citizens of the EU.

Studies conducted after the adoption saw a shift in the paradigm to the examination of the laws as it is laid out by the EU themselves and how it evolved from mere discussion to codification (Waldschmidt, 2009). Incidentally, re-emergence of disability studies as a discipline in social science and the call for a meaningful inclusion of disabled people in the field also took place in this period, it is also the first recorded instances whereas the link between disability activism and academic circle can be used to influence state policy, marginal or not (Oliver & Barnes, 2010). However, as is the case with several other studies, many researchers fell flat in addressing the affected groups whether they are satisfied by the legal rights given or not. Other legally binding treaties and related documents will be utilized to examine the effect of legal influence, foundation, and effectiveness as a tool to foster civil rights such as the EU Charter of Fundamental Rights (2012). Secondary comparative legal analyses will also be used to provide a cursory view into the background, such as those conducted by Quinn and Flynn (2012) to point out the advantages and disadvantages of the EU laws and their American counterpart, although this research will only be sparingly utilized for the focus of the research, for the paper is not strictly a legal analysis.

The discussion on European disability rights in academia seems to come full circle in recent years, as the focus shifted to include the PWDs themselves into the equation as well. As an illustration, van Campen and van Santvoort (2013) observed the happiness of PWDs in comparison to the non-disabled population of Europe via the measurement of the self-report questionnaire on subjective well-being (SWB), which pointedly demonstrate that persons with disability on average reported themselves as being unwell in a higher rate than the non-disabled. Regardless, severity of disability and socioeconomic status are ambiguous determinants to conclude whether the group is satisfied with the rights they are entitled to or not. Ferri (2015) suggested that accessible technology and infrastructure should be the first step toward integration of persons with disability into the larger society for they would have more convenient access to public spaces, which the EU can contribute by subsidizing the Member States through the legal mechanism. Similarly, Bonfiglioli-Stagni and others (2015) study on the historically predominant medical model of disability as a rehabilitable condition in Italy after the First World War, in which

disabled veterans are entitled to social welfare and physical rehabilitation for the first time in order to quickly reconstitute them back into the workforce system is interesting research as it implicated that this viewpoint has been predominant in governance since the 1920s. Subsequently, Waldschmidt et al. (2015) observed the very nature of disability rights activism in nine European countries which evolved therefore, both inside and outside of the EU, then an evaluation was made to scrutinize how nations of either category interpreted the principle for self-representation differently. It is also recurrently suggested from a political angle used in recent studies that the empowerment of persons with disability in the European Union should be universally guaranteed across all Member States and this sentiment is echoed in later works. Interestingly, more attention is being devoted to the rising tendency toward social justice from the end of the 2010s upward until the present day and it was reflected accordingly in the more recent research. A critique offered by Mladenov (2016) utilized Nancy Fraser's theory of justice as a model to argue in favour of the inclusion of the perspectives from the persons with disabilities themselves alongside the traditional inputs from the academia and activists in the promotion of equality, of which he identified the three major dimensions to be achieved; economic redistribution, cultural recognition, and political representation. Consequently, a study by Rowell (2017) was also created to explore the EU's reaction to the growing awareness on disability rights through the official restructuring of the definition of "disability" to identify public policy shortcomings and to prepare themselves for a future solution.

In the context of this specific field of study, disability is a multifaceted concept, as persons with disabilities were often affected by different variants of disability ranging from physical, intellectual, or mental and whether it is congenital or is a condition gained later in life. Consequently, researchers concluded that the multifaceted nature of representation of PWDs in each country hampered the discussion of disability rights as an academic field and the discussion also had a spillover effect into the cultural and political context, (Vanhala, 2015). Furthermore, in the later study Ferri (2020) also noted the unorthodox relationship and the clash in interpretation and implementation of the various European and international treaties within the EU concerning rights for persons with disabilities using the conventional legal mechanisms. Regardless, pre-existing studies failed to account for the inherently intricate nature of disabilities and its consequence on the discussion of disability rights, preferring to generalize persons with disabilities for the sake of convenience in the progress. Despite the condition that the research on disability rights is an ongoing trend in the current European politics or culture, the movement merited as much attention as any others, for any social issues are worth an insight into their struggle in general as it is uncontroversial that Europe is becoming an aging society and social progress had allowed marginalized groups to make their voice heard. Recent and past studies on mass mobilization and contentious politics can provide us with valuable insights into how social movements could affect the European political scene and cultural norm.

A limitation of the past research that one could observe is a notable lack of heed paid to the agency of the person with disability that campaigned and struggled for the end of discrimination and acceptance into the public life themselves, rather the emphasis was mostly placed on the legislations and the governance process made by the European bureaucracy at the expense of the social

movements it supposedly studied. Those trends implied that academics currently possessed little knowledge regarding how the social movement led by the interest groups and their allies materialized themselves in the last twenty years. Subsequently, the relative lack of research on this topic is a critical concern in this field of study, researchers ought to have a better understanding of the very group they were observing in relation to the policy-making processes to improve the conditions and integrate this very group of the underprivileged into the larger society.

Further research can be conducted to investigate the following aspects in greater detail. Firstly, past works, dialogue, and coordination made by organizations involved ranging from official actors in the European Commission's Directorate-General for Employment, Social Affairs, and Inclusion (DG EMPL), European NGO actors such as the European Disability Forum (EDF), or Inclusion Europe themselves are an interesting actor, and are worthy enough to be a subject of study on its own in the future. Secondly, the characterization of the disability rights movement throughout the various phases of history, such as how each group operated, their history in lobbying, cooperation, and asserting direct action with or against the states and the intergovernmental institutions are often an overlooked field in academia. In contrast, the political and legal after-effects of such actions are well-documented and those can be utilized to evaluate the public satisfaction of the implementation of the public demand themselves. Thirdly and lastly, the influences that the disability rights movement may possess to sway public opinion and the administration of the EU in the legislation of laws in support of persons with disability, as well as to devote additional focus on the disability rights movement and the normalization of disability in European culture. Such research could greatly contribute to identifying the mode of discrimination and the concerns of the disadvantaged groups that the policymakers must consider to improve the life of persons with disabilities not only in Europe, but also in the rest of the world.

## Scopes

The scope of the research can be divided into two spatial categories, which would be the demographic and the location itself, and the period used in the study.

The first of the outlined scope will be regarding the subject of the research, who would be the PWDs, preferably also living in the EU's Member States as well. If that is not possible, the geographical criteria will be expanded to include the rest of the European continent. Nevertheless, defining a PWDs for the research will be a difficult and sensitive task, for disabilities come in many forms, visible in terms of physical disability or invisible in the form of mental or intellectually disabled. Persons with disabilities themselves found their own rights infringed upon or were generally barred from integrating themselves into the public sphere via socioeconomics, cultural, and institutional norms, this intersectionality are also to be considered as well. Furthermore, it should be also noted that the inclusion and integration of persons with disabilities in the larger society is also an ongoing, coinciding process with the social movements for disability rights worldwide.

The sample group will be potentially picked from persons with disabilities, the disability rights advocates, legal entities such as NGOs. However, the primary sample will be drawn from a PWDs, which would also include those with physical, intellectual, sensory, cognitive, or multiple disabilities through a collection of answers gathered from a 19-questions online questionnaire submitted to Internet spaces for the PWDs such as Reddit's r/Disability and r/Disability\_Survey subreddits and other platforms. In a geographical sense, the participants of the questionnaire should be preferably a citizen or at least a resident of one of the twenty-seven Member States of the European Union, although inputs from a citizen or a resident of a non-EU European country are also accepted for comparative study. On the other hand, those who otherwise do not fit the criteria will be excluded from the questionnaire sample group by default, namely those who are not disabled and respondents from a non-European country, whereas the questionnaire would "remove" their data by instantly concluding the form by default. Furthermore, the research will mainly rely on the UNCRPD's definition of "persons with disabilities" to establish the scope and the meanings of the terminology, that is "persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (Convention on the Rights of Persons with Disabilities, 2006).

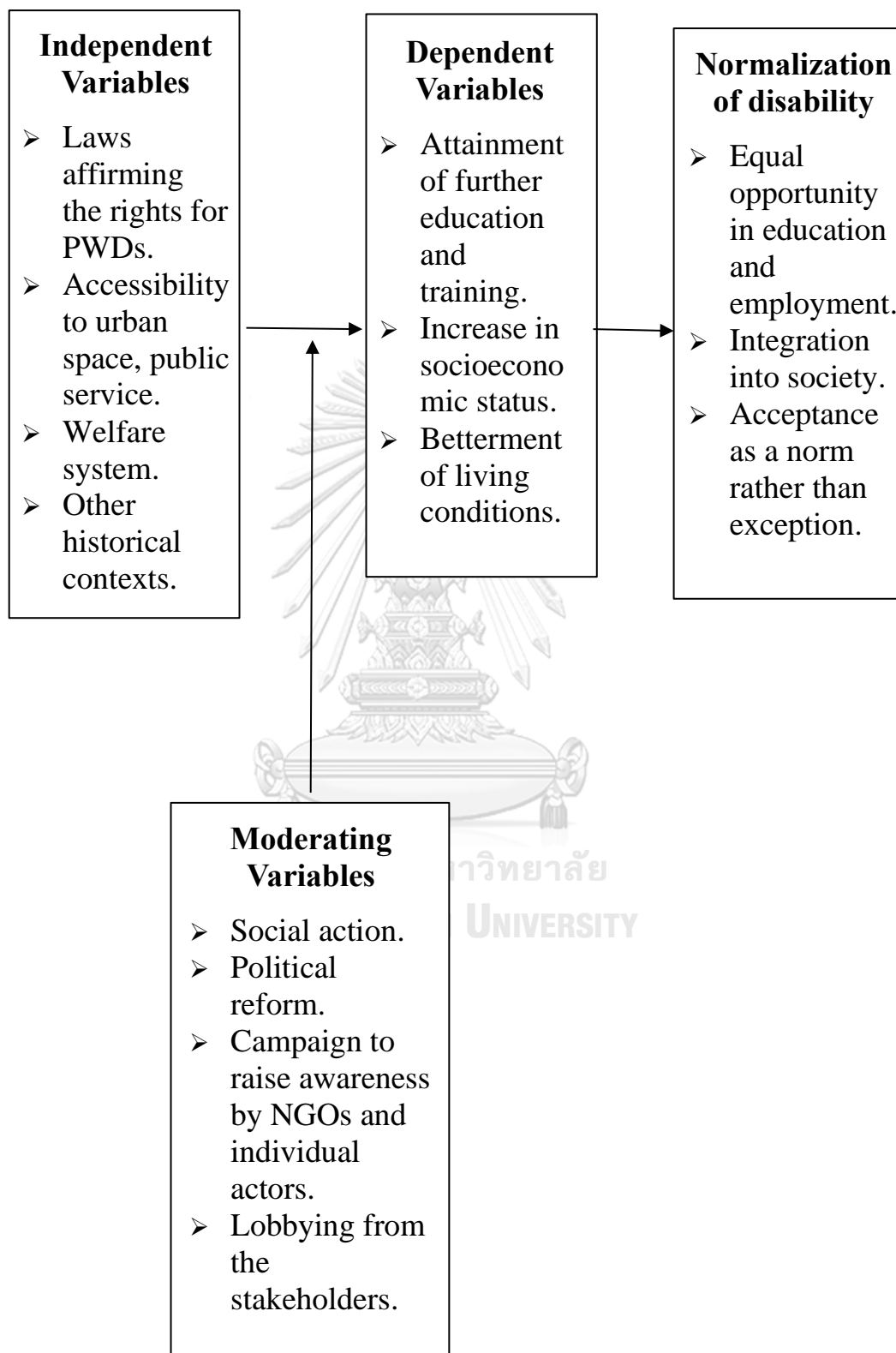
The last category is the location and the period used as an analysis. In a best-case scenario, the location of the research subject will be identified in a selected number of the Member States of the European Union to be scrutinized. Otherwise, data collected from the sample outside of the European Union which is still located within the geographical continent of Europe, commonly known as non-EU European nations will also be included. As for the time period, the study will focus on the trends in recent years, which means since the end of the Cold War onward, that is the time period after 1991 and beyond, although a cursory background of disability in various time period up to the present day will also be briefly explored in the research to provide a clearer image of the historical trends and evolution of the various model of disability.

The criteria for the questionnaire respondents are briefly outlined in the prior paragraph, although there are several other eligibility criteria which need to be further delineated. Overall, the eligibility criteria would include the respondent who fit the following characteristics: being around 18 years and older, be an EU national or resident who are currently residing in the EU or the continent proper, and possessing conditions that could be either legally or medically qualified as a person with disabilities per the United Nations' definition. The questions featured in the questionnaire will include both the mandatory questions and optional questions, the latter of which the respondents can opt out from due to the potentially sensitive or otherwise distressing nature of the question. Consequently, the data without the optional answers will be accounted for during the analytical phase of the research for its nature, regardless there will be some questions at the beginning of the questionnaire that will instantly end the questionnaire should the participants answer that they do not live in the EU's Member States, whose submission(s) will not be included.





## Conceptual Framework



## Methodology

Several methodologies will be utilized for the study and the creation of the research paper, namely the data gathering, and the analysis of the data accumulated. As the research is characteristically qualitative and is mostly interdisciplinary study in the field of social science, the methodology and theory used for this research will be accordingly drawn from the practices in the field as such.

Firstly, data and other relevant information will be collected from diverse sources, which will in turn be further divided into two categories: primary sources and secondary sources. The primary sources used in the research will be mainly compiled from the states and international organizations' official policy or laws such as the European Commission's Directorate-General for Employment, Social Affairs and Inclusion (DG EMPL), charter of rights as outlined by the United Nations' Convention on the Rights of Persons with Disabilities (CRPD), or local laws if applicable. Secondary sources such as legal analysis or a comparative legal analysis will also be utilized to a smaller extent to explore the potential result of the movement and the subsequent attempt to find a common ground with the demographics and the political sectors themselves. Additionally, public consensus on the legal text and the actual implementation will also be considered as additional criteria of the movements' realization of their objectives.

Secondly, data will also be collected from the disability rights movement through the works or campaigns of the NGOs such as the European Disability Forum (EDF) and other individuals advocating for the rights of persons with disabilities through a thorough analysis on the prior works to advance the cause of disability rights in the field or campaigning for awareness among general public. Furthermore, the publicly available information or news concerning the direct action, campaign, or lobbying to the institutions of the EU or national governments will also be included for analysis.

In addition, an online questionnaire<sup>1</sup> will be released to provide supplementary data to accompany the other data gathered through other means for this research. The questionnaire will be posted online on forum or discussion platforms such as Reddit, specifically on the relevant subreddit on the topic at hand in the like of r/Disability, r/Disability\_Survey, r/SampleSize, or r/takemysurvey, as well as direct dissemination of the online link to the survey to friends or family who may know or had acquainted with the relevant group. The questionnaire accepted answers from March 12, 2023, to April 13, 2023. The participants are also allowed to withdraw from the forms without the need to specify their reasons to do so and they shall suffer no repercussions from the withdrawal. The input received during this phase will be pseudonymized to further protect the identity of the participants while still retaining the usable information for the research<sup>2</sup>.

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<sup>1</sup> See the *Appendix: Original Online Questionnaire Form* section of this paper for the original, blank form of the online questionnaire as it was published and disseminated on the Google Form by the researcher.

<sup>2</sup> To ensure compliance with the EU's *General Data Protection Regulation (GDPR)* and to maintain the ethical standard, the answers submitted to the questionnaire will not be made publicly available.

The analytical process would be straightforward. Accumulated data will be analyzed through the lens of the conceptual framework as outlined in the subtopic “Conceptual Framework” earlier in this research proposal, as well through other frameworks of critical, literary, and conceptual theory once it is seen as applicable to the topic. Synthetization of the data acquired from the primary and secondary sources alike will be carried out in order to illustrate the core idea of the findings and identify the limitations of the research in the future. And lastly, any commentary regarding the daily life and their general situation and other input as documented in the questionnaire will also be considered in the analysis, this is in order to gain a clearer image on reality, and to see if the analysis is accurate or reflective of the situation or not.

A major critical framework that will be utilized is the interdisciplinary study regarding social movement theory, especially on New Social Movements (NSM) which the movement could be classified as such. To clarify, New Social Movements are more concerned with social and cultural malaises than those of political and economic ones. The cultural atmosphere of post-industrial Europe in the aftermath of the Second World War had advanced beyond materialism in favour of individualism and personal identity, which resulted in a social or cultural conflict rather than economic or class conflicts. Collective action and mass mobilizations to contend in politics in the contemporary period put an emphasis on expression of humanistic values such as human rights, pacifism, or environmentalism. In this case, it could be argued that the disability rights movement fell within the criteria of the framework to be applicable. Thus, this theory will find extensive usage in this research. One of the theories developed under this model is the Social Mobilization theory by Karl Deutsch (1961), which utilized the historical process of mobilization of groups of people to transform political behaviour and discourse of the society they are inhabiting to force a social change. However, it should be noted that social mobilization goes hand in hand with economic development or urbanization and each society’s unique historical circumstances. Circumstantially, those factors are present in the context of the European Union’s Member States which allowed for the manifestation of such movement through economic and social development, necessitating the application of this theory in this research. Another notable concept that will also likely see application in the works is the intersectionality theory. Intersectionality, originally coined in the context of feminist and critical race studies is an analytical framework which postulated the classification of intersecting relations in the like of gender, race, social class, or socioeconomic status as being interrelated and mutually shaping each other to form a person’s subjectivity or worldview / weltanschauung. This theory is a crucial tool in this specific research to understand how the different, overlapping aspects of a person’s identities would go on to create a different subjectivity and modes of their daily life. In this context, intersectionality is a valuable tool to understand the nuance and complexity of how each PWDs perceived the world around them, and whether subsequently, intersectionality are applicable on the context of an analysis on disability rights, especially on a person’s subjectivity, as not only disabilities came in many forms whether it is physical, mental, or intellectual to be taken into consideration but also the factors of economic status, sexual preferences, gender, or ethnicity would also affected their daily life and their participation of politics in one way or the another. In addition, the legal and

political measures undertaken by the governmental and intergovernmental actors should also be explored in tandem with the social movements to evaluate the trend of social movement as a vector for political, social, and cultural transformation.

Lastly, the processed data will be once again categorized in accordance with the outlined theories and critical frameworks before it is completed. Hypothetically speaking, the information will be sorted across the timeframe and the location, this is to reflect the discursive formation throughout the time and how discourse on disability shifted and evolved up until the present day. Coincidentally, the theme of the research will also be created. The spirit of the research will be centered around the formation and evolution of the discourse surrounding disability, from the initial theme of demand to acknowledge their existence in the public healthcare, inclusion into general society as a socioeconomic equal in education and workforce, and lastly in the strive for inclusion amidst the ongoing calls for social justice in the 21<sup>st</sup> Century.



## Ethical Issues

Ethical issues that could have arisen from the research would be potentially traced back to collection of data for the primary sources through an online questionnaire. Therefore, informed consent, confidentiality, and consideration of the potential for harm are three of the most key factors to be taken into consideration in this research.

Firstly, consent must be acquired from the participants or contributors of the research during the information gathering process through an online questionnaire. All potential participants will be informed of the benefits, the risks, and the information on the personnel who may be related to the research such as the academic supervisor or the director of the program. As the research would be conducted on people with disabilities, assistance will be provided to the best of the researcher ability per request. Participants will be asked for their agreement and consent to participate at the beginning of the questionnaire, as well as other relevant information on the research, they will also be informed that their data will be kept confidential, and they are free to withdraw from the questionnaire at any given point should they wish to do so.

Secondly, the right to privacy of the participants shall be protected. This notion is extremely important for a study conducted on vulnerable groups, as some might be subjected to discrimination, persecution, or stigmatization. Personal identifiable information (PII) will not be collected, and other identifying information shall be pseudonymized to extract only the necessary study data. To briefly elaborate, pseudonymization is a one of the procedures of the data management to remove or replace the PII with a pseudonym, this is to protect the identity of the participants and in order to comply with the European Union's *General Data Protection Regulation* (GDPR) law of which EU citizens are legally subjected to. In addition, the participants will be informed of the risks involved. The risks are mostly identified within the content of the questionnaire questions, most of which would contain potentially distressing material such as discrimination, physical or mental abuse, or ableism. However, measures will be taken to minimize harm caused during the processes.

Lastly, research in the discipline of social science or anthropology, especially those concerning the minority group or a marginalized demographic in general called for minimization of harms which may be unintentionally inflicted upon the participants. A person with disabilities should be shielded from harm ranging from the psychological, social, physical, and legal aspects during the processes. Some of the potential discussion topics, especially those regarding discrimination or hardship may trigger negative reactions from the participants and thus, it is vital to inform the participants ahead and reassure the confidentiality of their participation to prevent distress and further harms.

## Findings

### Historical Development of Disability Rights in Europe

#### 1.1 Terra Incognita: The Concept of Disability Prior to the 20<sup>th</sup> Century

Prior to modernity, disability is poorly documented and sparse information regarding people with disability was recorded or survived to the modern day in the first place. However, it could be inferred that people with disabilities were sparsely recorded in the Middle Ages in several religious and medical texts.

In the medieval period, several conditions were already well known to the public and were also highly visible in European society. Many early terminologies were coined in this era, and some were still occasionally used in the present day, ranging from “the blind, the dumb, the lame, the leper, the dwarf, or the fool” which were an attempt to conceptualize those afflicted with various conditions as being disabled. According to Scarborough (2015), general opinions of the population are mostly indifferent to apathetic towards those with impairments, for it is rooted in Christian attitudes toward deformities whereas it is typically associated with divine punishment for one’s past transgressions. Subsequently, people with disability in the European Middle Age are often left to fend for themselves by working, begging, or relying on the almshouse and hospitals to survive. Although dwarfism and intellectual disabilities were instead seen as a curiosity by the aristocracy, many were employed in royal courts as fools. Regardless, it should be noted that the notion in which disability is seen as an inherently undesirable quality, or a lack thereof did not materialize until the later period through the rise of the eugenics movement in 18<sup>th</sup> century Europe.

#### 1.2 The First World War and the Paradigm Shift

To say that the First World War changed the face of Europe forever is an understatement. The “War to end Wars” instead ended empires, obliterated Europe’s collective political standings as a global power, and the continent was engulfed in revolutions and upheavals that would lead to another world war. However, it could be argued that the true impact could be found on a smaller scale.

The First World War pioneered deadly trends associated with land war in Europe, the most infamous of which were long range artillery, trench warfare, and the pioneering of chemical warfare. Firstly, trench warfare is a type of military operation centered around the military trenches, which were originally developed to protect soldiers from long-range artillery but soon turned the war into a contest of attrition as an army advanced to seize a trench, and casualties were enormous as many were killed, wounded, or succumbed to injuries or diseases in the structure. Furthermore, chemical weapons were pioneered to break the ensuing stalemate in the trenches via the weaponization of chemical compounds into poisonous gas such as chlorine, mustard, or phosgene and were deployed accordingly throughout the entire war. The

result of exposure to poison gasses is nothing short of horrific<sup>3</sup>. Naturally, soldiers from all sides of the war returned from the war with at least one form of injury or disability in one way or the other. Some were physically impaired from being blinded, losing their limbs, or otherwise were shell shocked from their experiences. To put it simply, the First World War introduced the people of Europe to the grisly consequences of war with their own eyes. It is the first instance in European history where disability became a tangible concept in the eyes of the people and the state, the latter of which had to suddenly handle the arrival of thousands of people with disability on an unprecedented scale. As a result, disability became an issue of public debate for the first time.

European nations in this period reacted by adopting a medical model of disability, in which people with disabilities are intrinsically linked to and defined by their physical conditions which worsened their quality of life. Therefore, it is of utmost priority at that time to rehabilitate them into the workforce. For example, in Italy, the military and the government provided healthcare service and issued prosthetics free of charge to the invalids and disabled veterans during and after the war. Bonfiglioli-Stagni (2015) illustrated the work of orthopedic surgeon Vittorio Putti (1898-1940) in lobbying the government to establish the Rizzoli Orthopedic Institute to not only produce prosthetics but also to “restore their dignity” by providing rehabilitation and retraining disabled veterans to be able to work menial jobs in spite of their prosthetics and disability, wide array of professional training workshops were also offered at the institute such as shoemaking, cuniculture, carpentry, tailoring, or basket-weaving (334-335) out of belief that disabled veterans can be rehabilitated.

Concomitantly, the Weimar Republic also passed the Law of the Severely Disabled or *Schwerbeschädigten* to support the employment of disabled veterans via affirmative action. The law, which was enacted by Germany in 1920 mandated all workplaces and corporations with twenty-five or more employees to hire at least one disabled person, and in case of larger workplaces or factories there must be at least 2 percent of the jobs available specifically reserved for persons with disability. Furthermore, pensions were also expanded for veterans with disability to formulate a safety net for them to retrain themselves for employment. Jackson argued that this is the first time in European history where a state exerted its power upon the private sectors to create welfare for persons with disability (*ibid*), marking the first-time disabilities were tackled as a national issue.

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<sup>3</sup> See Pruszewicz (2015) for more detailed explanation on the devastating effect of poison gas in maiming and killing troops during the First World War

### **1.3 The Rise of Eugenics: The 1920's - 1945**

However, as it was for many movements throughout human history, the progressive trends were short-lived, and it faced many setbacks in the aftermath of the First World War. One of such movements with the most vocal opposition to the trend is the contemporaneous eugenics movement, originating in North America and spreading to Europe later.

“Eugenics” are commonly defined as a set of practices which advocated for selective reproduction and classification of traits and characteristics as “superior” and “inferior”, which was originally developed by Sir Francis Galton who derived the ideas from Charles Darwin’s concept of “survival of the fittest” to improve mankind via direct application of the hypothesis on humanity. Consequently, the movement called for and successfully lobbied for forced sterilization and other related measures of those they deemed possessing “undesirable traits” such as the mentally or intellectually disabled in several European nations. It is argued by many that eugenics belief and practices spread from the United States where it enjoyed massive popularity into Europe. The Eugenic Archives (n.d.) pointed out that eugenics policies were practiced in several European countries from the 1900’s to 1940’s, this would range from forced institutionalizations to forced sterilizations of persons with disabilities regardless of the severity.

However, it is the Third Reich who took eugenics to its logical conclusion, murder. Hitler himself could be classified as a eugenicist, having read many books regarding the concept of “racial hygiene” and outright named the United States’ eugenics laws as an inspiration to his own laws. In 1933, compulsory sterilization was mandated on people with hereditary defects through the *Law for the Prevention of Genetically Diseased Offspring* or *Gesetz zur Verhütung erbkranken Nachwuchses*. Subsequently, the policy escalated into outright murders by the more infamous Aktion T4 mass euthanasia program. The program is a campaign of mass involuntary euthanasia on the physically and mentally disabled children and adults, German physicians were recommended to administer the patients in a hospital, mental asylum, and nursing home a “mercy death” (Gnadentod) and the killings took place from 1939 to the end of the war<sup>4</sup>. The target for mass murders under the Nazi brand of eugenics are commonly identified as “life unworthy of life” (Lebenunwertes Leben), specifically people with congenital cognitive impairment, physical disabilities, and “feeble-mindedness” (Schwachsinn) under the assumption that they are all “useless eaters” (Unnütze Esser) and will not only fail to contribute to the Reich but also become its burden.

Naturally, eugenics as a social movement has been largely discredited since the end of the Second World War as it was cited by Nazi Germany as an inspiration behind their genocidal practices; to rid the world of the so-called “undesirable subhuman” that is the Jews, Slavs, homosexuals, and people with disabilities and the discontinuation of the practices largely correlated with this historical development.

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<sup>4</sup> The number of victims is commonly estimated to be from 275,000 to 300,000 people in Germany, Austria, and other Nazi-occupied territory in Central Europe.



#### **1.4 The Nascent Struggle for Equality: 1945 - 1990's**

In the aftermath of the Second World War up until the end of the Cold War, the issues and the advocacy of disability rights were admittedly under-documented in this specific time. This historical development or a lack thereof was a result of several factors.

Firstly, the prevalent political and historical development in Europe has mostly overshadowed the issues. The reconstruction of the continent and the inevitable arrival of the Cold War had taken hold of public sentiment and the issues of disability were sidelined into that of a private one.

Secondly, mobilization of people with disabilities into a social movement in this era are best defined as being based on loose affiliation, cooperation, or an alliance between specific single-issue disability organizations along national lines. Waldschmidt et al. (2015) delineated on the network structures in each contemporaneous European nations which would act as a liaisons or political representatives between the PWDs and national governments from the 1950's to the 2000's, in which those umbrella organizations are commonly consisted of several disability movement organizations (DMOs), disability advocacy organizations (DAOs), or service provider organizations (SPOs) up to as much as in the hundred (p.129). The same study also pointed out that the presence of the differing interest groups, stakeholders, and the multidimensional characteristics of disability under the aegis of a singular national cooperation structure had made self-representation difficult and the movement inherently fractious in this era.

Lastly, the paradigm for disability issues had not shifted from that of the medical model to the social model of disabilities, which resulted in a lack of interest from the state to provide for the demographic. A study by Vanhala (2015) pointed out that perceptions toward disability in this time were commonly seen as that of health or charity issues rather than a social one. It was also noted by Vanhala that the predominant discourse in this period is that a PWDs "should be segregated and excluded from mainstream society and provided with separate schools, workplaces, and housed in separated institutions" out of an assumption based on the medical model of disability which posited that they would not live in an otherwise "normal" society. It was not until the end of the Cold War which saw the changes in international law and order facilitating the paradigm shift into a social and human rights issue.

### **1.5 The Struggle Continued: 1990's - the present day.**

The shift of paradigm away from the medical model of disability into the social or human rights-based model of disability is a gradual process. The conclusion of the worldwide civil rights movements, social mobilization, and political campaign for equality, as well as the end of the global division of the Cold War made the re-examination of the issues and reframing of disability rights as a human rights issue possible. One of the major characteristics of the new framework is the recognition of the relationship between an individual's impairment and sociopolitical environment, and that exclusion, segregation, and institutionalization are based on a misconception and false assumption regarding impairments. It is also put forth that inaccessibility problems are not as much as it is a healthcare concern but rather a series of political decisions to refuse accommodation or provide accessibility to persons with disability, which in turn originated from the predominant medical discourse toward the community (Vanhala, 2015, p.840). Furthermore, scholars, NGOs, and persons with disabilities also assisted the shift of discussion on disability issues as a healthcare-related topic into a matter of non-discrimination, equality, and social justice in the last twenty years.

Advocacy for disability rights in this period is mostly rooted in the argument for integration, equal opportunity, and to increase accessibility of the demographic group into the general society as an equal to what their able-bodied peers are already enjoying such as housing and transportation to also include social liberation. Lawson (2005) thoroughly documented the theoretical inclination of activism in this period, in which she defined the tendency as a "rights-based approach" to disability. The key concept behind this methodology is "the idea that the inability of disabled people to participate fully in the life of their communities is not to be attributed solely to the limitation of function resulting from their impairment [but rather] societal factors operate to exclude them" and thus had identified socioeconomic and attitudinal barriers as an obstacle to integration (pp.272-273). Henceforth, the new consensus has been created among the group ever since the 1990's and activism in Europe are centered around advocates and NGOs such as the European Disability Forum (EDF) and other organizations<sup>5</sup>. However, the EU were mostly lukewarm and unreceptive to the demands made as they also lack a cultural or societal incentive to enact such measure until the designing of the United Nations' Convention on Rights for Person with Disabilities (UNCRPD) in 2006, and the lack of necessary legal mechanism caused various guarantees or provisions unenforceable until the creation of the Treaty of Lisbon in 2009 delegating the authority for them to do so.

The increasing awareness for other contemporary social movements for civil rights, such as the LGBTQ movement and women's rights movement, as well as the popularization of the Internet or telecommunications had increased disability rights activism in Europe. Using Karl Deutsch's theory which posited that "social mobilization is a name given to an overall process of change, which happens to substantial parts of the population in countries which are moving from traditional to modern ways of life" (Deutsch, 1961) one can see that disability rights activism of the

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<sup>5</sup> Due to the inevitably varied nature of disability and difficulty to organize a social action among people with disability.

late 1990's up until the present day fit the definition. To elaborate, the movement is a concentrated effort of people, ranging from the activists, the NGOs, sympathizers, and the PWDs in a mostly urban background, who, after exposure to modernization and economic prosperity, attempt to caused change in society, politics, and culture whether is it a drastic or gradual change to accommodate their needs (ibid, p.498). Mladenov's study (2016) also observed a substantial application of social justice theory and practices found in several disability rights movements or in disability rights studies scholarly circles in the 21<sup>st</sup> Century, especially since the 2020's, which is a result of interaction with and diffusion of ideas between disability and gender vis-à-vis the framework of intersectionality. To elaborate, intersectionality is an analytical framework in the field of social science. Originally developed to approach feminism and social exclusion, the framework utilized the multidimensional identities of a person to examine discrimination and empowerment (Atewologun, 2018). The framework saw a widespread adaptation to fit the social model of disability among academics and experts in the field as a supplementation to social justice. The notion of social justice calls for parity in resources and opportunities in society, within the context of disability social justice are commonly invoked as an argument for the transformation of both public policies and societal attitudes to facilitate and normalized acceptance of persons with disability in the larger society, which is a dominant school of thoughts in many organizations and academic circles today.

The 2020's saw several disruptions taking place, especially the COVID, which the Commission had written in the synthesis report (2021) that the group has been "hit disproportionately hard by the COVID-19 virus itself, by measures to contain its spread and to protect health systems and by non-inclusive methods by which countries have sought to permit life to continue" and lamented that persons with disabilities make up an unclear yet disproportionate number of casualty. In the same report (ibid, pp. 6-7), it is documented that the European Disability Forum had criticized the EU for paying no attention to disability rights, evidently found in the arguably failed measures such as institutionalization, which contribute to high mortality rate<sup>6</sup> among PWDs from 38 percent to as high as 51 percent of the total recorded death from the Coronavirus disease as of September 2021.

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<sup>6</sup> See Crowther (2021, September), specifically in the chapter "3.2 Data on mortality among people with disabilities connected to COVID-19" for additional data on COVID-19 mortality among people with disabilities in 2021.

## **The Rule-of-Law governance as a facilitator of disability rights**

### **Legalistic and Rule-of-Law based approach to disability rights.**

The EU is established under the principle of the rule of law, whereas the enactment of policies and initiatives are conducted via the legislation and enforcement of laws to guarantee the rights or the measures to have a legally binding effect on every Member States to follow. To briefly summarize, how rights would work in the EU is based on its own legal basis, and this would in turn require the European institutions such as the Commission, the Parliament, or the Council to legislate the initiatives into laws. The principle is also enshrined in the Treaty on the European Union per the Article 2 TEU that “The Union is founded on the values of respect for human dignity, freedom, democracy, equality, the rule of law and respect for human rights, including the rights of persons belonging to minorities”, which would also ensure that each of the member nations will recognize these values and follow the laws accordingly.

Legislation of disability rights on the supranational level is a recent topic of discussion, as many past legislations did not explicitly mention “people with disability” as a demographic group until the post-Maastricht EU was established in 1992. Subsequently, the reforms of the Treaty of Amsterdam in 1997 also overhauled the operational procedure of the Council of the European Union to enable the supranational mode of governance at last. Furthermore, the 2007 Treaty of Lisbon established the EU as a legal personality to allow the EU to exercise personal jurisdiction and to further provide the Member States a mechanism to enact policies for disabled people under the EU’s oversight as a shared competence.

Owing to the recent nature of the EU supranational disability laws and policies, pre-existing studies are scarce and the gaps in the literature in this discipline is wide. However, some studies devoted to comparative legal analysis have been made beforehand. Quinn and Flynn’s research (2012) observed how the “EU law can trace its roots to American and even broader international influences.” To elaborate, the study had drawn upon the 1990 *American with Disabilities Act (ADA)* as a source of influences upon the later EU laws, whereas disability was perceived as a civil rights issue to facilitate the prohibition of discrimination in goods and services. Under the ADA, the act had a redistributive effect which saw the deinstitutionalization of the disabled as the Supreme Court of the United States ruled that institutionalization are restrictive and discriminatory on the federal level, and the Bush Administration also approved \$600 million aid package to all states in their deinstitutionalization process (Quinn & Flynn, 2012, p.33). Nevertheless, this model is initially inapplicable to the EU due to the lack of cohesion in social services during the pre-Maastricht and pre-Amsterdam EU, and it is still arguably observable today as healthcare and social services are regarded as broadly “unexportable” as a concept across Member States. The aforementioned study also put forth on how the Directorate-General for Employment, Social Affairs and Inclusion (DG EMPL) of the European Commission came to be dominated by UK-based academics and activists who saw the success of the ADA in the United States and encourage the discussions between the European

civil society and their American counterparts, this is when the discussions of disability rights in Europe shifted from healthcare and social services into equality and the principle of non-discrimination (ibid, p.37). Subsequently, by the end of the 1990's Europe had the power to supersede the prevalent medical model of disability in favour of the social model and enact anti-discriminatory measures through the supplementation of initiatives with legal basis.



## **Selected Laws, Rights, and Regulations for the PWDs in the European Union**

### **2.1 The UN's Convention on the Rights of Persons with Disabilities (CRPD)**

The Convention on the Rights of Persons with Disabilities (CRPD) is an international human rights convention established by the United Nations to legally establish the fundamental rights of persons with disabilities.

According to the United Nations, the convention “is intended as a human rights instrument with an explicit, social development dimension” and that it “adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms” (“Convention On The Rights Of Persons With Disabilities (CRPD), 2006) To summarize the convention’s contents, the conventions underlined the working principles<sup>7</sup> under the social model of disability, the rights it entailed, and recommendations or guidelines for every party's members to the treaty to be implemented within their own countries.

Originally adopted on 13 December 2006, this international, legally binding instrument had 164 signatories and 186 parties to the treaty, it came into force on 3 May 2008 and the EU ratified the treaty on 23 December 2010 and the convention subsequently entered into force on 11 January 2011, notably being the only multilateral organization to collectively ratify the treaty entirely. On the policy’s practices, the implementation of the CRPD in the EU are operated in a monist logic, in which the EU has a framework consisting of the Parliament, the Ombudsman, the EU Agency for Fundamental Rights (FRA), and the European Disability Forum (EDF) to propose, coordinate, and evaluate the subsequent implementation of the CRPD on a national basis before reporting back to the UN on a yearly basis. To conclude, the EU itself only assumed a strictly monitoring role in the implementation and had little legal mechanism to invoke the convention on its own but would rather work jointly with each Member States to achieve a desirable outcome together.

### **2.2 The Charter of Fundamental Rights of the European Union**

*The Charter of Fundamental Rights of the European Union (CFR)* is a legally binding charter drafted by the European Convention in the year 2000, although it has no legal effect until the entry into force of the Treaty of Lisbon in 2009.

On paper at least, the CFR guaranteed the generalized political, social, and economic rights for every EU citizen via legislation of those rights into EU laws. The Charter consisted of fifty-four articles, which were in turn divided into seven titles. The titles delineated by the CFR included the following: Dignity, Freedoms, Equality, Solidarity, Citizen’s Rights, Justice, and General Provisions. However, the charter’s

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<sup>7</sup> Defined in Article 3 of the CRPD as the following: Respect for inherent dignity, Non-discrimination, Full and effective participation and inclusion in society, Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity, Equality of Opportunity, Accessibility, Equality between Men and Women, and Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

protection of disability rights is unclear, as it is only briefly mentioned in Article 21 that “any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited” (“Charter of Fundamental Rights of the European Union”, 2012, p. 400). Similar proclamation could also be found in Article 26 which claimed that “The Union recognizes and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.” Despite the supposed legal effect of the protocol, while the United Kingdom was still a member of the EU it chose to opt out from the charter but reversed the decision on the Charter<sup>8</sup> and later most of the other European disability rights initiatives after Brexit as well<sup>9</sup>, Poland also similarly followed suit, arguing that the Charter is merely interpretative, and the legal effect are inconsequential (Pernice, 2008). Those historical developments made the Charter a weak argument for disability rights in the EU in actual practices.

### **2.3 The 17<sup>th</sup> Principle of the European Pillar of Social Rights (EPSR)**

*The European Pillar of Social Rights (ESPR)* is a white paper conceived by the European Commission and backed by the European Parliament. The document outlined twenty principles in total whereas it is hailed by the Commission as being “the beacon guiding us towards a strong social Europe that is fair, inclusive and full of opportunity” (The European Pillar of Social Rights in 20 principles). It identified three pillars of values as the following: Equal opportunities and access to the market, Fair working conditions, and social protection and inclusion. Regarding disability, the seventeenth principles of the third pillar called for “Inclusion of people with disabilities” and declaring that “People with disabilities have the right to income support that ensures living in dignity, services that enable them to participate in the labour market and in society, and a work environment adapted to their needs”.

However, it should be noted that the ESPR are subjected to skepticism and criticism from all sides. The ESPR itself remained yet to be implemented and was seen as being vague, baseless, and vapid in terms of policy. Furthermore, Member States are also not subjected to any legal obligation to enforce the ESPR and the initiative is remarkably controversial among lawmakers as several governments are also wary of what they perceive as the European overreach into each of their domestic policies.

### **2.4 National Disability Benefits and Allowances System**

In absence of the common disability benefits scheme in the supranational level, many Member States opted to aid a disabled person or injury for an extended

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<sup>8</sup> The EU Charter of Fundamental Rights are inapplicable in the UK after Brexit became effective on 31<sup>st</sup> January 2020

<sup>9</sup> The government of the United Kingdom had chosen to uphold only the European Convention on Human Rights (ECHR), but not necessarily the ruling made by either the European Court of Human Rights or the European Court of Justice (ECJ)

duration of time through pension or lump sum payment. For this research, the policy designed by the governments of Austria, Malta, and Ireland will be briefly examined as a case studies.

Disability benefits in Europe typically have a prerequisite or criteria for qualification in the scheme, the conditions and strictness often varied in each Member States. For example, the government of Austria defined disability on quantitative degree and declared “a person is considered disabled if their degree of disability is at least 25 per cent” (Government of Austria, 2023). On the other hand, the government of Malta simply stated that the applicant must be 16 to 60-year-olds and currently suffering from diseases or impairments to be eligible (Public Service of Malta, 2023), while the Republic of Ireland (Government of Ireland, 2023) had no qualitative requirement existed to as a criterion at all, which were substituted in favor of income test to determine the adjustable payment rate.

Allowances and stipends for PWDs in the EU are commonly regulated by the state at variable rate to accommodate the varied characteristics of disability and severity. For instance, in Malta the weekly rate for common physical disability has no minimum rate but only the upper ceiling at €90.59 or €116.12 for those with visual impairment, as well as the fixed €174.80 stipend for severe disability (Public Service of Malta, 2023). benefits are not necessarily a weekly or monthly payment in many cases, but also as a tax break or a waiver of their medical or public transportation expense. Meanwhile, in Ireland the weekly rate started at €220.00 and one can apply for extra payment to their dependents (Government of Ireland, 2023). Nevertheless, in Austria’s (2023) case the pension would be individually calculated in a case-by-case basis and no uniform rate exist. The system is often specifically tailored by governments to cover the basic needs and expenses in the recipients’ daily life were not meant to be a substitute to income from employments, which were condition for disqualification or reduction of the received benefits to incentivize PWDs into gaining employment. Regardless, recurring complaints are widespread among PWDs and their able-bodied family and close one alike that the stipends are neither adequate to cover their independent living expense nor it is easy to become employed as a person with disability in the first place.



## Selected case of future policies and Initiatives by the EU

### **3.1 Strategy for the rights of persons with disabilities 2021-2030**

*The Strategy for the Rights of Persons with Disabilities 2021-2030* is a set of initiatives and policies adopted by the European Commission to further improve the lives of persons with disabilities within the EU. Effective from March 2021, the strategy will be a set of ten-year long plan, guideline, and recommendation laid out by the Commission to the Member States and each EU institution to follow or adopt.

To summarize, the strategy expanded on the pre-existing European Disability Strategy 2010-2020 which originally mostly focused on the issues of accessibility and universal design. Regardless, the Commission admitted that the previous strategy failed to tackle barriers, rampant unemployment, and social exclusion. Thus, the Commission declared that the new strategy would prioritize the following dimensions, accessibility to move or reside freely and participate in democratic process, decent quality of life, equality in daily life, and they also hoped to promote this rights or rule-of-law based approach to disability rights model worldwide as well (“Union of equality: Strategy for the rights of persons with disabilities 2021-2030”, 2023). To elaborate on the methodology, the Commission proposed several “flagship initiatives” such as AccessibleEU<sup>10</sup>, European Disability Card<sup>11</sup> and further coordination effort between EU institutions and Member States on the issues. Notably, the Commission only called for contribution from the Member States to contribute to these policies to implement the CRPD on their own, rather than treating the topic as a supranational concern.



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<sup>10</sup> The program itself is yet to be fully launched as of May 2023.

<sup>11</sup> Currently valid in Belgium, Cyprus, Estonia, Finland, Italy, Malta, Romania, and Slovenia. The card is also scheduled for adoption in other Member States soon.

### **3.2 European Accessibility Act**

The European Disability Act, officially known as *Directive (EU) 2019/882 of the European Parliament and of the Council of 17 April 2019 on the accessibility requirements for products and services*, is an EU legislation pertaining to the functioning of the internal market to improve accessibility to accessible products and services via the further removal of barrier to trade.

Originally proposed in 2011, the legislation was subjected to many changes and was the centre of contentions between European institutions and other Member States According to the Commission, the act mostly covered “products and services [that have been] identified as being most important for persons with disabilities”<sup>12</sup> and the obligations deriving from the CRPD to make such goods or services accessible. Presently, the act is still in the preparatory phase, which saw the Commission consulting and negotiating with stakeholders ranging from individuals with disabilities, general population, NGOs, SMEs, and experts. Although in a de jure sense, the laws were considered effective since the Directive (EU) 2019/882 was already in force since 17 April 2019, the legal requirements, regulations, and administrative provisions are unenforceable and the EU demand that by 28 June 2022 the European Accessibility Act must be transposed on national laws in 27 Member States. However, according to the European Disability Forum, only Denmark, Estonia, and Italy had done so while other 24 Member States were still behind the deadline as of the year 2022 (Denninghaus, 2022, July 6), with no further updates provided to the Commission as of 2023. As a result, the EU hoped that the laws and requirements for the act must be enforceable at least within the year 2025.

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<sup>12</sup> The Commission claimed that the coverage included products and services such as computers, ATMs or ticketing, smartphones, digital television services, telephony services, audiovisual (AV) services, public transportation system, banking and finance, e-books, and e-commerce.

## **The Other Side of the Coin: Voice of the Person with disability concerning the policies and their own daily life as a PWD in the European Union**

As a part of the ongoing research on how policies, public healthcare system, and legal mechanism of the affect the daily life of persons with disabilities in the EU and to the lesser extent, those living in a non-EU European countries, I decided to conduct an online survey titled “**The Situation of Disability Rights in Europe: a Survey**”<sup>13</sup> to collect data and opinions of European PWDs, specifically on their general satisfaction of daily life in the EU Member States or a non-EU European nation, satisfaction on the access or the quality of public healthcare or welfare service, their personal evaluation on their political and legislative representation in the national and European level, and the efficiency of national or European policies and laws to improve their rights and general quality of life. The data will assist us to gain further insight and understanding on the reality in which the demographic is currently living and how policies help shape the status quo accordingly. To preface, my question which I formulated while designing this survey is that “*if European PWDs’ rights were guaranteed by legislation and political measures as it currently is, they would have gradually attained a better quality of life and equal opportunity in their daily life up until today*”. Furthermore, I was also inspired by prior research, such as those conducted by van Campen and van Santvoort (2013) which measured happiness of the same demographic group in comparison to the able-bodied population of Europe via the measurement on subjective well-being (SWB) values.

The online questionnaire targeted persons with disabilities<sup>14</sup> who are EU nationals in one of the 27 Member States or otherwise a resident of the Union, although inputs from non-EU European nationals with disabilities were also accepted. It was conducted in the year 2023 from March 12 to April 13 through the publication of the survey on social media or internet forums and sharing / forwarding on an individual basis. Overall, thirteen people answered the online survey, although only twelve responses are valid while one form is invalid.

To provide further demographic information, the Republic of Ireland made up the largest EU place of origin at two respondents, while other respondents declared France, Austria, Germany, and Portugal at one respondent. The non-EU nationals were represented through the United Kingdom and Switzerland as one respondent, as well as two others who identified as non-EU European nationals from unspecified countries. The survey counted three respondents who refused to provide information regarding their specific place of origin in Europe and one response was invalid. In

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<sup>13</sup> The reader can view the original, blank questionnaire form at the *Appendix: Original Online Questionnaire Form* section of the research, although the answers themselves will not be made publicly available for the sake of the respondents’ anonymity.

<sup>14</sup> For more information on the definition and the scope of the term “persons with disabilities / (PWD)” in the context of the research, please see the “**Scopes**” section of the paper.

terms of genders, seven respondents identified themselves as a man, three as a woman, and three as a non-binary individual. As for disabilities, those identifying as having multiple disabilities and physical disabilities shared the same amount and percentage of respondents, at five people or 38.5 percent of all responses, followed by sensory at two responses or 15.4 percent of the total number, and then mental disability at a single response or 7.7 percent.

Subsequently, all respondents will be hitherto referred to with the anonymized / pseudonymized identity of “person A” to “person M” with their respective country of origin as another identifier (if available) to protect their identity after their participation in the research. As the survey is broken up into multiple sections, the results of the survey will be reported according to each respective section.

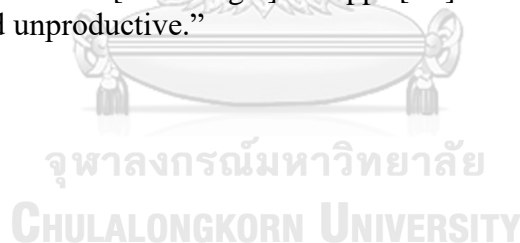


## Daily life as a Person with Disabilities in Europe

The first section of the survey is mostly concerned with how public policy in the political, juridical, and cultural dimensions affects the daily life of a PWDs and vice versa.

This section of the survey mostly consisted of qualitative linear scale to measure the respondents' satisfaction toward the policy to improve the rights and conditions of PWDs in local and European levels, ranging from the matter of general accessibility, welfare system, quality of life or living condition, and political representations, there are also optional questions to provide insight on the improvement of those attributes. Furthermore, questions regarding discrimination<sup>15</sup> were also made toward the end of the section to pave the way to the next section of the questionnaires.

To summarize the findings, many respondents have a mostly negative experience living with a disability in European society. For example, Person I from Austria stated that they had encountered an instance of discrimination due to their disability, adding that “[the discrimination is] almost daily to multiple times a day, either from family, in the workplace, or from professors. Mostly neurotypical-normatism [*sic*], accusing me of faking sensory issues, noticeable negative reaction such as scolding or yelling for the way I talk and react to things or when I stim [*sic*], getting mad when I voice that I am unable to do a thing or talk about my needs that relate to my autism”. Person K from the Republic of Ireland put forth that “Cities, towns etc. are just inaccessible in itself and they don't do anything to make it accessible at all!”. Similarly, Person L from Portugal voiced concern that “casual ableism are [*sic*] common [in Portugal] and ppl [*sic*] are really prejudiced, they just see us as idiots and unproductive.”




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<sup>15</sup> The questions stated “(TW: Discrimination, ableism) Have you encountered an instance of discrimination due to your disability? This can range from an individual to institutional basis” followed by optional question “Please describe the frequency of the occurrence and the nature of the discrimination” both of which were preceded with a content warning to the respondents who may find the nature of the question distressing.

## **Opinion on the civil rights movement and how can the EU do more for the PWDs?**

The second section, which is titled “Disability rights as a social movement” in the online questionnaire’s subtopic, mostly consist of inquiry toward the respondents’ opinion on the disability rights movement, and on the general public awareness on the movement or participation in the campaign of the movements.

Questions found on this section can be roughly divided into three categories: that of a linear scale, yes-no questions, and a short query on the effectiveness of the disability rights movement to campaign for the improvement of disability rights.

To summarize the findings in this specific section, respondents were mixed, but slightly leaned positive on the prospect of the improvement in general society’s attitude toward persons with disabilities. Furthermore, many of the respondents stated that they had taken part in activism in one way or the other such as attending demonstrations or taking part in social media campaigns, and many also considered themselves updated on disability-related topics in the news and other media. However, opinions on the disability rights movement are a mix of optimism and slight skepticism toward its effectiveness. For examples, person C from Finland thought that “[I think] they have done a good job informing the politicians about these issues”, Person J from Germany also stated that “Disabled [*sic*] stood up now, speaking on their own behalf, changing their status thus from objects of interest to self-confident subjects. That, in my opinion, is a great improvement.” However, Person H from France replied he “have only noticed changes for the worse in the past 30 years.”

## **Is there a light at the end of the tunnel?**

For the last section of the questionnaire, I asked several questions concerning the disability rights movement in the EU and non-EU European countries to the respondents, as well as other questions about their future in the society such as the end of discrimination, ableism, or integration.

The main point of this section is to assess the respondents' speculation or opinion on their daily life and representation in the larger European society. Unlike the previous sections, this section is mostly open-ended questions to allow for the free formulation of opinions. The main questions inquired **“On an individual basis, what is to be done to improve the political representation for the person with disabilities themselves?”** and **“Do you think that society can overcome prejudice or ableism altogether?”** which will be interchangeably referred to as the “first” and “second” question in this report.

According to the results, most, if not all shared the sentiment from a mixed feelings of reserved or cautious optimism to declaration of outright skepticism toward their future as a PWDs in Europe. To quote a few opinions from the respondents in a chronological order, person D from Finland answered that representation issues have to consider the unique situation which each PWDs are facing, and that she is “very skeptical” of the prospect of the total end of prejudice and ableism altogether. Person H from France believed the most political or cultural representation for persons with disabilities are capable to do is to “Throw bricks at government buildings I guess, what else can an individual do. Either way it's a self-solving problem since nothing is accessible no action can be taken” and added that “I suppose you could do sit-ins like they did at the U.S capitol a few years ago” and for the question regarding the overcoming of prejudice and ableism, the respondents stated that “not absolutely but we're so far from there. The end of segregation would be a good first step.” Person 2 from an unspecified EU Member State however believed that society could overcome prejudice or ableism altogether “but there is work to be done.”

To provide a non-EU perspective as a counterbalance, the prospect is consistent with the EU counterparts. To illustrate, Person G from an unspecified Eastern European nation responded to the overcoming of prejudice or ableism as “Of course not, unless something drastic happens that could affect it, but not in the near future.” However, this is not to say that optimism does not exist in the circle, with Person A from the United Kingdom stating that representation for PWDs is only possible through the “Efforts to ensure disabled people are represented in parliament and local government, [and to] move away from the corporatisation of government” and believed that society can overcome ableism, to quote “yes absolutely, and I think people in general are making surprisingly great strides! But government are not.”

## Policy Review / Conclusion

The EU's policy toward persons with disabilities is ambiguous and vague, especially in terms of defining its own boundary and shared competence with the Member States. Consequently, this would result in well-intentioned but half-hearted initiatives conducted by the Commission and to a lesser extent, the Council in pursuit of equality with negligible effect done in general.

The advantage that the EU possesses in terms of improving rights and the life of persons with disability is that they have the legal mandates and contractual prerogative to its 27 Member States into following any given laws, regulations, or policies which were passed onto them per the Treaty on the European Union through its derived legitimacy and mutual consents. Furthermore, the supranational characteristic and the rule-of-law basis of governance could facilitate the improvement of civil rights through its robust bureaucratic and legal institutional pillars.

However, the major obstacle the EU are currently facing pertaining to this matter is the fact that healthcare and social services are delegated as a shared competence between the Union and each of its 27 Member States, which resulted in the EU having its' hand tied and could only assume a monitoring role through the framework it developed with the Commission and experts' bodies. Moreover, there are little to no instances of the EU exercising its supranational authority to legally intervene in the fields, a notion which remains unpalatable in the eyes of many Member States in what they believed to be its own concerns. Lastly, it could also be summarized that the inherently multidimensional nature of disability would also result in the impossibility and impracticality for a government from the national, much less for the continental authority to design and implement a one-size-fits-all measures for the PWDs in the first place (Vanhala, 2015).

Several prospects for the improvement of the EU's policy and initiatives to improve the life of PWDs can be conducted within the limitations of the available framework. Ferri (2015) stressed the importance of the EU to innovate accessible infrastructure and technology to further integrate PWDs into general society, aside from what has already been conducted beforehand such as a hypothetical common subsidiary scheme for nation states to improve their local conditions before invoking the treaties to observe and potentially intervene. Likewise, the EU should also assume an initiative-taking role to improve civil rights and service to the demographic through the invocation of legal mechanisms, coordination and calibration of local initiatives, and the subsequent consolidation of disability rights' policy into a single, common social policy across the EU itself.



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## Appendix

### Original Online Questionnaire Form

#### *The Situation of Disability Rights in Europe: A Survey*

You are invited by a postgraduate student of the Interdisciplinary Department of European Studies, Master of Arts (M.A.) in European Studies (MAEUS) program, Chulalongkorn University, Bangkok, Thailand to participate in the survey titled "The Situation of Disability Rights in Europe: a Survey". This survey will be used to evaluate the condition or the quality of life for persons with disabilities (PWD) living in one of the 27 current Member States of the European Union and optionally also from those living in the non-EU European Countries. The information you provided will not be used for any other purpose than what is originally stated, which is to gather information for academic research. For further questions, you can contact the researcher and the owner of the survey directly through his email address ([6584008320@student.chula.ac.th](mailto:6584008320@student.chula.ac.th)) or his academic supervisor on the project Dr. Martin Holland, University of Canterbury in the following email address ([martin.holland@canterbury.ac.nz](mailto:martin.holland@canterbury.ac.nz)).

We would appreciate your consideration to complete the survey. The survey contained 19 questions in total, consisting of 16 mandatory and 3 optional questions and the survey is divided into five sections. This survey should take approximately five to ten minutes to complete, which in turn depends on the length of your input. (Content Warning: some questions in the survey are of sensitive nature as it would discuss topics such as discrimination, such questions will be marked with a boldened italics content warning at the header).

Your responses are entirely voluntary and will be confidential. Responses will not be identified on an individual basis, instead it will be pseudonymized to protect your identity. All responses will be compiled and analyzed for research purposes only.

\* Indicates required question

### General information (location)

\*\*\*\*\*We have ensured that the questions in this section will not lead to personal identification, as we greatly valued your personal anonymity and privacy. Your personally identifiable data (PII) will not be collected in this survey in compliance with the EU's General Data Protection Regulation (GDPR) and other equivalence in the other nations. Data submitted will remain strictly confidential and will only be anonymously utilized for academic purposes only. \*\*\*\*\*

1. Are you a resident or a citizen of one of the 27 Member States of the European Union or otherwise a resident / citizen of other non-EU European countries? \*

**Mark only one oval.**

- Yes
- No
- Non-EU European countries

### General information (continued)

\*\*\*\*\*We have ensured that the questions in this section will not lead to personal identification, as we greatly valued your personal anonymity and privacy. Your personally identifiable data (PII) will not be collected in this survey in compliance with the EU's General Data Protection Regulation (GDPR) and other equivalence in the other nations. Data submitted will remain strictly confidential and will only be anonymously utilized for academic purposes only. \*\*\*\*\*

2. **(For those answering "yes" or "non-EU European country")** which country are you from?

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3. What is your gender? \*

*Mark only one oval.*

- Male
- Female
- Nonbinary
- Transgender
- Prefer not to say.

4. What is your type of disability? \*

*Mark only one oval.*

- Physical
- Intellectual
- Sensory
- Cognitive
- Mental
- Multiple disabilities



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8. On the scale of 1 to 10, how satisfied are you toward your local or national public welfare system in terms of providing services or treatment on conditions relating to your disability? This would also encompass other issues pertaining to the institutions such as accessibility or the service's expense. \*

**Mark only one oval.**

Least satisfied    1   2   3   4   5   6   7   8   9   10    Most satisfied

9. (Optional) How could the welfare system be improved in your opinion?

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10. On the scale of 1 to 10, how would you say that you are satisfied with the general living condition as a person with disabilities in the European Union? \*

**Mark only one oval.**

Least satisfied    1   2   3   4   5   6   7   8   9   10    Most satisfied

11. **(TW: Discrimination, ableism)** Have you encountered an instance of discrimination due to your disability? This can range from an individual to institutional basis. \*

**Mark only one oval.**

- Yes
- No (Skip to question 13)
- I do not wish to answer (Skip to question 13)



12. (OPTIONAL - If you wish not to answer then you may proceed to the next question, this is entirely optional) Please describe the frequency of the occurrence and the nature of the discrimination.

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### Disability rights as a social movement

This section will ask questions concerning the disability rights movement in Europe, mostly regarding your opinion or evaluation of the movement itself or its cultural or societal impact.

13. On a scale of 1 to 10 with 1 being least improved and 10 being most improved, in your opinion do you think whether there is improvement in the cultural and societal attitude toward people with disabilities? \*

**Mark only one oval.**

Least improved    1   2   3   4   5   6   7   8   9   10    Most improved

14. Have you participated in actions relating to the movement e.g. demonstrations, social media campaign, lobbying etc. \*

**Mark only one oval.**

- Yes
- No

15. On the scale of 1 to 10 with 1 being least updated to 10 being most updated, how frequent is your following of the news concerning disability rights in your locality or your nation? \*

**Mark only one oval.**

Least updated    1   2   3   4   5   6   7   8   9   10    Most updated

16. How effective do you think the movement has been in improving the situation as a whole? An answer of any length is welcomed. \*

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## VITA

**NAME** นายธีรวุฒิ ธีรัตน์พงษ์

**DATE OF BIRTH** 9 มีนาคม 2542

**PLACE OF BIRTH** กรุงเทพมหานคร ประเทศไทย

**INSTITUTIONS ATTENDED** ปริญญาตรี อักษรศาสตรบัณฑิต จุฬาลงกรณ์มหาวิทยาลัย (22 มิถุนายน พ.ศ. 2565)

**HOME ADDRESS** ห้อง 1016, ชั้น 10, จามจุรีเรสซิเดนซ์ อาคารจัตุรัสจามจุรี, ถ. พญาไท, แขวงปทุมวัน เขตปทุมวัน กรุงเทพฯ 10330



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