

**Health inequalities and disabled people in South Korea:
A mixed-method analysis**

Hanna Lee

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Abstract

The purpose of this study is to explore health inequality among disabled people in South Korea. More often than not, disabled people have been considered as “unhealthy people,” and the concept of health was confused with impairment. Though, this study assumes that disabled people can certainly live healthy lives and aimed to prevent their impairments from leading to unhealthiness due to social barriers. This study considers the social model of disability, which regards disability as social constructions, and the International Classification of Functioning, Disability and Health framework, which includes diverse domains as factors related to health. The concept of health inequality and social determinants of health that covered in health inequality research is also focused on. Approaching the health issue of disabled people with this framework, this study explores the socio-economic features of health of disabled people.

This thesis adopts the explanatory sequential model, a mixed-method of a quantitative and qualitative approach, prioritising quantitative. The quantitative approach, carrying out the secondary data analysis of the Korea National Health and Nutrition Examination Survey, is carried out to illustrate the actual condition of disabled people, including health problems compared to that of non-disabled people. Between and within the health inequality of non-disabled people and disabled people and the impact factors are also pointed out through quantitative analysis.

The research results demonstrate that the health gap, according to socio-economic status within disabled people, is larger than those within non-disabled people. This implies that with adequate sources and intervention, the health inequality of disabled people can be reduced effectively. The qualitative approach demonstrates the diverse aspects of secondary impairments and barriers in health service use, which influence disabled people’s health.

Qualitative data are collected from focus groups and interviews of 26 disabled people about their healthcare service use experiences, and thematic analysis is performed. A synthesis of both approaches is following, deepening the findings from each data analysis. In the discussion, the concept of disability and health is reviewed in relation to the method of this study. Also, the perception about the health of disabled people and their health inequality social determinants of health are discussed. Lastly, this thesis demonstrates that the health inequality of disabled people, even within them, can be tackled by social intervention and suggests the policy implications to improve the health of disabled people.

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List of Abbreviations

CI: Concentration index

CIL: Centre for Independent Living

CSDH: Commission of Social Determinants of Health

ICF: International Classification of Functioning, Disability and Health

IL: Independent Living

LTCI: Long-Term Care Insurance

NBLS: National Basic Living security

NHI: National Health Insurance

OECD: Organisation for Economic Cooperation and Development

PAS: Personal Assistance Services

RI: Rehabilitation International

SAH: self-assessed health

SDH: social determinants of health

UN CRPD: UN Convention on the Rights of Persons with Disabilities

UPIAS: Union of Physically Impaired against Segregation

USDHHS: United States Department of Health and Human Service

WHO: World Health Organisation

Introduction

It has been a while since health inequality emerged as a global matter. Since it was first raised in the UK through the Black report in 1980 (Black, 1980), this issue was dealt with as one of the most serious social problems, and related studies were carried out in many countries, exposing a health gap among various social groups and inhumane results (Mackenzie et al., 2017; Ataguba et al., 2015; Liu et al., 2014; Read and Emerson, 2005; Humphries and Van Doorslaer, 2000). South Korea was not an exception. Health inequality gained attention in South Korea since the mid-2000s (Korean Society for Equity in Health, 2007; Lee, 2007), and many studies investigated the prevalent inequalities in South Korea through health inequality (Shin et al., 2017; Kim, 2012; Yoon, 2010; Lee, 2005; Lee, 2004d). Social inequality in South Korea became particularly prominent after the financial crisis in 1997 (Hwang and Kye, 2018), and among serious social inequalities in South Korea, health inequality is significant as a process and result of structural contradictions (Lee, 2007). Health inequality is one of the mechanisms revealing the reality of social vulnerability, and disabled people are included in these vulnerable groups.

In most societies, disabled people are generally considered as a disadvantaged group. One of the reasons is that they cannot perform some functions that non-disabled people can, in specific situations. This is called the “absence of ability,” and it is why they are called “disabled,” and consequently, their disabled conditions cause the disadvantaged socio-economic status of disabled people (Breslin et al., 2007). This is just an assumption based on one particular perspective. On the other hand, sometimes, the disadvantaged status of disabled people is regarded as social exclusion and segregation (Goering, 2015; Oliver, 1996). From this perspective, their socio-economic status is regardless of their ability to function.

No matter which perspective one takes, though, the low socio-economic status of disabled people is demonstrated by empirical evidence (Kim et al., 2014a; Kim et al., 2011; Barnes and Mercer, 2005). In other words, disabled people have fewer resources.

Most disability policies aim to intervene in the tangible or intangible resources owned by disabled people (Roulstone and Prideaux, 2012). It is grounded on the clear recognition of the relative insufficiency of resources disabled people have. This resource includes both as a result, such as higher living standards, and as means, such as job competency. That is, the range of disability policies covers all of these. For example, an income security programme (such as Personal Independence Payment in the UK) secures disabled people a certain level of income to acquire more and better goods and services in the markets (GOV.UK, 2020). Rehabilitation programmes enable disabled people to achieve more physical and social functions. Assistive technology supported by the government develops and distributes assistive devices and personal assistant services funded by the public budget are provided so that disabled people do jobs more autonomously and effectively. Community care services support improving the quality of life of disabled people. That is, through disability policies, disabled people acquire better resources, including ones allowing the approach to other resources.

Health is one of these representative resources. It is a meaningful life outcome in itself and can be a source to achieve other valuable goals at the same time (Sen, 2002). These characteristics of health, distinct from other resources, are so obvious that the well-known announcement “Of all the forms of inequality, injustice in health care is the most shocking and inhumane” by Dr Martin Luther King Jr. is often quoted and accepted (Luther, 1966).

Like many other resources, health is what disabled people have less of. The main purpose of health policies for disabled people is the better health of disabled people (US Department of

Health and Human Services, 2005). However, compared to the representative social resources such as income or education level, the view that the health gap of disabled people is socially constructed is relatively unclear because health is closely connected to the definition that distinguishes disabled and non-disabled people: disability. This might disturb the approach to health policy for disabled people from another viewpoint. My thesis presupposes that the health of disabled people is socially constructed and the result of the interaction of socio-economic resources. Like health inequality among other disadvantaged groups, the health inequality of disabled people might be tackled if socio-economic inequality is reduced. In this thesis, I attempt to show this through empirical research.

This premise embodies the health rights in the UN Convention on the Rights of Persons with Disabilities (UN CRPD). In Article 25 of UN CRPD, it is announced that disabled people “have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability (United Nations, 2006: 18).” Since health is a social construct, then intervention in health must be related to the social structure. In South Korea, the Health and Access to Healthcare Service for Disabled People Act was enacted in 2017 as the outcome of the persistent effort to achieve the declaration of UN CRPD. With the enactment of this law, the government provides various healthcare programmes for disabled people, which will be detailed in the final chapter of this thesis. These circumstances became a catalyst for this study, which explores the health inequality of disabled people and contributes to the improvement of their health by understanding the factors influencing the health rights of disabled people.

Using a mixed-method approach, this study engages with theoretical debates about impairment, disability, and ill-health by exploring the factors affecting physical status of disabled people and the effects of physical status on their quality of lives. This theoretical

debate contributes to the review of perspective on impairments, which has long been discussed in disability studies.

With this perspective in mind, chapter one starts with a brief theoretical background of this study's basic concepts. An attempt to distinguish concepts of disability and health is made. Diverse perspectives on disability, including the social model of disability and related discussions as the main idea, are reviewed to identify the social attribution of disability. The concepts of health inequality and social determinant of health in recent research trends are addressed as well. Within this context, the development of policies to tackle health inequality in South Korea and abroad is summed up. Health and health inequality of disabled people is conceptualised in this chapter as well.

The main purpose of chapter two is to understand the background of this research. This chapter includes two major topics. The first one is the context of South Korea. An overview of the recent history and culture of South Korea is summarised, and the characteristics of South Korea based on the welfare regime theory is identified. The examination of the societal attitudes toward disabled people and family culture is added since it has effects the care for disabled people in South Korea. The next part displays disability and health-related policies in South Korea. A wide range of disability policies and general health policies such as National Health Insurance are reviewed.

Chapter three presents the methodology adopted for this thesis. A clear introduction of the main aim and objectives, research questions of this study are proposed. Ontological and epistemological consideration of this study is reported, and the explanatory sequential model putting the priority on quantitative data, a mixed-method applied for this study, is explained. In this study, secondary data analysis as a quantitative approach and focus group and interview as a qualitative approach were adopted. The detailed research process is described

to show how this study is carried out, including data collection and analysis. In the end, the ethical issue of this study is addressed.

Chapter four states that the general and health-related characteristics of disabled and non-disabled people in South Korea are compared through the secondary data analysis of the Korea National Health and Nutrition Examination Survey. Comparing both groups clarifies the reality and provides a broad overview of the disabled people in South Korea by quantitative analysis of the study sample. A comparison of the health inequality of disabled and non-disabled people by the income level is performed. This analysis is differentiated at the point that it divides disabled and non-disabled groups and estimates the severity of both groups' inequality separately. In addition, the impacts of related variables on the health inequality of each group are analysed and compared. The analysis of this chapter uses a concentration index analysis and concentration index decomposition.

Chapters five and six contain the results of qualitative approaches: focus groups and interviews. The keyword of chapter five is "secondary impairment," derived from the thematic analysis of qualitative data. This chapter represents the various aspects of secondary impairment. Through the vivid voices of participants, the causes and effects of secondary impairments are illustrated and the social determinants of health come into view. Medical treatment of secondary impairments and its trade-off benefits and risks are explored as well. Other topics, such as personal assistant service use and its benefit and side effect, are also addressed.

Chapter six concentrates on the second theme, "inequality in healthcare utilisation." Focused on the healthcare service use perceived by the research participants, social factors such as physical structure or human attitudes are drawn as barriers to equal healthcare service use. In this chapter, how these social determinants reinforce health inequality of disabled people is

examined following the process of service use: before using the service, during the trip to the hospital and healthcare service centre, inside and outside the hospital, during the consultation, and in the ward, and after using the service.

Chapter seven integrates and synthesises quantitative and qualitative analysis results for the abundant analysis of health inequality of disabled people. How the results from each data underpin and supplement each other or whether there are conflicting evidence is investigated. This chapter is more than a summary of the previous chapters, presenting the strength of mixing methods for a deeper and multi-dimensional analysis.

In chapter eight, the major question of this study, “how can disabled people live healthy lives?” is discussed. First, an attempt is made to disentangle the ambiguous and contested disability and health-related concepts. This is a deliberate effort to expand this study’s findings at a theoretical level in association with the preceding research. Contemplation is also made on the concept of the health of disabled people, the factors influencing their health, and inequality in social level. It is a procedure to find out the practical implications of this study, followed by the policy recommendation for South Korean society.

In conclusion, this thesis is summarised and reviewed, and implications and policy recommendations related to findings are presented.

Chapter 1 Understanding disability and health inequality

This chapter provides a theoretical background of the major concepts of this study: disabled people and health inequality. Through considering related theory and previous literature of disabled people and health inequality, three key themes will be addressed.

First, diverse conceptualisations of disability and the significance and criticism of the social model of disability, which this study is mainly based on, will be analysed. Next, conceptual definitions and related research about health inequality and social determinants of health will be explored. In addition, how the initiatives and policies to tackle health inequality in the whole population are developed in South Korea and international society will be reviewed. Finally, concepts associated with health and health inequality of disabled people will be investigated.

1.1 Theoretical review on disability

The perspective on disability is a critical topic of this study which contemplates the concepts of health and disability. Thus, the theoretical way in which disability is treated will be looked back on.

1.1.1 Challenges and implications of the social model of disability

The emergence of the social model of disability was a significant event in the formation of disability studies (Shakespeare, 2010), but it has confronted considerable challenges, defense,

and support. In this section, the concept and discussion of the social model of disability will be explored.

1.1.1.1 Concept of social model of disability

Perspectives on disability affect how disability-related matters are approached (French and Swain, 2012; Kim and Lee, 2012; Priestley, 2003). Since this study addresses health-related phenomena among disabled people, it is required to explore the various models and concepts of disability to clarify this study's position.

The disability model can be said to be an answer to the question "What is disability?" Since the human body can be manifested in infinite forms within a certain range, the notion of a flawless perfect body is a mere fiction, and a solid dichotomy of disability versus non-disability does not make sense. Disability is a multi-dimensional concept that must be understood in terms of a continuum (Shakespeare, 2017: 5). It is an artificial choice to define the range of bodily function variations or structure (or other variables) correspondent to disability. Therefore, this artificial choice is influenced by worldviews trying to explain social phenomena from their perspective.

Diverse perspectives on disability have been categorised in different ways by several researchers. For example, Oliver (1996) contrasted the individual model, which regards disability as an individual problem, and the social model, which sees disability as social oppression. Priestley (1998) proposed a four-fold typology of disability: individual materialist models, individual idealist model, social creationist models, and social constructionist models. This categorisation is a combination of the contrasts of materialist

versus idealist and that of individual versus social models. Swain and French (2000) differentiated between the tragic model of disability and the affirmative model of disability in addition to the individual and social model of disability. Mitra (2006) presented the medical model, social model, Nagi model, ICF (International Classification of Functioning, Disability, and Health) model, and Sen's capability approach. More recently, Berghs et al. (2016) mentioned four models: the medical model, the human rights model, the social model, and critical disability studies. Table 1.1 shows a quick overview of several examples of categorisation of disability models.

[Table 1.1] Categorisation of disability models

Researcher	Models	Description
Oliver (1996)	Individual model	Defines disability in terms of individual deficit. It focuses on the individual's medical condition and locates disability within the person.
	Social model	Defines disability as a social creation, a relationship between people with impairment and a disabling society.
Priestley (1998)	Individual materialist models	Disability is the physical product of biology acting upon the functioning of material individuals (bodies).
	Individual idealist model	Disability is the product of voluntaristic individuals (disabled and non-disabled) engaged in the creation of identities and the negotiation of roles.
	Social creationist models	Disability is the material product of socio-economic relations developing within a specific historical context.
	Social constructionist models.	Disability is the idealist product of societal development within a specific cultural context.
Swain and French (2000)	Tragic model	It presents impairment and disability in terms of personal tragedy and incapacity.

Researcher	Models	Description
	Affirmative model	Non-tragic view of disability and impairment. It is grounded in the benefits of life style and life experience of being impaired and disabled.
Mitra (2006)	Medical model	Disability is a problem of the individual directly caused by a disease, an injury, or some other health condition and requires medical care in the form of treatment and rehabilitation
	Social model	Disability is a social construct. It is created by the social environment and requires social change.
	Nagi model	Impairments are anatomical or physiological abnormalities or losses. Disability is functional limitations that impairments impose on the individual's ability to perform the tasks of his/her roles and normal daily activities.
	ICF model	Disability has its genesis in a health condition that gives rise to impairments, and then to activity limitations and participation restrictions within contextual factors.
	Sen's capability approach	Disability results from individual's personal characteristics, resources, and environment.
Berghs et al. (2016)	Medical model	Views impairment as a problem located in an individual.
	Human rights model	Accords fundamental rights to disabled people and sees disability issue as human rights problem.
	Social model approach	Makes a distinction between impairment and disability.
	Critical disability studies.	Questions the dualism between impairment and disability.

Source: Oliver(1996), Priestley (1998), Swain and French (2000), Mitra (2006), Berghs et al. (2016)

Detailed explanations about these diverse classifications do not be mentioned in this section due to the low relations of the main topic and space limits. However, there are some finding

points from these categorisations. Each model is not mutually exclusive. Also, there is disagreement in the literature between the classification and hierarchy of models, and there is a wide variety of how models organised in previous studies. For example, Berghs et al. (2016) placed the ICF model as a subcategory of the medical model; on the other hand, Mitra (2006) listed the two models independently. That is, there is no unarguably agreed standard of categorisation of disability models. Therefore, in this section, the most well-known, widely accepted, and frequently used positioning in disability studies will be presented: the contrast of the medical (or individual) and the social model of disability (Shakespeare, 2013; French and Swain, 2012; Goodley, 2011; Priestley, 2003; Shakespeare and Watson, 2002).

The basic assumption of the medical model of disability, established dominant in today's society and for a long time, is that the difficulties disabled people experience are a medical matter and occur due to their impairment (Oliver, 1996). It was argued that this model regards the individual as a cause of the problem and consequently, can do serious harm (French and Swain, 2012). For example, Atkinson (2000) and Potts and Fido (1993) demonstrated that people with learning disabilities were institutionalised and abused due to the medicalisation of learning disabilities. On the other hand, the social model of disability emerged as a counterpart of this medical model. From the perspective of the social model of disability, disability is not the individual's impairment but is generated by environmental, structural, and attitudinal barriers (French and Swain, 2012: 4-6). That is, the social model focuses on the process and forces which make people with perceived impairments disabled, as a minority in society (Priestley, 2003:14). This distinction was stated by Oliver (1983) academically for the first time, and he found the origin of the social model in the Union of Physically Impaired against Segregation (UPIAS)'s definition of impairment and disability (Priestley, 2003). UPIAS (1975), the British disability organisation, distinguished the concept of impairment and disability as follows:

[Box 1.1] Definition of impairment and disability

-Impairment: lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body

-Disability: the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities

Source: UPIAS (1975: 14)

This impairment-disability distinction is a core aspect of the social model of disability (Shakespeare, 2013: 21), and the connection between impairment and disability that was regarded as necessary and inevitable is broken within it (French and Swain, 2012: 6). In other words, from this point of view, disability is not a physical problem but social oppression (Barnes, 1996). The definition of UPIAS influenced not only academic fields but also the global disability movement (Priestley, 2003). The spectrum of social models based on this perspective is quite broad (Owens, 2014; Priestley, 2003); thus, it varies according to the point of emphasis. Goodley (2011) suggested the minority model, the cultural model, the relational model, and the social model - also known as the social barrier model - as the main disability studies perspectives and linked them to specific countries (see Table 1.2).

[Table 1.2] Disability studies key perspectives

Category	Description	Based area
Social barrier approach (Disability as	Disability is a social construct and disabled people are oppressed by society.	UK

Category	Description	Based area
social barriers)		
Minority model (Disability as minority politics)	Disabled people are one of the minority groups who are deprived of civil rights and equal access.	USA and Canada
Cultural model (Disability as cultural construction)	This model has developed within the interdisciplinary works with feminism, queer and critical race studies. Disability is a cultural construction.	USA and Canada
Relational model (Disability as relational)	Disabled people are disabled through the dynamic interaction between body/mind and the environment.	Nordic Europe

Source: Goodley (2011: 13-18)

While the social barrier approach of the UK makes a thorough distinction between impairment and disability (Barnes, 1999, Oliver, 1996, Barnes, 1991), other models do not (Owens, 2014). Nevertheless, within all these models, disability is considered beyond the physical body and formed in a social context. Therefore, as noted above, in a broad sense, these models can be regarded to form the “social model of disability approach.” This section discusses the “social barrier model (French and Swain, 2012; Goodley, 2011),” also known as “strong social model” (Shakespeare, 2013; Shakespeare and Watson, 2002), or “UK social model” (Owens, 2014). For convenience, this social barrier model will be stated as “a social model” in this study, and if necessary, the diverse spectrum of the social model of disability will be identified specifically.

The differences between the social model and other disability models could be summarised as follows: the social model strictly distinguishes impairment from disability with a strong focus

on “social oppression,” while the minority group model follows a rights-based approach, which is based on the individualisation of disability and tends to omit the group or social focus (Owens, 2014; Siebers, 2002). The social model also concentrates on equality in political and social participation while the USA and Canada based cultural model focus on the issue of psychology, identity, personal affirmation and moral development (Owens, 2014; Meekosha, 2004). From the perspective of the social model, the true nature of disability is social and political, and it is clear that to remove disability, eliminating social barriers is essential. This social model has led the disabled people’s movement (Oliver, 2013: 1024) and influenced disability studies in the UK (Owens, 2014; Goodley, 2011). Advocates of the social model emphasise the close connection between theorising and researching disability and related political action (Barnes and Mercer, 2010: 33), and therefore have raised and led political issues, and for decades have made efforts to seek social change. Although the social model of disability played a major role in driving the disability movement in many countries, there was constant criticism since its beginning (Oliver, 2013), as will be described in the following section (section 1.1.1.2).

1.1.1.2 Criticism of the social model

Among many researchers who evaluated the social model of disability critically (Shildrick, 2009, 2005; Edwards, 2008; Vedder, 2005; Corker, 2002; Hughes and Paterson, 1997; Morris, 1991), Tom Shakespeare might be one of the most well-known scholars. He suggested the social model became “an obstacle to the further development of the disability movement and disability studies” because it was i) designed not as a social theory but a political intervention (Shakespeare, 2013), which clarifies the political position and makes straightforward and

emotional phrases; ii) It delved too much in the sense of self (disabled activist) because it offers stronger identity and self-esteem to its advocates. Since it is deeply involved with self-conception, the criticism of the social model is easily regarded as a criticism of oneself, and it is difficult to judge the criticism rationally; iii) The social model has hardly evolved since it was first designed by Barnes (1991), Finkelstein (1980), Oliver (1990), and Thomas (1998) in academic forms more than 30 years ago (Shakespeare, 2013: 20).

Owens (2014) divided the criticisms of the social model of disability into three points; embodiment, oppression, and an inadequate theoretical basis: The first point, “embodiment,” was about the strict distinction of disability from illness and impairment (Edwards, 2008; Hughes and Paterson, 1997). This is deeply involved with the main point of this study, so it will be described more in the next paragraph. The second point, “oppression,” presented the criticism about the rigid approach to oppression. It was criticised that the oppression in the social model was rather nebulous (Imrie, 1997), not conceptualised elaborately (Hughes, 1999), and it was used only in one form, with no consideration of interpersonal and cultural aspects (Williams 1999; Shakespeare, 1994). The last point, “inadequate theoretical basis,” criticised its theoretical vulnerability (Longmore, 2003; Finklestein, 2001; Corker, 1999), meaning that since there are still many that cannot be explained by the social model of disability, it needs to be developed more.

Among these criticisms, the main point related to this study is the first one: there is no place for impairment within the social model of disability (Crow, 1996; French, 1993; Morris, 1991). French and Swain (2012: 8-10) noted “neglect of impairment”, which cannot be divorced from social factors, as a major limitation of the social model. Anastasiou and Kauffman (2013) also pointed out the strict distinction between impairment and disability and disdain of the role of biological and mental conditions as the weak points of the social model. They noted that to reduce disabilities to a single social dimension-social oppression was too

simplistic. Thomas (1999, 2004), one of the founders of the social model of disability, introduced the term “impairment effect” to explain disabled people’s experiences, which result from emotional and psychological aspects rather than social factors. Impairment effect is defined as “the direct and unavoidable impacts that impairments (physical, sensory, intellectual) have on individuals’ embodied functioning in the social world” (Thomas, 2010: 37), and it was believed to be “required to acknowledge that impairments do have direct and restricting impacts on people’s social lives (Thomas, 2004: 43).” Also, Thomas (2004: 43) claimed that “theorising this socio-biological dynamics associated with different types of impairment” - impairment effect- needs to be considered in disability studies. This idea was similarly repeated by other scholars: Difficulties experienced by disabled people caused by their impairment, such as pain or fatigue, really exist (Crow, 1996), and they have a considerable impact on the lives of disabled people (Albrecht and Devlieger, 1999). Even though the social barriers are removed, the impairment effect would remain (Owens et al., 2014). Crow (1996) argued that impairment in the form of chronic illness or pain could reduce activity and participation so that the external barriers might become irrelevant, and impairment would remain without disabling barriers. It seems to address the highly nuanced, personalised, and individualised dimension of impairment (Shakespeare, 2010; Crow, 1996), which most disabled people also experience. Owens et al. (2014) appraised the impairment effect notion to overcome the dichotomised approach of impairment versus disability. Thomas (2010; 1999) mentioned that her notion of impairment effects was an attempt to make room for impairment within disability studies.

Even though all these criticisms offered significant insight into the social model of disability to some point, Oliver (2013) noted that some criticism seems to originate from a misunderstanding of the social model. The social model does not say that to consider impairments is a problem. Nor does it say that medical interventions are unnecessary. The

social model is an analytical tool to recognise the barriers that society creates (Oliver, 2013). By emphasising the importance of the social environment, and in that process of awareness, the barriers are also changed. The social model of disability has led society to pay attention to and resolve environmental barriers. Therefore, the biggest strength of the social model is the potential to improve the real lives of disabled people (Oliver, 2013: 1024). Oliver (2013) insisted that focusing on impairment and the differences between disabled people, allegedly ignored in the social model, could not lead to the development of a useful model to improve the lives of disabled people. Similarly, Vehmas and Watson (2014) argued that Critical Disability Studies (CDS), which made a cultural approach attempt to a disability, failed to take part in the ethical and political issues experienced by disabled people. They claimed the CDS could never be a good political or theoretical perspective of disability, cause it did not provide certain implications for policies for society (Vehmas and Watson, 2014). In this way, the discussion on the implication and limitation of the wide range of social model of disability is still going on.

In South Korea, the social model can be much more powerful because the structural, environmental, and attitudinal barriers are still sturdy, and disabled people face physical and institutional obstacles in their daily lives. The material investment and economic support for disabled people in South Korea are insufficient (Kim et al., 2014a; Kim et al., 2011; Byun et al., 2009), and the socio-economic status of disabled people is very low (this will be discussed in detail in chapter two and four). Under these circumstances, the social model can account for the barriers disabled people experience and improve disabled lives through changes in society. From the perspective of changes and development of realities, the social model should be more highly emphasised.

1.1.2 Other key concepts: capability approach and ICF

In this section, Sen's capability approach and the ICF will be addressed. These concepts are different from the aims of establishing and developing the social model of disability so that they may seem unfit to compare to the models. However, it is significant to mention these concepts in a study on health inequality of disabled people.

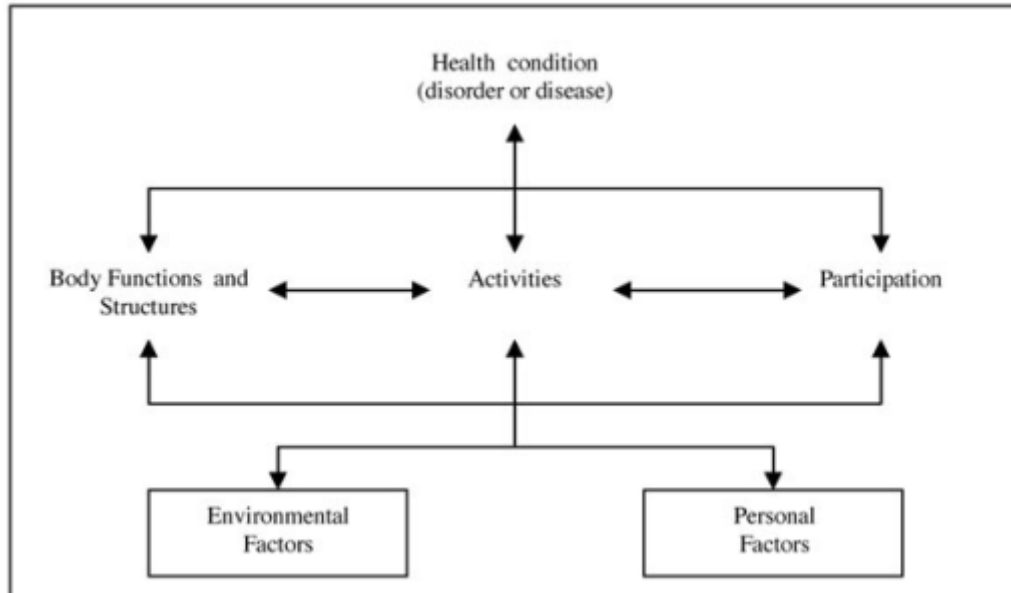
Amartya Sen, an economist, emphasised the unfairness of health inequality (Sen, 2002; 1981) by developing a "capability approach" which conceptualised the deprivation confronted by individuals in society, by focusing on the socio-economic barriers to equality (Burchardt, 2004). He distinguished between the concepts of "functioning" and "capability (to function)" and related them to commodities, environments, and personal characteristics. Functioning is "the actual achievement of the individual, what he or she actually achieves through being or doing" (Sen, 1981) and the whole set of combinations of functionings which an individual could achieve (including what is actually achieved) form the "capability set." That is, "capability" is defined as a "practical opportunity." This means that each individual requires personal ability, resources, practical tools, and knowledge to achieve something, and without them, opportunities to functioning are lost. The absence of personal ability, resources, practical tools, and knowledge is the lack of capability. This absence results not in personal failure but from the external circumstances (social, economic, and physical environment) beyond one's own ability. Sen (1981) described how a person's capability is deprived when he or she cannot access resources and how functioning is limited as a consequence. With this, he incorporated the possibility that the economic resources and environment of disabled people can be disabling (Mitra, 2006). Burchardt (2004) highlighted the complementarity of Sen's capability approach and the social model of disability. By arguing that the capability

approach provides a more general theoretical framework than the social model of disability, she also demonstrated the utility of the capability approach in applied disability studies.

ICF, International Classification of Functioning, Disability and Health, is one of the classifications of the WHO (World Health Organisation) such as ICD (International classification of disease) or ICHI (International classification of health intervention). ICF was developed by the WHO as a successor of ICIDH (International classification of impairments, disabilities, and handicaps) developed in 1980 as a classification of disease consequences. ICIDH proposed a disablement process composed of a four-stage sequence of disease/disorder-impairment-activity limitation or disability-handicap (Fujiura and Rutkowski-Kmitta, 2001). In the ICIDH framework, impairment, disability, and handicap lie on the body function or structure, individual activity, and social dimension, respectively, and in this sequence. That is, it offers a causal relation in which diseases or disorders in medical dimensions give rise to physical or psychological impairments, and these impairments limit activities in the individual (disability). This limitation leads to social disadvantage (handicap) (Berghs et al., 2011). This classification was revised as ICIDH-2 in 1999 under the criticism that it implied unrealistic causality (for example, the described causal relation is unidirectional and unilinear) and was formed within a medical perspective on disability which regards disability as abnormal deviation (Bickenbach, 2013; Pfeiffer, 1998). After a series of criticisms and corresponding revisions, the ICIDH framework was finally redrafted as the ICF. The WHO emphasised the distinction between the ICF and the ICD, which sees health from the aetiologic point of view and argued the ICF could “provide a scientific basis for understanding and studying health and health-related states, outcomes and determinants” (WHO, 2001:5).

The ICF is regarded as an extension of the medical model and has been criticised by many disability researchers, while other disability scholars advocated its advantages (Bickenbach,

2013; Thomas, 2007; Hurst, 2003; Pfeiffer, 2002). In this thesis, the ICF is considered to offer some opportunity to expand the notion of health; at least it is applied to disabled populations. This is because according to the WHO (2001: 7), the ICF covers and depicts all facets of human health and health-relevant components of well-being in terms of health domains and health-related domains. The ICF's basic assumption is that health state is an interaction between functioning and disability and contextual factors. The first domain, "functioning and disability", consists of "body functions and structures" and "activities and participation." Each of these components is a renewed concept of impairments, disabilities, and handicaps from ICIDH, making an effort to use neutral terms, without undue negative connotation (WHO, 2001: 217). The second domains, contextual factors, consist of "environmental factors" and "personal factors"



[Figure 1.1] Interactions between the components of ICF (WHO, 2001)

Figure 1.1 illustrates that all these components are interconnected and interact with each other and influence health conditions. The component “activities and participations” encompasses individual activities such as self-care, interpersonal relationships, education, employment, religion, and political life. Environmental factors cover products and technology, natural environment, social attitudes, and systems and policies. Due to this extensive coverage and interrelational approach, the ICF was recognised as an alternative model to innovate the concept of disability when it was first introduced in South Korea in the mid-2000s. Park (2004) and Kim (2002) noted the significance that the ICF can have, for instance, in social work and the special education fields. Shin (2004) argued that the ICF was a universalistic approach to disability, which embraces the medical model and the social model of disability. Hwang (2004) noted that the ICF could be applied to reconstruct the notion of disability rationally and systematically, paying attention to functional disability. This might be seen as a somewhat exaggerated interpretation, but under the circumstance of South Korea, where disability ideology and policy is emerging and still immature, the possibilities of the ICF are seen as greater than its limitations. Recently, an ICF study has been carried out in South Korea focusing on applying to the field of special education (Park et al., 2018; Choi and Kim, 2017; Park et al., 2017; Lim et al., 2015).

Sen’s capability approach and the ICF model are reviewed in this section because they consider what a study on the health of disabled people should include, but the social model of disability did not discuss. To refer to the health of disabled people inevitably entails the mention of impairment. The debates covered here will be mentioned again when discussing this study’s findings in relation to previous literature.

1.1.3 Disability and secondary impairments

There seems to be a hesitation to talk about the individual impairment of disabled people in disability studies based on the social model of disability as partially seen in section 1.1.1.2. Oliver (2013: 1025) made a counterargument to the criticism that the social model neglects impairment, noting that focusing on impairment would “only de-politicise the social model” and not lead to the improvement of disabled people’s lives. However, many scholars claimed that impairments have an unneglectable impact on disabled people’s lives (Thomas, 2010; 2004; 1999; Albrecht and Devlieger, 1999; Crow, 1996), and referring to impairment can be justified if it can contribute to the better lives of disabled people. This section links it, saying that maybe the point is not whether the impairment is dealt with or not but how it is dealt with.

In former studies, the terms secondary impairment, disability, and condition were used interchangeably (Bohn et al., 2008; Drum et al., 2005; Kinne et al., 2004; Whiteneck, 1994; Noreau et al., 1993) and this term was presented too broadly. Some scholars defined it focusing on health outcomes, which signifies another impairment or aggravation of health caused by the primary impairment/condition (Whiteneck, 1994; Noreau et al., 1993; Harper et al., 1992). This definition focuses on the health outcome. The second definition focuses on the risky conditions that affect health rather than health outcomes, meaning an increased risk for additional health and social conditions experienced by people with a primary disabling condition. It occurs after their primary condition and leads to poorer health (Drum et al., 2005: 36). This involves not only environmental factors but also behaviour affecting health (see section 1.3). It identifies that disabled people are more often exposed to secondary conditions (Coyle and Santiago, 2002; Pope and Tarlov, 1991; Marge, 1988), including more risky health behaviours (drinking, smoking, lack of exercise) (Weber et al., 2008). Considering

both definitions, it could be implied that “secondary condition” involves both the process and the result. To distinguish two definitions of secondary impairment, only in this thesis, the word “secondary impairment” will be used as a result, and the word “secondary condition” as process and condition. As far as within this context, the secondary condition leads to a secondary impairment.

In relation to the first meaning, secondary impairment, the procedure that the primary impairment leads to the secondary impairment can vary according to the type of impairment. In some cases, the secondary impairment is aggravated by an internal condition, while in other cases, the cause is external. However, the causal relations in which people’s biological characteristics with the primary impairment promote the secondary impairment are often not that clear. For example, Emerson et al. (2010) mentioned the high risk of leukaemia of children with Down’s syndrome compared to the general population reported in preceding studies (Hermon et al., 2001; Hasle et al., 2000) and argued that the medical explanation about the relation of these variables was not obvious. That is, some of the causes of secondary impairment may be preventable, while others may not. The definitions from previous studies did not coincide with each other; thus, some people defined the secondary condition as preventable (Simeonsson and Leskinen, 1999) but others did not (Campbell et al., 1999). No matter if it involves unpreventable impairment, as far as preventable a secondary impairment is concerned, the elimination of a secondary condition is one of the means to prevent the secondary impairment, and many health policies for disabled people focus on this (Department for Work and Pensions et al., 2005; US Department of Health and Human Service, 2000; Rimmer, 1999).

The range of secondary conditions presented in the literature is very broad. It encompasses not only medical diseases but also the social, emotional, family, or community problems that people with impairments are likely to experience (USDHHS, 2000). Medical conditions

generated by primary impairments give rise to an uncompetitive labour force in industrial societies, followed by lower-income and social status. This, in turn, increases exposure to harmful environments to health and lower accessibility to healthcare resources (Wilber et al., 2002; Seekins et al., 1994). The lack of knowledge and experience of healthcare professions about disabled people is also a factor in which secondary conditions occur (Melville, 2005; USDHHS, 2000). This approach incorporates the process in which disabled people are socially marginalised and how their health deteriorates due to this situation and demonstrates how a hostile environment for disabled people's health is constructed. Considering secondary condition as responsible for the health status differences observed between disabled people and non-disabled people is probably the broadest application (Wilber et al., 2002; Seekins et al., 1994). In the end, secondary conditions extend to all conditions of disabled people's lives, making it impossible to distinguish it from the reality of discrimination and exclusion. In summary, secondary conditions deteriorating health echoes discussions about societal disabling barriers oppressing disabled people's lives, and consequently, the social model of disability is an ideal tool to frame the study of how these secondary conditions impact on disabled populations differently because of the disabling societies in which they live.

This thesis will use the core concepts discussed so far to examine the health of disabled people. Table 1.3 presents the basic principles for using the terms, although sometimes they can be used interchangeably depending on the context.

[Table 1.3] Conceptualisation of major terms

Term	Conceptualisation
Impairment	"Impairment" will be used to emphasise the physical, sensory, and mental dysfunction.

Term	Conceptualisation
Impairment effect	“Impairment effect” is a direct and unavoidable impact that impairments (physical, sensory, intellectual) have on individuals’ embodied, citing Thomas (2010)
Disability	“Disability” will be used in the most neutral meaning. “Disabled people” is used to refer to the main subjects of this thesis. The legal terms such as “disability type”, “disability grade”, and the legal name of specific disability type will be referred with the term “disability”. It is also used to present the “disabling barriers” located in the external environments.
Secondary impairment	“Secondary impairment” is the physical, sensory, mental dysfunction mainly caused by primary impairment. Sometimes the cause of secondary impairment is not clear, but in qualitative analysis (chapter five and six), the use of the word “secondary impairment” follows the perception of research participants.

Since these discussions have been developed around the global north such as the UK, US, and other European countries, the usefulness of applying these concepts and frameworks in South Korea can be questioned. Although this framework is based on a common phenomenon rather than a specific one, as the cultural context is reflected in the framework, the validity will be accepted because such discussions are introduced, accepted, and influencing in South Korea currently. As background for this claim the increasing debate about disability rights in South Korea, the effects of these advanced discussions on disability as an active disability movement, and the substantial policymaking process in the country will be presented in chapter two.

1.2 Health inequality and social determinants of health

To inquire into health inequality of disabled people, the concept of general health inequality needs to be considered first. In this section, how health inequality was conceptualised in the

literature, and what was the role of the social determinants of health, a core entity of health inequality, will be reviewed.

1.2.1 Conceptualisation of health inequality

Large gaps in health status are commonly observed around the world population. They exist at global, national, and local levels. For example, it was reported that deaths from HIV, non-communicable diseases, and injury, all cause age-standardised death rates, were 2.2 times higher in black South Africans than in white South Africans in 2012, and 1.4 times higher in women than men (Pillay-van Wyk et al., 2016). In 2012, globally 15.4% of cancers were estimated to be attributable to infections, and more than 65% of these preventable causes occurred in developing countries, where they are related to one in four cancers (Plummer et al., 2016). These differences in health statistics also appear within one country or one city. In Glasgow, there is a 10-year gap in life expectancy between those living in the most disadvantaged and the most affluent neighbourhoods, and in the Netherlands, a five-years gap also exists (Whitehead and Dahlgren, 2006: 6). The report by Sir Douglas Black (1980), also known as the “Black report,” noted health inequality for the first time in the UK and demonstrated that the risk of death of infants at birth and during the first month of life was double the risk in unskilled manual workers household than professional workers’ households. These phenomena are regarded as “health inequality” (CSDH, 2008; Whitehead and Dahlgren, 2006; Marmot, 2005), and it has been defined as “differences in health that are unnecessary, avoidable and unfair and unjust (Whitehead, 1992: 431).” The terms “health inequality” and “health inequity” are frequently used interchangeably, but Braveman and Gruskin (2003) distinguished them by stating that “equity” is an ethical concept, meaning

social justice or fairness, while “equality” is not. Equity is a value-based concept, but equality focuses on the unequal condition itself, not necessarily normative (Braveman and Gruskin, 2003). Ritsatakis (2013) also distinguished equity and equality, admitting that the formulation is problematic because inequity and inequality are separated only in the English-speaking world. In some studies, “health disparity” is used indistinctively instead of health inequity or inequality (Lemstra et al., 2006; Read and Emerson, 2005; Carter-Pokras and Baquet, 2002; Pearcy and Keppel, 2002). In this thesis, the term “health inequality” will be used to refer to the unequal health status and healthcare service use between disabled and non-disabled people.

Health inequality is different from mere variations in health because it is systematically patterned and socially produced (Whitehead and Dahlgren, 2006; Asthana and Halliday, 2006). That is, a higher socio-economic status means a healthier life and longer life expectancy, and this is structurally unequal and unfair. Synthesising the former studies, Braveman (2006) summarised the definitions of health inequality suggested by diverse authors highlighting each definition’s strength and weakness (see Table 1.4).

[Table 1.4] Definitions of health inequality, equity and disparities

Author	Definition	Strength	Weakness
Whitehead (1992, 1990)	Health inequalities are differences in health that are “avoidable,” “unjust, and unfair” Equity in health means that all persons have fair opportunities to attain their full health potential, to the extent	Intuitive, clear and accessible to nontechnical audiences	Open to interpretation Does not provide guidance on measurement

Author	Definition	Strength	Weakness
WHO/Braveman et al. (1996)	Pursuing equity in health means trying to reduce avoidable gaps in health status and health services between groups with different levels of social privilege	Explicitly refers to comparisons among more and less socially advantaged groups	Does not explicitly mention health determinants apart from health care
Braveman/ WHO (1998)	Equity in health is operationally defined as minimising avoidable disparities in health and its determinants- including but not limited to health care- between groups of people who have different levels of underlying social advantage	Explicitly includes health determinants	Does not appeal intuitively, as brief, or as clear to nontechnical audiences. Neither does WHO/Braveman (1996) above.
International Society for Equity in Health (ISEqH) (2005); Macinko and Starfield (2002); Starfield (2001)	Equity in health is “the absence of systematic and potentially remediable differences in one or more aspects of health across populations or population subgroups defined socially, economically, demographically, or geographically”	Introduces the important criterion that the relevant differences are systematic; specific comparisons between socially defined groups	Social justice relevance is not clear: groups could be defined socially, demographically without reference to social advantage.
Graham (2004a)	Health inequalities are “systematic differences in the health of groups and communities occupying unequal positions in society”	Succinctly covers many key concepts, including systematic nature of differences comparisons between groups, and relevance of social position	Does not explicitly define health determinants Does not restrict comparisons to those in which the socially disadvantaged are disadvantaged on health Does not address

Author	Definition	Strength	Weakness
			avoidability

Source: Braveman (2006: 173-175)

The analysis of Braveman's categorisation of definitions concludes that a desirable definition of health inequality should mention fairness and socially disadvantaged groups (e.g., by race, ethnicity, religion, gender, disability, sexual orientation) beyond simple low socio-economic status and the social determinants of health (to be further explained in section 1.2.2).

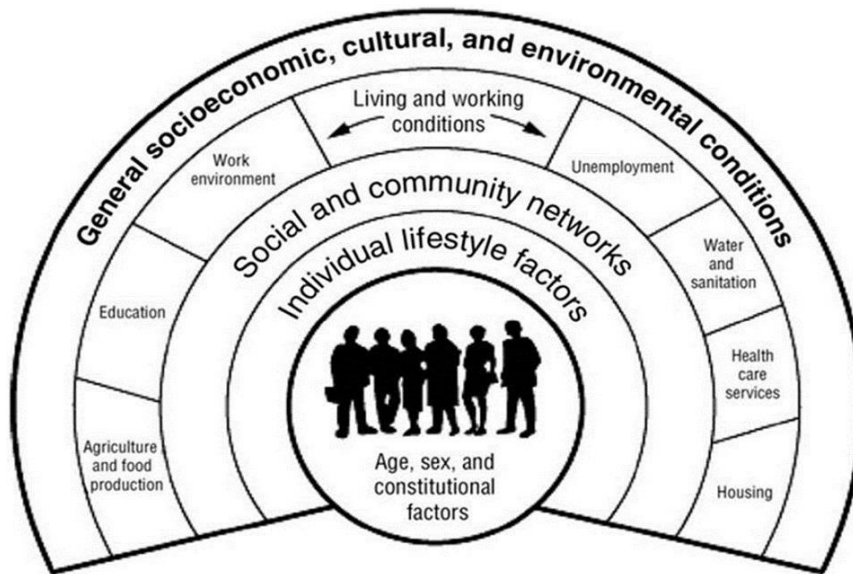
Besides the materialist approach emphasising socio-economic status as the key factor in health inequality, several scholars accounted for this phenomenon. Asthana and Halliday (2006) presented several theories about the health inequality described in the Black report. For instance, social selection theory explains that those who have worse health move into lower social classes while healthier people achieve a higher class. Cultural/behavioural explanations argue that irresponsible individuals with careless lifestyles voluntarily choose inconsiderate behaviours, which are to blame for the reduced health status in lower classes.

Previous studies on health inequality include different facets of health-related variables largely divided into health status as a health outcome and impacting factors to these outcomes. Health outcome includes variables such as life expectancy, the prevalence of diseases, or subjective health status; while impacting factors include health behaviours such as smoking, drinking, exercise, and utilisation of preventive healthcare services like regular health check-ups (Korean Society for Equity in Health, 2007; Asthana and Halliday, 2006; Braveman et al., 2005). Sometimes healthcare service usage for treatment activities such as the number of outpatient visits, hospitalisations, or healthcare expenses is also used to measure healthcare needs and patient satisfaction (Brinda et al., 2015; Say and Raine, 2007; Morris et al., 2005).

The majority of studies on health inequality focus on the “inequality in health status,” and the term “health inequality” is often regarded as meaning “inequality in health status” (Asthana and Halliday, 2006). The most frequently used method in these studies to demonstrate the reality of health inequality is to compare certain indicators between populations. The representative indicators are life expectancy (Auger et al., 2013, Brønnum-Hansen and Baadsgaard, 2012, Hosseinpoor et al., 2012), health expectancy (Bajekal, 2005, Nusselder et al., 2005, Perenboom et al., 2005), all-cause mortality (Townsend and Davidson, 1992, Kitagawa, 1973), cancer incidence and survival (Kogevinas and Cancer, 1997; Lim, 2005), and self-rated health (Idler and Benyamini, 1997; Van Doorslaer et al., 1997).

1.2.2 Social determinants of health

The WHO defined social determinants of health (SDH) as “the condition in which people are born, grow, live, work, and age (WHO, 2015)”. It assumes that health is determined by an interaction of complex factors beyond mere biological and individual factors. Dahlgren and Whitehead (1993; 1991) suggested the determinants of health as five categories: “age, sex, and constitutional factors,” “individual lifestyle factors,” “social and community networks,” “living and working conditions,” and “general socio-economic, cultural and environmental conditions”. As seen in [Figure 1.2] below, they expressed these factors as multi-level layers.



[Figure 1.2] Determinants of health (Dahlgren and Whitehead, 1991)

At the centre of the semi-circle are biological factors, and the genes inherited are also included in this factor (French and Swain, 2012) because these are given factors by birth, and there is little room for social intervention. The further distance from the centre means more social and general factors. The second layer, “individual lifestyle factors,” is relevant to health behaviour such as eating habits, smoking, drinking, or exercise mentioned above. Many policy initiatives from government focus on these factors to change people’s behaviour as a means to improve their health (Wiles, 2008; Jones, 2000). The next layer is about social and community influence which is social resource impacting individual psychology and encompassing variables such as social cohesiveness and isolation. People around (communities) may be supportive or hostile, and these networks have a positive or negative impact on health (Ellaway et al., 2001). Wilkinson (2006) exemplified the community’s influence in stress and social trust, demonstrating that supportive relationships can be resources for good health. The fourth layer includes agriculture and food production, education, work environment, unemployment, water and sanitation, health care services, and

housing. All these factors affect health in different ways. For example, the living and working environment can affect one's health (Giagloglou and Graveling, 2019). The outermost layer includes macro factors such as the country's economic state, the level of employment and social attitudes toward minorities (French and Swain, 2012).

The SDH is present in policy debates and instruments to reduce health inequality. Marmot (2005) suggested three main responses needed to reduce health inequality: The first response is controlling major diseases and improving the health system which is a direct intervention to health outcome-related factors. The second response is to eliminate poverty by tackling poverty in the world's poorest countries, which is a direct intervention to the national and international economy. The last response is to take action on SDH by improving the overall environments where people live beyond the elimination of extreme poverty (WHO, 2015; Marmot, 2005).

To respond to health inequality and intervene in the SDH effectively, the WHO established Commission on Social Determinants of Health (CSDH)" in 2005, a global network of policy makers, researchers and civil society organisations (WHO, 2015). In 2008, the CSDH published a report illustrating the globe conditions of health inequity and asserted that health inequality is "a matter of social justice" (CSDH. 2008: 8). This perspective on justice expanded the concept of health inequality to human rights. That is, ill health means a deprivation of the right to enjoy the highest attainable standard of health in their society, declared in the WHO Constitution - "Health for All," stating that health is a way of enhancing the freedom of individuals and societies (Sen, 2002).

Within their report, CSDH (2008) suggested three overarching recommendations about SDH to alleviate health inequalities: first, to improve daily living conditions emphasising an early intervention to health inequality. This recommendation is significant, especially in

developing countries where meeting the basic conditions for a dignified life is difficult. Second, to tackle the inequitable distribution of power, money, and resources. This principle implied that socio-economic equity is a prerequisite condition of health equality. This is similar to the previously mentioned definition of health inequality, where reference to socio-economic inequality as a cause of health inequality is considered indispensable. Because the social environment and low socio-economic status of disabled people are secondary conditions of the health deterioration of disabled people (Wilber et al., 2002, Seekins et al., 1994), these recommendations have significant meaning to disabled people as well. The last recommendation is to measure and understand the problem and assess the impact of action. Through this last principle, a policy approach to health inequality can come into effect.

These recommendations and the concept of SDH imply that health should matter not only to those within the health sector but also to all policymakers (CSDH, 2008; Marmot, 2005). Also, it demands that a deeper understanding of the determinants of health and health inequality is needed. Krumeich and Meershoek (2014) alerted against the inclination to consider the SDH as mere obstacles to health behaviours to be modified by lifestyle interventions rather than by structural relationships. Unhealthy lifestyles such as overeating, smoking, and drinking can result in chronic diseases such as hypertension or diabetes, but these can be the result of structural factors as well. Rose (1992) called it “causes of the causes.” In a similar vein, Marmot and Allen (2014) pointed out this lifestyle drift and overconcentration on health self-care appearing health policies, which can overlook the more macroscopic aspects by paying attention to individual causes and practices. Whitehead and Popay (2010) demanded attention to the structures that create and maintain these social inequalities, caused by inequalities in power, which in turn cause health inequality. Furthermore, Navarro (2009: 423) highlighted the political approach to distributing resources, focusing on the subject of the power and those who benefit from inequalities – “the alliance

between the dominant classes of developed and developing countries.” He opposed neo-liberalism, which intensifies global polarisation, and encouraged a more structural approach in the broader context to deal with health inequality. In section 1.3, the health inequality of disabled people will be discussed, demonstrating how populations vulnerable in socio-economic status are particularly affected by health inequalities.

1.3 Disabled people and health inequality

In this section, the relations between disabled people and health inequality, the core concepts of this study mentioned earlier, will be examined together. In addition, the pattern that the health of disabled people is treated, ethical issues, quality of life, and control over the life of disabled people, and relation with health will be looked back on.

1.3.1 Health and quality of life of disabled people

Disability seen from the social model lens is beyond the sphere of the simple health domain (Shakespeare, 2017). The discourse of disability embodies the issues of identity, social culture, civil rights, and equality (Goodley, 2011; Barnes and Mercer, 2003; Albrecht et al., 2001), compares disabled people with other minority groups, and finds commonalities (McDowell, 2018; Rogers et al., 2017; Ward, 2008; Sanders, 1994; Riggins, 1992; Hutnik, 1991), which would be unnecessary if a disability is a simple health problem. Therefore, it is imperative to not focus on the negative view of impairment or to not align with medical discourse, which attempts to remove impairments. It is also necessary to hold off the

stereotype that health, a contentious term in the disability literature, has been considered to overlap with the medical point of view in disability studies.

There is a pattern to refer to the health of disabled people: prevention and rehabilitation. The first focus is on preventing the occurrence or onset of impairment, and then, to minimise the impact of occurred impairment and ensure “normal” daily life, rehabilitation services are recommended. The prevention of impairment is a contested topic in disability studies, an ethical issue for a long time. Debates about prenatal screening and selective abortion are still proceeding ethical issues related to the right to life of disabled people and eventually to eugenics. Disability scholars see these as a representation of disablism, regardless of an agreement to women’s right to abort (Shakespeare, 2017; Roulstone and Prideaux, 2012; Barnes and Mercer, 2010; Hubbard, 2010; Asch, 2001).

With regard to rehabilitation service, aiming to prevent secondary impairments and promote a return to daily life, these interventions can affect “whether [disabled are] being included or being left on the margins of community” (Shakespeare, 2017: 88), consequently improving lives of disabled people in practice (French and Swain, 2012, Iezzoni and O’Day, 2006, De Jong and Basnett, 2001). Nonetheless, some scholars did not favour the emphasis on healthcare services claiming that the way in which healthcare services hold the paternalistic markings of the medical model and it focuses on assigning the sick role to its users including disabled people (De Jong and Basnett, 2001) consequently rehabilitation of disabled bodies. It was often repulsed because it was thought to be normalising or inappropriate (Shakespeare, 2017). Though, if they are deprived of equal rights to access healthcare services that improve their lives, it should be addressed in terms of health inequality and reinforcement of the initiative of disabled people.

Such prevention and rehabilitation tend to be described in a passive sense that focuses on body function and avoids and minimises the primary impairment's negative physical and mental effects. A more affirmative sense of health can be found. The statement that disabled people can be healthy (Albrecht & Devlieger, 1999; Krahn, 2003; Drum et al., 2005) is an example. Disabled people, like non-disabled people, can enjoy a healthy life and knowledge of factors that cause or prevent diseases can help disabled people do so (USDHHS, 2005). They should enjoy health as an essential resource for freedom to work, learn, and live in a community with their family. This is a feasible task. Even if impairment would be a condition of poor health, it can be coped with.

Albrecht and Devlieger (1999) exemplified this with the term "disability paradox." The disability paradox means a person with severe impairment feels that s/he enjoys a good or excellent quality of life. They explained how this paradox could occur. Within balance theory, which sees life satisfaction and wellness is dependent upon the person's balance between body, mind, and spirit, they highlighted the importance of "personal experience with disability in defining the self, one's view of the world, social context and social relationships" for better lives (Albrecht and Devlieger, 1999: 978). It seems to overlook material factors somewhat and overemphasize individual factors, though, shows the implication of social relations in disabled people's health. Schwartz et al. (2007) associated this disability paradox with response shift theory, which addresses the problem of measuring people's health with chronic illness or disabled people with self-reported health-related quality of life scale. According to Schwartz et al. (2007), because people with a disability or chronic disease have different standards of quality of life from others, the scale's reliability and validity of need to be adjusted (Schwartz et al., 2007). This will be discussed more deeply in chapter eight.

The health index for response shift theory is not an objective indicator such as blood pressure or heart rate, but self-reported subjective health. This measures the subjectively perceived

limitation of function or subjective wellbeing, which is “health-related quality of life (HRQoL).” In this regard, Wiles (2008) argue that one cannot be fully healthy if s/he is not satisfied with oneself and does not enjoy their lives in their learning, work, family life, or social relationships. This can be widely expanded concept than HRQoL. Having a sense of control over lives and relationship with others are important for health and well-being (Wiles, 2008).

The “fully healthy” lifestyle described above is a presence and participation in daily life. One of what make it possible for disabled people in the health field is care. Care is an integral part of every human being, but concerning disabled people, especially in social policy, care has a specified meaning. Social care for disabled people involves the support of daily living and the promotion of assistant to participate in mainstream society. In the delivery of social care, the control and autonomy of disabled people as consumers is one of the core issues and has more affirmative meaning in their quality of life. Social care, even such service not directly for health promotion as personal assistant service or that in the workplace, would reinforce the health rights declared in UN CRPD Article 25.

1.3.2 Previous studies on health inequality of disabled people

The lower health of disabled people has been reported through numerous studies (Emerson et al., 2014a; Emerson et al., 2014b; WHO, 2011; OECD, 2009; Haverkamp et al., 2004). However, different from other minority groups, to talk about “the health inequality between disabled people and non-disabled people” or “the ill health of disabled people compared to non-disabled people” seems to be tautological. Because even not always, but most of the time, disability is regarded as ill-health and sometimes impairment is used as a health outcome. To

demonstrate the reality that disabled people have poorer health than non-disabled people looks meaningless, unlike the comparison between gender or ethnicity. For this reason, studies on health inequality of disabled people have several characteristics to be depicted later. However, even considering the differences, studies on health inequality of disabled people demonstrate something by reporting this taken for granted inequality in health. Some part of inequality is due to the biological difference; it is unavoidable. However, another part of the gap is explained by the social determinants such as poor socio-economic circumstances of disabled people (Emerson et al., 2012; Honey et al., 2011; WHO, 2011; Emerson and Hatton, 2007; Graham, 2004b; Emerson, 2003). That is, even though the statement “disabled people are not as healthy as non-disabled people” is tautological, if the cause lies in social factors, then it is a social phenomenon that should be approached and intervened socially.

The common features of studies on health inequality of disabled people are as follows.

First, in many studies, disability or activity limitation is considered as a health outcome -poor health- rather than determinants of health and adopted as an indicator to measure ill health (Klijs et al., 2014; Chen et al., 2013; Hosseinpoor et al., 2013; Korean Society for Equity in Health, 2007). These studies assumed that low socio-economic status increases the possibility of activity limitation and disability, supposing that people in lower socio-economic status are likely to be more sensitive to a specific chronic condition, less accessible to treatment and this situation brings about the worse condition (Korean Society for Equity in Health, 2007). That is, disability is not an independent variable but a dependent variable in these studies. The concept of SDH shows that various socially disadvantaged conditions bring about poor health, and here, disability is not regarded as a “socially disadvantaged condition,” but “poor health outcome caused by the conditions.”

If it is compared to other minority groups, factors such as class, gender (Malmusi et al., 2012; Prus, 2011; Fryback et al., 2007), occupation (Landsbergis et al., 2014; Murcia et al., 2013), and race-ethnicity (Brown et al., 2012; Rossen and Schoendorf, 2012) were regarded to have a close association with determinants of health, although they are not the direct cause of health itself. Further, more often than not, these factors were intertwined with each other like women and ethnic minorities with low-paid jobs (Warner and Brown, 2011). Therefore, there is a difference between studies about disabled people's health inequality and those of other vulnerable groups.

Second, most of the researches put disability as an independent variable are about people with learning disabilities. People with learning disabilities had a higher prevalence of many diseases (Ouellette-Kuntz et al., 2005; Brown, 2004; Horwitz et al., 2001), lower self-rated health (Emerson et al., 2011), higher rates of obesity (Nocon et al., 2008; Ells et al., 2006) and diabetes (Havercamp et al., 2004; Kerr, 1998), lower psychological health (Emerson et al., 2012), higher mortality and morbidity (Emerson et al., 2014b) and shorter life expectancy (Bittles et al., 2002; P. Janicki et al., 1999). This phenomenon has been reported in many countries such as the USA (Horwitz et al., 2001), Canada (Ouellette-Kuntz et al., 2005) and Scotland (Brown, 2004). Emerson et al. (2014b) proposed the main reasons for this to be associated with two broad scopes: biological and social factors. Researches carried out in the medicine field identified what medical conditions related to learning disabilities led to people with learning disabilities' early deaths. For example, Hollins et al. (1998) identified the relationship between down syndrome and heart disease. As social factors, it was pointed out that people with learning disabilities are more likely to be exposed to conditions that bring about poor health such as poverty, social exclusion, discrimination, and reduced access to healthcare services. Emerson et al. (2014b) compared the self-rated health of people with intellectual disabilities to people without intellectual disabilities. The result is considerably

notable. People with intellectual disabilities were more likely to report having fair or worse health than people without learning disabilities. However, the degree of association was significantly weakened under the control of risk factors such as socio-economic disadvantage, discrimination, and violence. In other words, poor health is attributable to poor living conditions rather than intellectual disabilities. Similar results were observed in a study about different subgroups. For instance, the large racial/ethnic differences have disappeared or markedly diminished after controlling for socio-economic factors (LaVeist et al., 2009; Glymour et al., 2008; Braveman et al., 2005).

The community network's influence as a layer of SDH mentioned above has been identified in studies on people with learning disabilities. Emerson et al. (2014a) studied the relationship between social relationships and the health of people with learning disabilities. The result showed that people with intellectual disabilities had more unfavourable perceptions of important neighbourhood characteristics and less often social participation than their non-disabled peers. The more favourable perceptions of important neighbourhood characteristics and higher social and civic participation were related to more positive self-rated health in both groups. It implies that social relations influence self-rated health, and partly, the ill health of people with learning disabilities can attribute to poor social relationships.

The third feature is that numerous studies focused on healthcare service use. Disabled people experienced more healthcare service barriers than non-disabled people (Merten et al., 2015; Peters and Cotton, 2015; Popplewell et al., 2014; Smith, 2008). Even though not a few studies reported that disabled people used more healthcare services than non-disabled people (Smith et al., 2009; Parish and Huh, 2006; Schenck et al., 2009), they had higher unmet needs and lower accessibility (DeJong et al., 2002).

Studies identifying specified barriers experienced by disabled people were also performed. Despite greater health needs, they lacked access to health and rehabilitation services. The barriers presented by previous studies had many similarities. The following table demonstrates several examples.

[Table 1.5] Barriers to healthcare service use in preceding research

Researcher	Areas of barriers to healthcare service	
Kroll et al. (2006)	Structural-environmental barriers	Facility, equipment, procedural accessibility issues
	Process barriers	Appointment scheduling Patient-provider communication Professional manner Disability-specific knowledge Personal motivation Having a personal doctor/usual source of care Cognitive issue Information and self-education
Drainoni et al. (2006)	Structural barriers	Health plan and insurance Policies and procedures Transportation Physical environment Communication with providers Time constraints Care coordination and continuity of care
		Financial barriers
	Personal/cultural barriers	Insufficient knowledge Misconceptions about people with disabilities Insensitivity and disrespect Failure to take patients' caregivers seriously Reluctance/unwillingness to provide care

Researcher	Areas of barriers to healthcare service
Rotarou and Sakellariou (2017)	Difficulty in reaching health facility Obtaining doctor's appointments Being attended to Not Paying for treatment due to cost Obtaining medicine
Badu et al. (2016)	Communication Medical equipment Physical accessibility
Smith (2008)	Delayed medical care due to cost Not to seek medical care due to cost Delayed healthcare because of not getting through on the phone Delayed healthcare because of not being able to get an appointment soon enough Delayed healthcare because of not being open when you get there Delayed healthcare because of transportation Delayed healthcare because of the cost To need prescriptions but cannot afford it To need mental health counselling but cannot afford it To need dental care but cannot afford it
Merten et al. (2015)	Intrapersonal (individual) factors: cognitive ability, anxiety and depression Interpersonal factors: spousal support, provider communication Environmental factors: transportation, physical barriers
Abdi et al. (2015)	Deficiency in the system that provides rehabilitation services Defect of education Deficiency in detecting and screening of disabled people Defect of stewardship in rehabilitation Ignoring socio-cultural factors Accessibility hardship Lack of identification Financial hardships in rehabilitation

The level and range of the barriers proposed by each study differ. For instance, items proposed by Badu et al. (2016) are fairly abstract and wide-ranging, to the extent that sub-items could be specified under existing items. On the other hand, Smith (2008) presented very specified difficulties. However, despite this difference, the barriers identified from previous studies can be summarised according to the Institute of Medicine (1993): the first is a physical and structural barrier. This includes all the problems with physical accessibility (to

healthcare facility or medical equipment), and service provision limitations. Delayed service due to insufficient supply is also included. The second is financial difficulty. It covers a situation that cannot be treated due to the financial burden. The third is a human or interpersonal barrier. This is related to a lack of human resources or their competence, including inadequate knowledge and healthcare professions' attitudes. However, this classification is not exclusive to other underlying issues. It is common for more than two categories to be intertwined in one situation. For example, a problem with making appointments for treatment can be, for example, a matter of service delivery or communication problems with staff. Although not presented in the table above, Nocon et al. (2008) pointed out limited health promotion, which may be a structural problem or a human resource problem. Therefore, it is important to understand in detail how these barriers interact.

These features reflect the perspective of researches on the ambiguous relationship between health and disability. Additionally, other minor characteristics as follows could be found: i) Studies employing a single index that illustrates the total scale of health inequality with a single number are very rare. ii) Plenty of studies inquired about the health inequality between disabled people and non-disabled people, but studies focusing on the inequality within disabled people are hard to find. In other words, a study revealing the scale of inequality within a group with a single index, which can be compared to other groups, carried out in many studies on health inequality (Kjellsson and Gerdtham, 2013; Erreygers and Van Ourti, 2011; O'Donnell et al., 2008), is difficult to find. This does not vary much in studies about other minorities. It seems that heterogeneity in a minority group is missed, paying attention to the majority and the minority gap. However, identifying the difference within disabled people by socio-economic status is also a way to demonstrate that disabled people can be healthy. It can present that health status can be enhanced through material resources and social support. Therefore, it would be quite significant to do a study that was not yet conducted – to measure

health inequality with a single index; to focus on the health inequality among disabled people in the healthcare service. This study will try to fill a gap in former studies.

1.4 Summary

In this chapter, the basic concepts and related previous studies about disability and health inequality were examined. Based on the social model of disability, which focuses on identifying the disabling barriers, this chapter put emphasis on the legitimacy to mention impairment and its impact on the health of disabled people. Sen's approach and ICF framework, which is useful to view the health inequality of disabled people from a social structural perspective, was presented. Through the basic conceptualisation and related discussions of health inequality and social determinants of health, it was identified that health inequality is not only a result of socio-economic equality but also a cause intensifying it. Finally, with a mention that there was bias in former studies about their health and health inequality, although disabled people were regarded as representative minority group, I found the significance of this thesis. The conceptual foundation of this chapter will provide useful information for a deeper understanding of this study.

Chapter 2 Contextual background and disability policy of South Korea

This chapter aims to describe the contextual background in which this study took place: contemporary South Korea society and, specifically South Korea policies related to disability welfare and healthcare. This chapter consists of two parts. The first part provides an overview of the recent history and culture of South Korea. To get an overall idea about the context in which social policy emerged in South Korea, and its status as a welfare state in welfare regime theory. A brief history of South Korea will then be presented, focusing on the situation after World War II. Finally, the societal attitudes toward disabled people and family culture, which significantly affect disabled populations' social care, will be examined.

The second part of this chapter reviews disability and health-related policies in South Korea. These include social policies for disabled people, such as cash benefits, social care services, anti-discrimination policies, and active labour market policies. Health policies reviewed are those related to delivering healthcare services and health promotion provided by the National Health Insurance programme. This comprehensive background will contribute to a better understanding of the health inequality experienced by disabled people in South Korea.

2.1 Contextual background of South Korea

In this section, a brief history of South Korea and its characteristics as a welfare state will be reviewed to understand South Korea society.

2.1.1 Welfare regime in South Korea

South Korea joined the group of welfare states very late compared to the advanced countries in the West. Many researchers regarded the formation of welfare state or a great transition of welfare in South Korea as around 2000 when the National Basic Living Security programme was introduced as public assist after the social insurance programmes established in the 1960-1990s (Kim, 2009; Yang, 2005) (see section 2.2.1). Though social expenditure of South Korea remains still at the lowest level (11.1% of GDP as of 2018) among OECD countries (average 20.1% of GDP as of 2018) (OECD statistics, 2018), there is an established welfare provision that currently operates supported by legislation, although it does not offer comprehensive welfare cover for all populations and specifically disabled people.

A welfare regime is a combination and interdependence of government, market, and family, which are the main providers of the production and distribution of welfare (Esping-Andersen, 1999). The theory on establishment and characteristics of welfare regimes is useful for finding out the identity of a society distinguished from others based on its history and systematised structure (Yeo et al., 2016).

The most well-known typology of welfare states was introduced by Esping-Andersen (1990), who suggested three welfare regimes as liberal, conservative, and social democratic types by analysing data from 18 European countries. His regime theory has been advocated and widely criticised (Bahle, 2003; Munday, 2003; Bonoli, 1997; Anttonen and Sipila, 1996), and many researchers have proposed alternative welfare regime theories. Critiques of Esping-Andersen's work criticised the invalidity of indicators (Munday, 2003; Hudson and Kühner, 2009) or the absence of gender perspective (O'Connor et al., 1999; Sainsbury, 1999; O'Connor, 1993; Orloff, 1993; Lewis, 1992). Equally important, the number of countries

included in the analysis were so limited that his regime theory was not appropriate for explaining countries in Southern Europe, Antipodes, and East Asia (Trifiletti, 1999; Bonoli, 1997; Ferrera, 1996; Leibfried, 1993).

In particular, the East Asian countries which South Korea belongs to were generally considered so unique that they could not be categorised into these three typologies. Other scholars have categorised East Asian welfare regimes. For example, Esping-Andersen (1997) categorised Japan as a hybrid welfare regime combining conservatism and liberalism and argued that other East Asia countries shared this characteristic (Esping-Andersen, 1999). Jones (1993) analysed the welfare system of Japan, South Korea, Hong Kong, Taiwan, and Singapore and argued that these states should be classified as the “Confucian welfare state.” He regarded these states’ characteristics as putting the community ahead of the individuals by following a strong Confucian tradition and, as a consequence, relying on the substitution of the role of a welfare state by family and community. Holliday (2005, 2000) named welfare regimes of East Asia countries as “productivist welfare capitalism,” explaining that they are characterised by the existence of interventionist states under strong growthism, and the introduction of welfare policy was aimed at promoting economic growth.

However, criticism about this “unique East Asian welfare regime” was not scarce. Takegawa (2005) argued that there is a risk of falling into welfare orientalism to pay excessive attention to cultural aspects and emphasise only the difference from the Western countries. Kim (2011c) argued that an emphasis on the exceptionality of East Asian countries is based on the premise that it is very difficult or impossible to establish a welfare state like the West in East Asia, and even if a state welfare system develops in East Asia, it would be very different from that of the West. Kim (2011c) also stated that East Asian countries already had a considerable welfare system generalised in the West; thus, the emphasis on the exceptionality of East Asia might be insignificant.

In this context, when it comes to the characteristics of the Korean welfare state, some studies using Esping-Andersen's regime framework considered South Korea as a liberal state (Baek and Ahn, 2009; Cho, 2000), a combination of liberalism and conservatism with a strong inclination toward conservatism (Nam, 2002). Others argued that South Korea belonged to the Confucian welfare state (Hong, 1999), "developmentalism welfare regime" (Kwon, 2002; Chung, 2002) or East Asia welfare regime (Shim, 2004). This categorisation reflects the characteristics of the Confucian state and the growthism of South Korea. In recent studies, the similarities between East Asia and Southern European countries have been highlighted. Kim (2013c) argued that the South Korean welfare regime shares Southern European characteristics such as insecurity and segmentation of labour market structure, and rapid ageing due to the low birth rate. Other characteristics such as segmentation and stratification of social security, and emphasis on the family responsibility in social care, are also presented in South Korea. Yang and Choi (2014) thought that although South Korea could be considered an outlier belonging nowhere, it was closest to Southern Europe regimes, but it also had some liberalism attributes. Yoon (2014) concluded that although the family culture of South Korea was evolving, it still shared some similar traits with Greece, Portugal, Italy, and Spain.

In summary, there are notable characteristics that distinguish South Korea's welfare regime from other countries, such as the state's weak role in providing welfare and the high reliance on family support due to the Confucian culture. There is a social class system that is considerably stratified, and the labour market is segmented. In section 2.1.2 and 2.1.3, these particular features and cultural context will be analysed in detail.

2.1.2 General factors and historical background of South Korea

A brief overview of South Korea will be addressed by identifying its location, area, population, economic indicators, and its major historical events and consequent transformations.

2.1.2.1 Brief overview of South Korea

Korea peninsula is located in the eastern end of the Asian continent, between China and Japan. The area of South Korea is 99,720 km² (about the size of Portugal or Hungary), and the current population is over 51,784 thousand as of March 2018 (Ministry of the Interior and Safety, 2018).

Politically, South Korea adopted the form of a Democratic Republic. However, because it is a divided state in a military conflict and tension, its military power is at the highest level globally, and there is compulsory military service for all male citizens between the ages of 18 and 35 for two years. In 2017, the IMF estimated GDP per capita of South Korea as 30.92 thousand USD. While in the same period, the UK's value was 40.03 thousand USD (International Monetary Fund; IMF, 2017b). The Gross National Debt to GDP was 38.3% in 2016, while the UK figure in the same period was 89.3% (IMF, 2017a). About 56% of South Koreans do not have any religion, according to the 2015 Census. Christians account for 27.6% of the population (of which are Protestants 19.7% and Catholics 7.9%), and Buddhists are 15.5% (Korean Statistical Information Service, 2018). However, there is a strong Confucian tradition in South Korea, and Korean shamanism also has its influences. The Confucian tradition is one of the most crucial factors to understand South Korea and greatly affects

South Korean society's care and family culture (Kim, 2005a; Lee, 2004b; Chang, 2003). It will be addressed in section 2.2.3. In this section, general factors and a very brief history of South Korea will be presented.

2.1.2.2 Historical background before the liberation

The establishment of the first tribe nation of the Korean peninsula was recorded as 2333 BC in the old Korean history book "Samgukyusa (Heritage of Three States)." Based on this record, the history of Korea is estimated at around 5,000 years. However, ancient history before the Joseon dynasty (1392-1910), which was the last dynasty of Korea, colonised by Japanese imperialism, is not within the scope of this study. Thus it is not be presented in this chapter.

In 1392, the former Goryeo dynasty was replaced with the Joseon dynasty. In Joseon's early times, Buddhism, introduced in the 4th century and flourished throughout the Goryeo dynasty, was widespread. However, in the 15th century, the Joseon dynasty adopted Confucianism as a ruling ideology and revered Confucianism while oppressing Buddhism. The Confucian culture, which emphasises courtesy and social order, became situated deep in Korea's general culture. The impact of Confucian culture on the attitude toward disabled people and care and family culture will be dealt with in detail under 2.2.4.

The Joseon Dynasty lasted about 500 years. Retaining the traditional lifestyle under the East Asian cultural sphere as an independent dynasty until the late 19th century, Korea was colonised by Japanese imperialism in 1910, and it lasted for 36 years (1910-1945). Because Korea was divided into North and South in 1948, there was only one Korea before then. While it is regarded that Korea began its autonomous modernisation from the late 19th

century, the pre-colonial period (Ko, 2009; Jung, 1999), there was a forced harsh modernisation under Japanese imperialism in succession. Japan, which succeeded in accepting the western culture and the earliest modernisation in East Asia, was armed with militarism and invaded neighbouring countries by force, and Joseon became its colony. After World War II, in 1945, Korea was liberated with the defeat of Japanese imperialism. Japan's defeat freed Korea from its rule, but an argument between the United States and the Soviet Union left a bittersweet liberation. A conflict between powerful nations due to the ideology divided a newly independent country into two governments. Almost right after the liberation, it was dragged into a world power struggle and ideological conflict (Lee, 2008). The capitalist United States and the socialist USSR (Union of Soviet Socialist Republics, current Russia), which defeated Japanese Imperialism, tried to strengthen their control in liberated Korea. As a result, Korea was divided into two governments and underwent a civil war (1950-1953). Since then, two Korean governments - North Korea (Democratic People's Republic of Korea) as a socialist regime and South Korea (Republic of Korea) as a capitalist regime - have developed thus far.

2.1.2.3 Socio-economic transformation after liberation

Under the colonisation, Korea was forced to modernise and experienced exploitation and oppression. It was divided, made a civil war, and suffered from dictatorship under the authoritarian government. These characteristics of the South Korean society for the past seven decades after liberation can be summarised into three features (Lee, 2014a). i) gradual development of democracy, ii) rapid economic growth, and iii) divided regime. The divided regime will not be treated here in detail because it goes beyond this study's bounds.

Development of democracy

The democracy of South Korea did not formalise institutionally until the 1980s. Right after the liberation, Korea was swayed by the world power struggle and ideological conflict of the Western powers that defeated Japan (Lee, 2008). Also, within the autonomous national liberation movement during the Japanese colonial era, the forces dependent on the United States or Russia were formed and ideological conflicts were emerging (Park, 2015a; Park, 2014a). The sharp confrontation between capitalism and socialism attempted to seize hegemony in the Korean peninsula; thus, the conflict and tensions in the Korean peninsula were similar to a proxy war of the Western powers. As a result, the separated governments were established in South and North in 1948, respectively (Park, 2015a; Kang, 2006).

Even after the liberation from Japanese imperialism, the pro-Japanese group remained dominant in Korean society. They had learned modern knowledge and skills and could take leadership position even in a liberated country (Lee, 2004a; Kim, 2002c). Then, the United States that had the greatest impact on South Korea society after the liberation, supported the pro-Japanese group in the name of stability and security (Kang, 1993; Lim, 1991). Since North Korea, which established the socialist regime, was more active in purging the pro-Japanese group than South Korea, the claim to clear the pro-Japanese group was regarded as North Korea and socialism-friendly assertion and suppressed in the name of anti-communism and anti-North Korea (Park, 2015a; Lee, 2014a). Even though there is a refutation that it is an excessive claim in a present period (Kim, 2012c), it is generally agreed that the division- the antagonism to socialist North Korea and the military tension- offers an excuse to suppress the demand for the expansion of the welfare system as socialist argument close to North Korea (Yoon, 2015; Kim, 2012a). The fear of military attacks by North Korea created an atmosphere that emphasises security rather than peace in South Korea, and this is one of the

reasons why establishing a reform-minded government is not easy in South Korea (Chung, 2003; Cho, 1998).

In 1948, Syngman Rhee, who had been a national liberation movement activist, was elected as the first president and established the government South Korea alone. He was a pro-United States conservative politician and confronted North Korea severely rather than tried to reconcile or make peace. Rhee was re-elected two more times and wielded dictatorial power, but finally, in 1960, after a blatant and large-scaled rigged election to extend his dictatorship, he resigned at the end of the strong protest against the unfair election and his autocracy (Park, 2015a). The next year in May 1961, the military took power through a military coup, and Chung-hee Park (father of the past president Geun-hye Park), who led the coup (then military rank was major general), became president. For the next 18 years, Park had maintained the position of supreme power in South Korea (1961-1979). During that time, the freedom of thoughts, speech, and expression was repressed severely, and the labour and the pro-democracy movement were persecuted harshly (Park, 2008; Kim, 1995). In 1972, Park amended the Constitution to concentrate all the power to the president and elect the president in the National Conference of Unification, composed of 2,000-5,000 representatives. Furthermore, the amended Constitution authorised the president to recommend one-third of National Assembly members and dissolve the National Assembly. This is called the “Yusin Constitution”. Park, settled the legal device of lifetime ruling by Yusin Constitution, was assassinated by his subordinate in October 1979. The opinions of Park are extremely divided. Some estimated that the Yusin regime was a regression losing an opportunity of a virtuous circle of peace and democracy, economic growth, and welfare development (Lee, 2015a). Though, some acknowledged that the economic growth during Park’s rule was his greatest achievement. However, the economic growth he led made light and shade of the Korean economy simultaneously. His economic policy made the structure of the economy fragile

(Kim and Park, 2005). As noted above, any criticism against the president is prohibited, and basic civil freedom like speech, press, association, and thoughts, were all oppressed very severely. The political manoeuvring was rampant, and the political opponents were denounced as spies or advocates of North Korea. Some of them were even executed.

After his death, the aspiration for democracy became fervent. However, in December 1979, during the interregnum of an absolute dictatorship, the new military power emerged again and took over the reigns, putting down the demand for democratisation by force such as the Gwangju democratic movement in May 1980. Then a general Doo-hwan Chun, who led a military coup and the armed repression of the democracy movement, was inaugurated as the new president of South Korea in September 1980. The new military power continued the anti-democratic dictatorship. After the dictatorship of seven years by the Chun regime (1980-1987), people gained a direct presidential election system in July 1987 through a large-scaled citizen uprising; an extensive and popular social action that progressed on national level. Nonetheless, despite the longing for democracy, the former army general Tae-woo Roh, a de facto successor of Chun, was elected in the next presidential election held in December 1987. This means that the new military power, driven out by the massive citizen resistance, was reinstated through an election. This event was due to the division of opposition candidates who led the pro-democracy movement (Chung, 2003; Park, 1998). Two influential leaders (Young-sam Kim and Dae-jung Kim) who led the pro-democracy movement, ran as candidates respectively and failed to get the necessary votes for the election due to the split of supporters. Each of them was elected as the next and the following president in 1992 and 1997, respectively.

The civil government was established by finally electing Young-sam Kim, the former pro-democracy activist, as president in 1992 - even though he ran as the ruling party's candidate. Under the civilian government, many reforms were attempted. Political persecution has been

relatively alleviated, but the oppression of the labour movement and progressive politics still remained. The confrontation with North Korea was often used as a cause. After five years, South Korean people achieved a peaceful regime change through the victory of Dae-jung Kim, who was a candidate of the opposition party in the 1997 presidential election. It was the first ruling of the reformists. The reformist (1998-2008) and the conservative (2008-2017) government were in power for 10 years, respectively, and the reformist came back in 2017 as noted above.

It is regarded that the formal democratisation of South Korea has been gradually developed like the above, but the reality of division due to the ideology conflict still acts as an obstruction of complete freedom of thoughts and conscience.

Economic growth

The post-war economic growth of South Korea is characterised as “a compressed economic development,” which took only a few decades to achieve growth that takes centuries for most countries. South Korea’s high economic growth since the 1960s, also known as “a miracle of the Han river,” attracted the world’s attention (Chung, 1993). It was a highly planned economic policy driven by the government. For example, the GNP per capita in 1960 was 79 USD, while the GDP per capita recorded 30.92 thousand USD in 2017, as mentioned above. In 2014, the yearly output of automobiles was 4,520 thousand; it ranked fifth in the world. On the other hand, in 1955, the yearly output of automobiles was only seven. In 2013, 21.23 million GT (gross tonnage) of ships were constructed in South Korea, while in 1955, the figure was 2000 GT. It was considerably rapid growth, undoubtedly. However, the growing severe polarisation issue remained at the hidden side of this brilliant growth (Chung, 2015).

Immediately after the liberation of 1945, Korea had a fairly vulnerable economic fundamental (Park, 2015a; Lee, 2002a). As a result of domestic resources exploitation for World War II by Japanese imperialism, the economy had nearly crashed. The vacuum of the administration system right after the liberation aggravated this economic situation, collapsing the economic system. To make things worse, a civil war broke out (1950-1953). As the aftermath of the war, the ground of manufacturing business had collapsed, and the South Korean economy was surviving by foreign aid. The industrial structure was underdeveloped. In 1953, agriculture, forestry and fishery accounted for 48.2% of industrial production, while the service industry comprised 40.3% and manufacturing business accounted for only 7.8% (Chun, 1971). At that time, South Korea was regarded as one of the world's poorest countries. In the 1960s, the Park (Chung-Hee Park) regime coming into power by the coup was considered to contribute much to economic growth. His economic policy was based on strong statism and centralism, enabled by the powerful dictatorship, and it was called "anti-communist developmentalism" because it followed the anti-communism thoroughly under the divided regime (Yoon, 2015). His economic strategy is characterised by an imbalanced growth strategy centred on industrialisation and an outward-oriented growth strategy centred on exports. The "five-year economic development plan", led by the government, had such a feature (Park, 2009). The first five-year economic development plan was implemented in the early 1960s, and after then, it was designed and implemented every five years until 1996. The first plan was a kind of opportunity for the structural transformation of economy. Because there was insufficient domestic demand, South Korean economy had developed based on the export industry. Most of the exports were rice, fish and non-iron ore until then, but the labour-intensive items such as clothing, textile, and shoes began to be produced and exported increasingly (Kim, 2011a).

From the mid-1960s to the early 1970s, the South Korea government dispatched mine workers and nurses to West Germany. In exchange, Korea acquired a loan from West Germany, and this became the seed capital of economic development. In the 1970s, the foundation of industrialisation was established. For instance, a petrochemical complex and steel mill were founded in 1972 and 1974, respectively. Even electronic devices and steel plank began to be exported. The quality of products was not high then; however, the low price due to the low wages was a very competitive factor. As a result, South Korea posted a trade of USD ten billion in 1974 (Kim, 2011a).

The mid-1970s was an apotheosis of the textile export industry. The main exports in 1975 were clothing (22.3%), fishery (6.3%), artificial fibre textile (5.4%) and so forth. However, the proportion of the textile industry went down gradually. Instead, items such as ships, electronic image devices, automobiles, and semiconductor replaced it (Kim, 1993). In the 1980s, the export market became diversified by introducing advanced techniques and continuing investment in the large-scale facilities. The construction boom of the Middle East was a favourable factor too. A chronic trade deficit turned into profit-making in 1986 for the first time (3.1 billion USD), and in 1988, trade had grown to 100 billion USD (Kim, 1993). In the 1990s, the former exports like clothing declined, and semiconductors, computers, automobiles, ships, and petroleum products became the main product of Korean export. As a result of continuous economic growth, South Korea could join the Organisation for Economic Cooperation and Development (OECD) in 1996. However, one year after, the Asian financial crisis in 1997 hit the Korean economy very severely. Foreign exchange reserves of South Korea fell below the minimum (20 billion USD), domestic currency value collapsed; therefore, the KRW-USD exchange rate soared, and Korea Composite Stock Price Index (KOSPI) was plummeted from over 800 to 330 (December 1997). South Korea called a relief loan from the International Monetary Fund (IMF).

The economic crisis of this period was considerably serious. From that time, the economy of South Korea continuing rapid growth began to enter a new phase, different from the previous one. Large companies executed restructuring and discharged their workers on a large scale. Small and medium-sized businesses bankrupted successively, and unemployment has increased exponentially. Before the financial crisis in December 1997, it was 2.6%, but in February 1999, it increased up to 6.3% (Statistics Korea, 2018a). Numbers of families were disrupted due to economic problems, and the number of homeless was surging at this time also. Finally, after four years, in 2001, Korea government cleared the 19.5 billion USD relief loan. However, the suffering of this time influenced the whole South Korean society very strongly ever since. The IMF-led neo-liberal economic trend had been kept on, so the corporate restructuring and privatisation of public enterprises continued (Kang and Lee, 2011; Yoon, 2009). The family dissolution and massive homelessness due to the mounting unemployment drove the need to arrange social policies (Shin, 2008; Ahn, 1999)

In the 2000s, the main industry of South Korea became information communication technology (IT). In the mobile phone market, world-class products like Samsung Galaxy began to be produced. The cultural contents and entertainment industry aimed at the global market is also developing rapidly these days. However, socio-economic polarisation has been getting worse since the Asian financial crisis (Kim, 2013b). In 2014, the proportion of temporary employees in South Korea ran to 22.5%. This figure is 10% p higher than the OECD average. In 2002, the wage of non-regular employees was 67.1% of regular employees, but it decreased to 55.8% in 2014. The wage gap between large and small-medium sized companies is also growing. In 2014, the ratio of the small-medium sized company to large-scale company was 100 to 174 (Chung, 2015).

With low fertility and ageing issue, this socio-economic polarisation is emerging as the most crucial and urgent issue that must be approached as a social policy. The low fertility and the

ageing issue will be reviewed within a section about family culture and South Korean families' transformation.

2.1.3 An overview of care, family culture and Confucian traditions in Korea

This section will explore the family tradition of South Korea, which is deeply related to the Confucian culture embedded in South Korean care culture. "Care" is often referred to when the topic of disability is discussed. According to the South Korea National Survey on Disabled People in 2014, 32.2% of disabled people need others' care for their daily living (partly or mostly). Among the care-needed respondents, 85.3% are looked after by others such as their spouses (37.7%), parent (20.1%), and child (16.7%), meaning that almost three quarters of caregiving to disabled people is provided by family members (Kim et al., 2014a: 260-261). The high proportion of family caregivers is relevant to the strong family culture pervasive deeply in South Korea.

Lee (2004b) stated that the major family cultures of South Korea are family centrism and expanded familism. The "family centrism" is to place the family at the core of all values, and "expanded familism" is to regard all social relations as family relations. Family centrism is acknowledged to be influenced by Confucianism (Son, 2006; Kim, 2005a; Seo, 1995). Confucianism, based on the lesson of Confucius and Mencius, developed in the 6th century BC in China and flowed into Korea in the 4th century, is basically about the moral ways of living and harmonious relationships (Kim, 2011b). Fidelity and filial piety are the ultimate social virtues, and ancestor worship is encouraged. It is embedded by a foundation of beliefs, values, and traditions that influence contemporary South Korean society. Confucian ideals lay in harmony beyond the conflict between the private and public sphere by expanding

affection from one's family to the whole society (Kim, 2002a). However, "Rai (禮) (courtesy)," the norms and standards of social order and behaviour in Confucianism, is based on hierarchy and emphasises differences. This has encouraged criticism of Confucianism because it can be seen as justifying authoritarianism and patriarchy (Kim, 2005a), further, it obscures deliberately or inadvertently the processes of exclusion and stratification, which affects attitudes toward disabled people as will be explained later on.

Family norms are also heavily influenced by Confucianism (Ham, 2014; Choi et al., 2011; Kong, 2008). The basic ethical principle of Confucianism - "Samgangoryun (三綱五倫)" (the Three Bonds and Five Relationships) specifies duties "between parents and children," "between husband and wife," and "between sovereign and vassal" as the most important three bonds in social relationships. The father is considered the centre of the family, and the gender-role stereotype is formed very strongly, so the mother's main job is to give birth to a son to carry on the family line and care for family members. The hierarchy between male and female is quite firm, so to women, fidelity and obedience to the patriarchal order are demanded.

Confucianism was indeed abused to justify the dictatorship's oppression and the authoritarian government, being glossed over as "Korean-style democracy" stressing order and allegiance to country (Lee, 2013d; Chung, 1999). During the Korean civil war and the authoritarian political regime period, the family had to care for their members themselves and nurture children as "human resources" to serve the state without any government support. It was women, especially as mothers, who took responsibility for it (Yoon, 2012). The situation has not much changed so far when it comes to care, thus the responsibility to care for family members is still assigned to women primarily, and contemporary South Korea society still operates on a male- father centred patriarchal family culture model (Shim, 2005).

Under the influence of these traditional values and a weak/scarce welfare system, caring for the family members was considered as women's job, and therefore the informal and unpaid care job of women had a great role in the country for decades. This was improved in the late 2000s when caregiving was institutionalised as a public programme explained later on.

A transition first appeared in the family structure. The continuing decrease in marriage rates and birth rates, increase in divorce rates, single-parent families, and single-person household (Korean Statistical Information Service, 2015) means the decline of traditional family structure. The patriarchal culture and strong gender role stereotypes have diminished (Paik, 2009), and the family function of economic production, welfare, and care which have been emphasised for a long time, got reduced. Also, family networks and intergenerational solidarity based on the paternal line have diminished (Choi et al., 2011).

Nowadays, with the families' role in transition, their role as caregivers is being weakened (Kong, 2008). As a part of Confucian filial piety, the primary target of care in South Korea was the elderly (Kong, 2008). For a long time, elderly care had been carried out by family members without any support from the government, and it was only in 2007 that the South Korean government introduced a new social care system to lighten the care burden of family members (the Long-Term Care Insurance and the Personal Assistance Service). This slightly decreased traditional family care and care for some, but the quantity of social care provided or funded by the state is still quite limited, so the continuous development of a social care system is required.

2.1.4 Disabled people in South Korea

Thus far, the political, economic, and family cultural backgrounds of South Korea were described. In this section, how this impacts societal attitudes toward disabled people will be examined.

2.1.4.1 Traditional attitude toward disabled people

Public perception of disabled people in South Korea is illustrated by the condensed word “Byung-shin (病身)”, which refers to a disabled person. “Byung (病)” means disease or defect, and “Shin (身)” means body. Although the meaning itself seems neutral, it has been used as vulgarism and a very offensive, pejorative word that can be used as an insult. It is unclear since when this term was used as an insult, but in a modern society, the word “Byung-shin” is definitely used in a derogatory way. Even when it is not addressed at a disabled person, it is often used to express disgust towards someone else. Sometimes it is used to express self-mocking or to ridicule themselves by disabled people. As in western society (Linton, 2006), the long-standing South Korea perspective on disabled people was of “contempt.” Researchers have argued that this notion came from the traditional Korean culture such as Confucianism, Buddhism, or shamanism (Hwang and Brandon, 2012; Jung, 2003; Hong, 1997; Lee, 1981). Along with this, the colonial experience, the blind pursuit of economic growth under the divided regime (capitalism of South Korea vs. socialism of North Korea), and militarism are also considered to have influenced societal perspectives on disabled people in South Korea (Jung, 2003).

Lee (1981) reviewed traditional terms used to refer to disabled people, old sayings related to disability, historical records, and literary works containing expressions related to disability, and he concluded that disabled people were treated with “contempt” by others, which cause a “sense of inferiority.” In other words, people held disabled people in contempt, who had a sense of inferiority. He suggested five reasons for forming such perspectives focusing on the difference between western society and Korea (not divided South Korea but Korea before its division). These are i) orientation to homogeneous human. Koreans prefer homogeneity and exclude heterogeneity, and this is why difference itself cannot be celebrated. Hwang and Brandon (2012) proposed a similar explanation referring to the term “Ijil (異質)” which means difference. In a “society that attaches such a high value to sameness and seeks blame of difference” (Grinker, 2008: 239), to be different can give rise to the sense of hatred. ii) Intention to completeness. Lee (1981) noted that Koreans tend to focus more on one’s minor flaw than his/her merits, which would make disabled people “incomplete’ beings.” iii) Transportation of frustration means that social discontent is projected toward those with a social vulnerability like disabled people. iv) Lack of super-ego. The super-ego was considered by Weber (1904) as the conscience built through communion and identification with God, and therefore it was influenced by Western Christian culture. According to Lee (1981), those who have superegos are not swayed by secular factors but live by their own conscience. Such a tradition was not formed in Korea; therefore, Koreans tend to care too much about how others see them. This tendency was considered by Lee as the causes of inferiority feelings that disabled people have about themselves. v) Scarcity of traditional welfare systems. The absence of public welfare provision contributed to disabled people’s perception as a burden to their families. Lee’s analysis seems to focus on psychological explanations and implies the self-deprecation of Korean. However, as reflected in

considerable literature (Goodley, 2011; Barnes and Mercer, 2010, 2003; Bogdan, 1996; Garland, 1995), contempt for disabled people in a traditional society is found globally.

Like Lee (1981), Hwang and Brandon (2012) also pointed out the long-lasting negative perspective on disabled people and connected it with the shamanistic thoughts of traditional society such as divination based on topography. Disability was believed to result from the geomantic system that evaluates various features of land, mountain and water, and then connects them to human fortune/misfortune, peace/calamity and advancement/decline. This belief linked disability with the choice of sites for graves and houses, sins committed in a previous life, the fault of an ancestor, or a wicked ghost (Hwang and Brandon, 2012; Kim and Kang, 2003; Kwon, 2000). These beliefs seem to be similar to Western societies' moral views of disability as a consequence sin (Goodley, 2011). In traditional society, disabled people's existence was also regarded as a dishonour to the family and the community. Hwang and Brandon (2012) used the word "chemyon (體面)" (social face) to explain that to have an impairment brought shame and humiliation to the whole family. Choi (1997) analysed the way disabled people were portrayed in swear words, folktales, proverbs, "gut" (exorcism), and classical novels to conclude that people responded to disability as individual resignation, concealment and protection of family members, and support of the state for a long time. Jung (2003) divided the attitudes toward disabled people of traditional society by whether the impairment is innate or acquired. In the cases of innate impairment, the concept of "Eob (業)" (karma) in Buddhism wielded strong influence. In numerous cases, mothers who gave birth to impaired babies were blamed for the birth of babies. However, in the cases where impairment have occurred due to disease or accident, the major societal response was of sympathy.

2.1.4.2 Modern South Korea society and perceptions of disability

In modern South Korea society, disabled people have been used as literary devices to describe hopeless existence under repressed circumstances. For example, during the Japanese colonialism era, disabled people often appeared in Korean literature. Choi (2001) explained this phenomenon as “a psychological projection of resistance and disablement which shared by character and author as historical existence,” claiming that it reproduced the contextual conditions of the time, including the contradiction of colonial capitalism, urbanisation, industrialisation, and underlying feudalistic thinking. Repression and literary disablement were related, and internal and external censorship was illustrated through disabled characters.

Even though the war broken out by Japan contributed to South Korea’s welfare system by building support plans for the war veterans, the classification of citizens by their availability to support the war, reinforced the stereotype that disabled people are worthless (Jung, 2003). These perceptions remained unchanged after the liberation from the Japanese occupation, and disabled people remained excluded from mainstream society. For example, after liberation, the “Report on disabled children in South Korea” was published in 1961 by the Ministry of Health and Social Affairs (current Ministry of Health and Welfare) and the Korean Committee on the Welfare for the Children. In this report, illegitimate and mixed-race children were included in the category of disabled children. This categorisation and aggregation of different vulnerable groups illustrate social construction on disability in South Korea. Within this illusion of a single-race nation, mixed-race children were considered disabled. So did children out of wedlock mixing moral values of “worth” with impairment.

In the 1980s, with the government’s establishment of disability policies and development of disability rights movement, a campaign to change disability-related terminology was

launched by disability organisations (Jung, 2003). For example, the Research Institute of the Differently Abled Persons Right in Korea (RIDRIK), established in 1987, proposed to use the word “Jangaewoo (障礙友)” to refer to disabled people. “Jangae (障礙)” means “disability” and “woo (友)” means “friend.” Thus “Jangaewoo” means “disabled friend” and it was an attempt to change disability perception by announcing that “disabled people are friends of all of us.” At that time, when the terms referring to disabled people were framed by despising and contempt, suggesting using the term “disabled friend” was an innovative and brave step. However, this word has fundamental limitations. First, the word “friend” cannot be used in the first person. Disabled people themselves cannot say “I am a disabled friend” and it reinforces the “otherness” in disabled people. Second, in the Confucian culture, friendship is usually formed within peer age groups. Even if two people are very close and deeply trust each other, they are not called friends if they are not similar ages. Also, people do not regard someone as a friend based on their physical/mental functioning. In addition, the word “Jangaewoo” ignores the diversity of disabled people and presents a homogeneous portrait of disabled people. In summary, “Jangaewoo” is one example of “nice words” that Linton (2006) identified as looking plausible but reflecting and reproducing prejudice against disabled people.

In contemporary South Korea, the study on disability-related terminology has not been as abundant as in the English-speaking world. Although campaigns for suppressing “nasty words” (Linton, 2006) and the issue on the discriminatory expressions have been continuously raised, deliberation on alternative terms has been scarce. Jung (2003) argued that this is because the concepts of disability rights and social disability were transferred from abroad rather than emerging internally. He mentioned that the history of the South Korea disability rights movement is very short and fragile internally. Consequently, the service-oriented perspective on disabled people embeds policies and practices (Jung, 2003: 56). The

disability rights movement in South Korea, however, has grown to the extent where it led a change of policy (see section 2.3) (Legislation of Disability Discrimination Act 2007, Mobility Facilities Promotion for the Mobility Vulnerable Act 2005); thus, it is expected that debate and consideration for disability will develop further.

Thus far, the contextual background of South Korea and the perception of disabled people in traditional and modern society were investigated. How disability policy in South Korea was built up through this process will be examined in section 2.2.

2.2 Disability related policies in South Korea

In this section, public policies for disabled people in South Korea will be investigated. It includes a wide range of social policies such as social insurance, public assistance, and social service.

2.2.1 Brief history of South Korean disability policy

Policies and legislation for disabled people were scarce until the 1960s (Jung et al., 2012; Kim and Yu, 2001). However, with the development of the economy and democracy, social policy, including disability policy, emerged with modern welfare systems such as public assistance and social insurance. Kim and Lee (2012) divided the development of disability policies in South Korea from the 1960s into five historical phases (See box 2.1).

[Box 2.1] Five phases of development of disability policies in South Korea

1. Residential care era (1961~1976)
2. Education and Training era (1977~1988)
3. Restricted economic support era (1989~1997)
4. Restricted social support era (1998~2006)
5. Fragmentary expansion of economic and social support (2007~)

The “residential care era” started with the enactment of the Livelihood Protection Act 1961, acknowledged as the first intervention of the South Korean government for disabled people. It was abolished in 1999 and replaced by the modernised and improved the National Basic Living Security Act 1999. The purpose of the Livelihood Protection Act of 1961 was to protect people without working ability, and the main target of this law included disabled people with income below a national standard (Kim and Lee, 2012). Rehabilitation institutions emphasised accommodation and care rather than rehabilitation (Kim and Yu, 2001). During this phase, disabled people’s care was mostly carried out by private charities and focused on large scale residential institutions (Jung et al., 2012; Kim and Lee, 2012; Kim and Yu, 2001). Most of them were in poor condition and were oppressive to their residents (Kim, 2007a; Kim, 2007b). In summary, in the 1960s, the disability policy was framed under institutionalisation and protection.

The “education and training era” began in 1977 when the Special Education Promotion Act 1977 (abolished in 2007 and replaced with the renewed Special Education for disabled people and others Act 2007) was enacted. This started special education and training for disabled people as a result of improved awareness that “disabled people can learn and work” (Choi

and Lee, 2013). Influenced by increasing interest in global movements (1971 UN Declaration of the Rights of Mentally Retarded Persons, 1975 UN Declaration of the Rights of Disabled Persons, 1981 The International Year of Disabled Persons), rudimentary policies began to be established in this period (Jung et al., 2012; Lee and Park, 2012; Shin and Lee, 2009). It is assumed that being the host of the 1988 Seoul Paralympic also promoted the establishments of policies that could portray a global image that the government had improved the overall living conditions of disabled people, including those in residential institutions (Kim and Lee, 2012; Kim, 2007a; Kim, 2007b). In 1981, the Welfare for the Physically and Mentally Handicapped Act 1981 (amended as the Welfare for Disabled People Act in 1989) was enacted, and in the following year, a job placement programme by Rehabilitation International (RI) South Korea was started as a vocational rehabilitation service (Kim and Lee, 2012; Lee and Park, 2012; Kim and Yu, 2001). (The RI, also known as RI global, is an international organisation empowering disabled people and RI Korea is its regional organisation in South Korea). However, these programmes were significantly limited in resources and the amount of services available were insufficient to cope with the needs of disabled people (Lee and Park, 2012). Equally important, this legislation continued to frame disability at the individual level without acknowledging the role of societal approaches to disabled citizens.

The third phase, called “restricted economic support era,” started from the amendment of the Welfare for Disabled People Act 1989. In this phase, regular and direct cash benefits were provided to disabled people, although the amount was inadequate, and a disability registration system was established. The law for the promotion of disabled people’s employment was also enacted in this period (Employment Promotion for the Disabled People Act 1991). This law adopted the Employment Quota system for disabled people requiring companies with more than 300 employees to have disabled people make up more than 2% of the company’s

workforce (Lee, 2013b; Lee and Na, 2011; Ryu et al., 2011). From then on, disability issues began to be recognised as a social problem by the active movements of disability organisations (Kim and Lee, 2012; Kim, 2007a; Kim, 2007b).

Nevertheless, in this phase, the focus of disability policy was the rehabilitation model, which aims to develop disabled people's the potential in physical, psychological, social, and vocational terms so that they live normal lives (Kim and Yu, 2001). This model is very close to "normalisation," which establishes services designed to "adapt disabled individuals to the non-disabled world"(Drake, 1999: 54). It is criticised because disability is still regarded as a target of treatment, and then disabled people are reduced to perform the role of patients (DeJong, 1979). In the 1990s, community-based institutions such as welfare centres for disabled people focusing on the staff interventions and practices grown rapidly (Kim and Lee, 2012) and reproduced the rehabilitation discourse. In this phase, the social model of disability, which regards disability as social oppression, was not broadly spread. However, this phase's greatest outcome is considered the definition of beneficiaries of the disability policies and the significant growth in public supports for disabled people (Kim and Lee, 2012).

The fourth phase, "restricted social support era," began in 1998 with the declaration of the "Constitution on the Rights of Persons with Disabilities in South Korea 1998." Although this constitution was non-binding, it reflected the increase of the awareness of disabled people (Lee and Park, 2012). Various actions for the social environment (expansion of facilities and accommodations, accessibility, and mobility) took place. Rather than large scale residential institutions in secluded areas, small scale local facilities became preferred in political terms (Kim and Lee, 2012; Lim, 2006). In this era, the philosophy of Independent Living (IL) was also introduced mainly to disabled activists, and as a result, the first centre for IL in South Korea was established in 2000 (Kim, 2009; Lee et al., 2007a; Lee et al., 2007b). Furthermore, when a tragic accident happened when a wheelchair user fell off a wheelchair lift and died at

the subway station in 2003, social activists conducted a campaign for accessibility and mobility of disabled people (Huh and Shin, 2011; Kim, 2002d). This social movement was led by disabled people organisations (Solidarity for the Mobility of Disabled People, 2015), and in 2005, the Mobility Facilities Promotion for the Mobility Vulnerable Act 2005 was enacted. In this period, the disability movement raising issues of oppression, abuse, and exploitation in residential institutions and multiple social barriers such as mobility and accessibility was vigorously active. In this way, the social model of disability framework became widespread in South Korea, and disabled activists played an active role.

The last “fragmentary expansion of economic and social support” phase began in 2007 when systematised social care services were adopted. The Personal Assistance Services (PAS) for disabled people began after a one-year’s pilot project (Ministry of Health and Welfare, 2015b) with a scale of 14,000 users and 7,000 personal assistants (Lee, 2010a: 144). Though this still represented insufficient support for the whole disabled population, it was undoubtedly a significant development in services to support disabled people (Kim and Lee, 2012; Kim et al., 2011b). Moreover, the enactment of the Disability Discrimination Act 2007 and the ratification of the UN Convention of Persons with Disabilities (CRPD) in 2008 are evaluated as a beginning point of the rights-based approach to disability (Lee and Park, 2012; Shin and Lee, 2009; Kim, 2008a). Furthermore, in the 2010s, the legal rights of disabled people were reinforced with the enactment of legislation for disabled children and people with learning disabilities. That is, during this period, the concept of IL and the social model from the late 1990s have continued to expand (Lee and Park, 2012; Lee et al., 2007a; Lee et al., 2007b).

To sum up, the disability policies in South Korea have transformed from segregation to integration, from the individual model to the social model, from rehabilitation to IL (Kim and Lee, 2012). However, according to Drake’s typology of disability policy approaches (Drake, 1999), South Korea has not yet reached the level of “welfare provision” or “rights and

citizenship.” For example, even when considering that the rise of the public welfare state in South Korea was late and most social security systems are limited (Won, 2014; Kim et al., 2010), the level of budget expenditure for disabled people is very low. In the year of 2011, when compared with the social expenditures of Organisation for Economic Cooperation and Development (OECD) countries with “Incapacity-related benefit,” the scale of expenditure of South Korea was 0.49% of GDP of that year, which is the lowest figure except for Turkey (0.28%) and Mexico (0.06%) (Korea Disabled people's Development Institute KODDI, 2016). It is even less than half of the OECD average (2.19%). Even though there has been some improvement in disability policy in recent years, the total amount of social resources for disabled people are still insufficient, and seamless services between the policies and life-course approaches are still inadequate. Social actions pursuing a more fundamental transformation of disability policy are continuing today.

2.2.2 Disability registration system

Disability registration is a system that allows the government to identify disabled people by setting the boundary of disabled people by law and registering them as disabled people. The South Korea disability registration system has significant meaning because the eligibility of services for disabled people are determined by this registration (Byun, 2008). That is, to be a disabled person regulated in the current Welfare for the Disabled People Act 2001, one must be registered. A formal registration is required to access welfare programmes such as cash benefits and vocational training.

As of 2020 there are 15 statutory disability types in South Korea. These can be categorised into 12 types of physical and 3 types of mental disabilities. Physical disabilities are classified

by external physical disabilities and internal organ disabilities. Body impairments are the standard of this classification (see Table 2.1).

[Table 2.1] Classification of disability type by Welfare for Disabled People Act

Large scale classification	Physical disabilities		Mental disabilities
Middle scale classification	External physical disabilities (6 types)	Internal organ disabilities (6 types)	(3 types)
Type	Disability of limbs	Kidney dysfunction	Mental disorder
	Disability of brain lesions	Cardiac dysfunction	Intellectual disorder
	Visual disability	Respiratory dysfunction	Autistic disorder
	Hearing disability	Liver dysfunction	
	Speech disability	Epilepsy	
	Facial disfigurement	Intestinal fistula/ Urinary fistula	

Source: Welfare for the Disabled People Act 2015

According to the severity of impairment, there were six grades of statutory disability in which a lower number means more severe disability as of 2018. For example, grade one was more severe than grade two. However, the grading system was abolished in July 2019. The main reason for abolition was the contention that it is not reasonable to divide disabled people into six grades and differentiate the social services according to this grade. Since August 2019, the division of severity of impairment was simplified into two categories- severe and mild, and comprehensive and individualised disability service assessment system was introduced as a needs assessment tool.

The disability registration system was adopted in 1989 with the amendment and renaming of the Welfare for the Physically and Mentally Handicapped Act 1981 as the Welfare for Disabled People Act 1989 (Kim and Lee, 2012; Park, 2005; Park, 1995). There were only

five types of disabilities (limbs, visual, hearing, speech, mental retardation¹) at that time. In 2000, due to the acceptance of the opinion that the range of disability is too narrow (Kwon, 1998; 1996; Park, 1994), types such as brain lesions, cardiac, kidney, development, and mental illness were added to the existing categories. In 2003, there was a second expansion of disability types, then respiratory dysfunction, liver dysfunction, facial disfigurement, intestinal fistula/ urinary fistula were admitted as new disability types (Byun et al., 2006b). After four years, in 2007, the names of two types of disabilities- mental retardation and developmental – were renamed as “intellectual disorder” and “autistic disorder” respectively (Kim and Lee, 2012).

The expansion of disability types aimed to advance disability policy by acknowledging more people like the disabled population. As the classification of disability in South Korea had been defined very narrowly compared to developed countries or states in similar economic conditions, before the expansion, mentally or internally disabled people were excluded from the welfare programmes (Byun, 2008; Byun et al., 2006b; Kwon, 1998). With the expansion of disability types, it seems that the rehabilitation and social integration of the disabled people and the equality of welfare was promoted. Henceforth, the long-term conditions such as dementia, chronic alcohol addiction, and cancer could be considered as types of disability (Byun et al., 2006b).

Statistics show there are 2,511,051 registered disabled people in South Korea as of December 2016 (Ministry of Health and Welfare, 2017: unpagged). It accounts for 4.9% of the entire population of the same period (51,696,216) (Ministry of the Interior and Safety, 2018: unpagged), but it is assumed that the real number is larger as many who would qualify are not registered (Kim et al., 2011; Byun et al., 2006b; Byun et al., 2001). For example, in the

¹ The term “mental retardation” is regarded as a derogatory expression of learning disability, but it is used in this text because it was a legal title at that point.

national survey on disabled people in 2014, the number of disabled people was estimated at 2,726,910 (Kim et al., 2014a: 5), and the estimated registration ratio was 91.7% (Kim et al., 2014a: 6). That is, 8.3% of the 2,726,910 were not registered as disabled people. In this survey, one-third of the reasons for the non-registration was “do not know how to register” (34.6%) and “do not think it would be useful to register” accounted for 21.2% (Kim et al., 2014a: 575). This implies that the accessibility to the registration process is not sufficient yet, and the current welfare benefits system for disabled people is not useful to some.

2.2.3 Cash benefit

The cash benefit programmes for disabled people are divided into three parts: Disability Benefit (for severely disabled adults (18+)), Disability Allowance (for mildly disabled adults), and the Allowance for Disabled Children. These cash benefits are not provided to all disabled people but given according to the income level. As of 2020, the Disability Benefit is given to people whose incomes are lower than the standard (for singles 1,220,000 KRW per month (793.26 GBP), for couples 1,952,000 KRW (1,269.22 GBP) per month (the bottom 70% of the income level of the whole population) (All exchange rate are as of September 2020), and the Disability Allowance and the Allowance for disabled children are provided to the people with below 50% of median income (Ministry of Health and Welfare, 2018b). The National Basic Living security (NBLS) benefit is not deducted due to these disability-related benefits, so the NBLS recipients take both if they have registered disabilities. The outlines of these three parts are as below.

[Table 2.2] Cash benefit for disabled people

(unit: per month)

Category	Eligibility	Supports
Disability Benefit	<ul style="list-style-type: none"> - Aged 18 or more - Registered, and severely disabled (grade 1-2, and grade 3 with multiple disabilities) - People whose income is and their spouse' are lower than the standard (for singles 1,220,000 KRW (793.26 GBP), for couples 1,952,000 KRW (1,272.40 GBP)) 	- See table below
Disability Allowance	<ul style="list-style-type: none"> - Aged 18 or more - Registered disabled people (grade 3-6) - Below 50% of median income 	<ul style="list-style-type: none"> - NBLS recipient and near poor group: 40,000 KRW (26.01 GBP) - Residential care recipient: 20,000 KRW (13.00 GBP)
Allowance for Disabled Children	<ul style="list-style-type: none"> - Aged below 18 - Registered, disabled children in households of NBLS recipient and near poor group (below 50% of median income) - Severely disabled (grade 1-2, and grade 3 with multiple disabilities)/ mildly disabled (grade 3-6) 	<ul style="list-style-type: none"> - NBLS/severely disabled: 200,000 KRW (130.04 GBP) - Near poor group/severely disabled: 150,000 KRW (97.53 GBP) - NBLS and near poor group/mildly disabled: 100,000 KRW (65.02 GBP) - Residential care/severely disabled: 70,000 KRW (45.52 GBP) - Residential care/mildly 20,000 KRW (13.00 GBP)

Source: Ministry of Health and Welfare (2020a)

Within these benefits, the largest part is the Disability Benefit which accounted for 28.4% (600.9 billion KRW (390.7 million GBP)) of the disability welfare budget of the Ministry of Health and Welfare (MOHW) in 2018 while the Disability Allowance and the Allowance for the Disabled Children constitute 12.3% (129.8 billion KRW (84.4 million GBP)) (Ministry of Health and Welfare, 2018b: 52-61). In 2018, cash benefits made up 34.5% of the budget for related disability welfare programmes in 2018.

[Table 2.3] Disability Benefit

(unit: per month. per person)

Income level	Age	Basic benefit		Additional benefit
		Single	Couple (for one person)	
Below 40% of median income	18-64	300,000 KRW (195.19 GBP)	240,000 KRW (156.15 GBP)	80,000 KRW (52.05 GBP)
	65+	-	-	380,000 KRW (274.24 GBP)
Below 40% of median income (residential care)	18-64	300,000 KRW	240,000 KRW	
	65+	-	-	70,000 KRW (45.54 GBP)
Below 50% of median income	18-64	Max. 300,000 KRW	Max. 240,000 KRW	70,000 KRW
	65+	-	-	70,000 KRW
More than 50% of median income	18-64	Max. KRW 254,760	Max. 203,800 KRW	20,000 KRW (13.01 GBP)
	65+	-	-	40,000 KRW (26.03 GBP)

Source: Ministry of Health and Welfare (2020b)

The amount of Disability Benefit varies according to the income level and age. Disabled people aged 65 or older are not entitled to claim the basic benefit because they are covered by the Basic Pension for the elderly (65+). The Basic Pension is provided to people whose monthly income is lower than 1,480,000 KRW for singles and 2,368,000 KRW for couples (Ministry of Health and Welfare, 2020c: unpagged). Besides these direct cash benefits, disabled people can use various discount, reduction, and tax benefits services (see Table 2.4 for examples).

[Table 2.4] Discount, reduction and tax benefit for disabled people

Category		Eligibility	Content
Discount and reduction	Reduction of entrance fees to public museums, art galleries, parks	Registered disabled (severe) and one carer	Free of charge
	Reduction of parking fees in public parking lots	Registered disabled owned or boarded vehicle	Reduction according to the local governments
	Reduction of railroad fees	Registered disabled	30-100% discount
	Reduction of wire and wireless communication fees	Registered disabled Facilities for the disabled	Discount according to the services
	Reduction of airfare and passage	Registered disabled	Discount according to the services
	Reduction of electric and gas charges	Registered disabled (severe)	Discount according to the services
Tax benefits	Tax benefit related to the purchase of vehicles	Registered disabled (severe)	Exemption of part of taxes
	Deduction of income tax, medical cost, special education cost	Registered disabled	

Source: Ministry of Health and Welfare (2014: 15-21)

The income security programme for disabled people has been expanded since the 1990s in succession (Yoon, 2013); however, it is still relatively weak. The OECD report demonstrated that the relative poverty rate of households with disabled people of South Korea is three times the average of OECD countries, while the disability benefit expenditure in the mid-2000s was only one-tenth (Kim et al., 2011: 101). This is significant because as the national survey of disabled people indicated that income support is the highest need of disabled people (Kim et al., 2014a; Kim et al., 2011; Byun et al., 2006a), which means that despite receiving benefits, they still have many welfare needs uncovered which could directly or indirectly impact on their health needs.

2.2.4 Healthcare policies in South Korea

To examine healthcare policies for disabled people, the general healthcare and social security policies of South Korea need to be described first. According to the Social Security Framework Act 2012, the social security system of South Korea consists of three parts: social insurance, public assistance, and social services (Article 3).

The “National Health Insurance” (NHI) is the most fundamental part of South Korea’s healthcare system (Lee et al., 2015; Moon, 2008), and since 2008, the “Long-Term Care Insurance” (LTCI) has been added to the social insurance system. Under public assistance, a “Medical Aid programme”, funded by general taxation, is applied to citizens with income below the threshold set by the government (Kim et al., 2010; Kim and Kim, 2006). Finally, under social service, there are various care services such as “elderly care services,” “personal assistance services,” “mother-infant healthcare services,” “nursing and home care services” (Ministry of Health and Welfare, 2018a). A brief overview of all of these health and social policies will be provided in this chapter’s remaining sections.

2.2.4.1 National Health Insurance (NHI)

The South Korean government’s NHI programme runs in accordance with the principle of social insurance in which the government runs public and non-profit insurance organisations to protect citizens from social risks such as old age, disease, industrial accidents, and unemployment. Citizens are required to contribute to this insurance, and this is how as a result of this obligatory join, social stability is secured (Gong and Lee, 2014; Kim and Kim, 2006). In this system, the single programme insurer provides health insurance to all the

citizens. This public insurer is an affiliate organisation of the Ministry of Health and Welfare (MOHW); thus, the MOHW takes responsibility for the design and implementation of the policies related to health insurance (Won, 2014; Kim and Kim, 2006).

As compulsory social insurance, the NHI is applied to all citizens except the Medical Aid system's beneficiaries. As of February 2018, the NHI covers 97.1% (50,941 thousand) of the whole population of South Korea, while the remaining 2.9% (1,503 thousand) are covered by the Medical Aid system (National Health Insurance Service, 2018: unpagged). The insured's categories have the entitlement of insurance benefit and are under duty to pay their contribution. Categories of the insured are classified into the employee insured and the self-employed insured (Lee et al., 2015; Won, 2014; Kim and Kim, 2006) (see Table 2.5).

[Table 2.5] The beneficiary and the contribution rate of NHI

	Employee insured	Self-employed insured
Eligibility	-Workers and employers in all workplaces -Public officers -Private school employees -Dependants of the above	-People whom employee insurance is not applicable (farmers, fishermen, self-employed people, etc.)
Contribution rate	-6.67% of monthly salary -Workers and employers each pay half (3.335%)	- Calculate the contribution score based on the income and the property, and then multiply the score by the amount charged per score (195.8 KRW(0.13 GBP) as of 2020)

Source: National Health Insurance Service (2020: unpagged)

Contributions from the insured and the government subsidy constitute the NHI's major finance source (Won, 2014; Kim and Jung, 2011; Kim and Kim, 2006). The benefits provided

by the NHI are divided into in-kind benefits, and cash benefits and these are summarised in Table 2.6.

[Table 2.6] The benefits of NHI

Category		Content
In-kind benefit	Healthcare benefit	Physical examination, medication, operation and treatment, prevention and rehabilitation, hospitalisation, nursing, transfer
	Health examination	General health examination, cancer examination, infant examination
Cash benefit	Healthcare cost support	Pay in cash equivalent to the healthcare benefit in case one uses healthcare service of a non-healthcare centre in emergency
	Assistance devices	Support part (within 80%) of purchase cost of given assistance devices
	Out-of-pocket payment of limit system	Set limits on out-of-pocket payment according to each contribution, and return the excess amount
	Pregnancy and delivery cost (e-voucher*)	Pay costs related to pregnancy and delivery through electronic vouchers

Source: National Health Insurance Service (2020: unpagged)

The rate of out-of-pocket payment varies for inpatients or outpatients, and in the case of outpatients, it is also different according to the scale of the healthcare centre and the region (see Table 2.7).

[Table 2.7] The rate of out-of-pocket payment

Category	Content
Hospitalisation	20% of total cost
Outpatient	Upper general hospital: doctor's fee + 60% of remaining healthcare benefit cost
	General hospital: 45% (rural area)-50% (urban area) of healthcare benefit cost

Category	Content
	Hospital: 35% (rural area)-40% (urban area) of healthcare benefit cost
	Clinic: 30% of Healthcare benefit cost
	Drugstore: 30% of Healthcare benefit cost

Source: National Health Insurance Service (2018: unpagged)

There are cost reductions for children under age six and patients with rare, incurable diseases, and to avoid the too demanding burden of medical cost, an upper limit of out-of-pocket payment also exists (National Health Insurance Service, 2018).

Healthcare centres delivery systems can be classified as public or private under the service provider. Private organisations account for most of the provisions as Kim and Choi (2008: 26) reported the proportion of public healthcare centres was only 15.5% of the whole when based on the number of in-patient beds. The absolute majority of primary healthcare centres are private. This is why primary healthcare centres struggle to carry out health promotion, prevention, treatment, and rehabilitation for individuals, families, and communities (Hwang, 2013; Kim, 2013a; Lee, 2007). This healthcare system's effect on disabled people and specific healthcare programmes for disabled people are investigated in the next sections.

2.2.4.2 Long-Term Care Insurance Programme

The Long-Term Care Insurance (LTCI) programme provides care services supporting care needs and housework to senior citizens who have difficulties in performing daily tasks due to their age (65+) or geriatric diseases (Lee, 2013c; Lee and Seomun, 2009). It was introduced to ease the financial burden of care on family caregivers in July 2008 (Won, 2014; Shin and

Baek, 2011; Lee and Seomun, 2009). Disabled people under 65 without geriatric illness have no entitlement to this service but can apply for the Personal Assistance Service (PAS), which will be explored in section 2.2.4.6 (Ministry of Health and Welfare, 2015b; National Health Insurance Service, 2015; Ministry of Health and Welfare, 2014; Lee, 2013c).

The LTCI is managed by the public insurer of NHI; those insured under NHI, are insured by the LTCI. This programme was initially designed for the elderly (65+). However, citizens under 65, who have difficulties in daily living due to geriatric illnesses such as dementia or cerebrovascular diseases, can now access this service. The contribution to LTCI is determined by multiplying 10.25% contributing to NHI as of 2020 (National Health Insurance Service, 2020: unpagged).

From its introduction, this service has been expected to reduce the burden of care on family members, and it seems to have had a positive impact (Kim, 2015; Kim, 2014a; Sunwoo, 2010). However, because most long-term care organisations are private, some researchers raised the concern that the quality of services and transparency within the organisations are compromised (Kim, 2015; Sunwoo, 2010).

2.2.4.3 Medical Aid programme

The Medical Aid programme aims to alleviate the healthcare problems of low-income households financially and assist with self-help by providing healthcare services (Kim and Kim, 2006). As most beneficiaries of this programme are under the NBLs programme, the NBLs programme will be described first.

The NBLs is a public assistance programme offering several sorts of cash or in-kind benefits implemented since 2000 (Won, 2014; Kim et al., 2010) (see section 2.3.1). The eligibility of

each benefit varies. For example; the “livelihood benefit” is for those with income below 30% of the median income and the “medical aid benefit” is for those below 40% of median income. The minimum living cost for four-member households in the most recent three years is seen in table 2.8. The minimum wages per hour and month, and the average household income per month are presented together.

[Table 2.8] Minimum living cost eligibility criteria according to different benefits

		2018	2019	2020
Eligibility	Livelihood benefit	1,355,761 KRW	1,384,061 KRW	1,424,752 KRW
	(Below 30% of median income) (4-household member)	(883.39 GBP)	(901.83 GBP)	(928.34 GBP)
	Medical aid benefit	1,807,681 KRW	1,845,414 KRW	1,899,670 KRW
	(Below 40% of median income) (4-household member)	(1,177.85 GBP)	(1,202.44 GBP)	(1,223.45 GBP)
Minimum wage	Per hour	7,530 KRW (4.91 GBP)	8,350 KRW (5.44 GBP)	8,590 KRW (5.60 GBP)
	Per month (working 209 hours a month)	1,573,770 KRW (1,025.44 GBP)	1,745,150 KRW (1,137.11 GBP)	1,795,310 KRW (1,169.79 GBP)
	Increase rate	-	10.9%	2.9%
	Average income of urban labour household per month (4/4 quarter) (4-household member)	5,950,915 KRW (3,877.50 GBP)	6,087,747 KRW (3,966.66 GBP)	-

Source: Ministry of Health and Welfare (2020d: 51), Minimum Wage Commission (2020: unpagged)

The eligibility threshold for the livelihood benefit (minimum living cost) was around 31% in 2016-2017 of the average income in an urban labour household per month. Interestingly, the

average monthly income of households with disabled people is 2,235 thousand KRW (1,457.86 GBP), and the average number of household members is 2.55 (Kim et al., 2014a).

This demonstrates that even when allowing fewer household members, the income level of disabled people is extremely low compared to that of the total population.

The NBLS system pays the cash benefit not individually but by the household unit. Therefore, household members who live with incomes below the upper amount can be the beneficiaries of NBLS after the means test. The Medical aid benefit is an in-kind benefit that registered disabled people are also entitled to. The recipients do not need to pay contributions to the NHI because the NHI does not insure them. Instead, they can use healthcare services for free or at a very low cost subsidised by general taxation (see table 2.9).

[Table 2.9] Users' fees for healthcare centres of Medical Aid beneficiaries

(unit: per visit)

Category		Primary centre	Secondary centre	Tertiary centre*	Prescription
First class	Hospitalisation	0	0	0	-
	outpatient	1,000 KRW (0.66 GBP)	1,500 KRW (0.99 GBP)	2,000 KRW (1.31 GBP)	500 KRW (0.33 GBP)
Second class	Hospitalisation	10%	10%	10%	-
	outpatient	1,000 KRW (0.66 GBP)	15%	15%	500 KRW (0.33 GBP)

Source: Medical Aid Case Management Programme Support Team (2015)

* 42 centres set by the minister of MOHW as of April 2018

There are two classes of beneficiaries in Medical Aid. The “first-class” composes those without working abilities (such as children, disabled people, and the elderly), those with rare and incurable disease (such as haemophilia), people with serious diseases (i.e., cancer, severe burns) (Korean Organisation for Rare Diseases, 2015), and those living in residential facilities. Those excluded from the first-class group are incorporated into the second class (Ministry of Health and Welfare, 2015a). When the programme started, the first-class group had no users’ fee, but due to the criticism of healthcare services overuse, from 1 July 2007, users’ fees for outpatients are also applied to those in the first class (Lee et al., 2015).

2.2.4.4 Social care services

There are several public care services available for groups in need of care such as the elderly, disabled people, pregnant women, and women in childbirth. Most of these social care programmes were introduced in the late 2000s, and they are universally managed by an electronic voucher (e-voucher) system (Kang et al., 2012; Kang et al., 2009). Traditionally, social care services in South Korea were provided following government guidelines or providers’ decisions rather than users’ needs, and public finances for the services were provided not directly to the service users but the service providers (Kim, 2014b). Under the old system, the relationship between social care service users and providers was similar to the “provider-directed model,” where the level of users’ rights are very low and choices of services by users are restricted (Yang, 2011; Nam, 2008). The e-voucher system was introduced in 2007 to overcome this weakness by promoting users’ choice, encouraging providers’ efficiency through competition (Kim, 2014b; Kang et al., 2012; Kang et al., 2009). It is an electronic system consisting of a card offered to each eligible service user and

preloaded with a set amount, which can then be used to pay for specific services outlined by the type of card distributed. This way, service users can choose between plural providers, as providers strive to offer services according to the users' needs. In particular, paying by vouchers in an electronic form, it is supposed to improve the transparency and efficiency of social service programmes (Kang et al., 2012; Kang et al., 2009). However, the e-voucher system has been criticised because it undermines government role and reinforces the dependence on the private sector, that is, marketisation. For example, most service providers are private, for-profit organisations who contract with the government (Ministry of Health and Welfare, 2018a). This demonstrates that the introduction of the e-voucher system was intended for the formation of a social care service market. Some scholars argued that the e-voucher system and private for-profit organisations degraded the quality of social care service and public values (Lee and Oh, 2012; Yang et al., 2012; Chung and Kim, 2010), whereas others claimed the marketization brought positive outcomes in users' satisfaction and service quality (Kim, 2010; Lee, 2008). So far, the conflicting evaluations of this system remain (Cho et al., 2013; Lee, 2011b; Kim, 2008b).

In South Korea, social care services are funded by general taxation and users' service fees (Park et al., 2013; Kang et al., 2012; Kang et al., 2009). The fees charged to the users differ according to the kind of service and within a service, they generally vary according to the income level. The higher the user's income, the higher the service charge; on the other end of the spectrum, they are free to the NBS recipients. Among these social care services, the Personal Assistance Service for disabled people will be detailed in section 2.2.4.6.

2.2.4.5 Current status of healthcare services use by disabled people

Herein, healthcare services for disabled people and the present condition of healthcare use by disabled people will be investigated. Comparing the proportion of disabled beneficiaries of the NHI and the Medical Aid with those of the total population (disabled and non-disabled people together) is as below.

[Table 2.10] Proportion of disabled beneficiaries of the NHI and the Medical Aid

Group		Disabled people (2014)		Total (disabled +non-disabled people) (2018)
National Health Insurance	Employees insured	53.6%	84.2%	97.1%
	Self- employed insured	30.6%		
Medical Aid	Frist class	14.3%	15.7%	2.9%
	Second class	1.4%		

Source: Kim et al. (2014: 212), National Health Insurance Service (2018: unpagged)

The fact that disabled people use the Medical Aid programme more than five times of general population reveals the poverty of disabled people as the criteria of this division is income level, as noted above.

In this healthcare system, Lee (2013a: 82-83) compared the current status of healthcare service use of non-disabled and disabled people in the Korea National Health and Nutrition Examination Survey 2005 data. According to the results, the quantity of hospitalization and outpatient use of disabled people was much more than non-disabled people. The healthcare cost paid by users per use was lower in the disabled group than non-disabled people in both hospitalisation and outpatient use. The total cost of outpatient use of disabled people was slightly lower than in the non-disabled group, but the cost of hospitalisation of disabled

people was almost four times that of the non-disabled group. That is, disabled people spent less healthcare costs than non-disabled people per use, but due to the frequent use of healthcare service, their total healthcare cost was similar or much higher than non-disabled people, which may create a heavy economic burden. It was also reported that the unmet healthcare needs of disabled people were nearly twice of non-disabled people. The details are described in the table below.

[Table 2.11] Healthcare service use of disabled and non-disabled people

	Non-disabled people (n=24,194)	Disabled people (n=1,021)
Hospitalisation (day)	1.32	7.41
Outpatient (day)	.53	1.06
Fee for hospitalisation (thousand KRW)	75.96	293.52
Fee for outpatient (thousand KRW)	13.10	12.40
Fee for hospitalisation per day (thousand KRW)	57.44	39.56
Fee for outpatient per day (thousand KRW)	24.63	11.62
Unmet healthcare need ² (%)	16.05	26.81

Source: Lee (2013a:83), modified.

The result of the national survey of disabled people in 2014, illustrating the most desired service of disabled people by the government is income security (38.5%), followed by healthcare security (32.8%) supported the high need of healthcare for disabled people (Kim et al., 2014a: 397). As most of them (75.3%) have additional expenditures due to disability (Kim et al., 2014a: 20), healthcare support for disabled people must be increased. Reflecting

²The proportion of positive answer to the question: "Have you ever been sick but not able to go to the hospital?"

this need, the Ministry of Health and Welfare (2011) set “to decrease the burden of healthcare cost expense on disabled people,” as one of their goals for the health promotion of disabled people.

2.2.4.6 Health and social care services for disabled people

There are several representative NHI related programmes for disabled people as listed below (Ministry of Health and Welfare, 2014: 6-8).

[Box 2.2] Health and social care services for disabled people

- The NHI contribution of disabled self-employed insured is reduced according to the disability grade (grade 1-2: 30%, grade 3-4: 20%, grade 5-6: 10%). This is applied to households with income below 3,600,000 KRW (2,363.60 GBP) per month and property below 135,000,000 KRW (88,635.02 GBP). This means they can use the NHI programme with less contribution.
- The Contribution of Long-Term Care Insurance is reduced by 30% for the severely disabled people (grade 1-2).
- The purchase cost of assistance devices can be supported. 80% for the NHI insured, 85% for second class recipients of Medical Aid service, 100% for the first class.
- NBLS recipients and the near-poor disabled can apply for free distribution of assistance devices. The items are different from the ones above.

Source: Ministry of Health and Welfare (2014: 6-8).

In addition, regardless of their income, every registered disabled person can use medical rehabilitation and the Community Based Rehabilitation (CBR) services provided mainly by Public Health Centres.

The “Personal Assistance Service (PAS)” programme, introduced in 2007, is the largest social care service for disabled people. It provides services such as personal assistance (physical activities support, home help, social activities support), home nursing, and bathing visits for severely disabled people through the electronic voucher system (Ministry of Health and Welfare, 2007). This programme is supposed to support activities for the social participation of disabled people rather than care. Disabled people, who fall under grade 1-3 of disability, aged 6 to 64, are eligible to claim this service. Since July of 2019, when the disability grade system was abolished, an assessment for eligibility is being implemented. For disabled people aged over 65, LTIC is available. Service users share 2-15% of the service fee according to their income level, but recipients of NBLs are exempted from this service fee (Ministry of Health and Welfare, 2015b: unpagged).

Research on PAS’s effectiveness concluded that users’ physical and mental health outcome were improved, and they were better able to integrate into the community and regarded themselves more positively (Kuk and Oh, 2014; Park, 2013; Lee, 2011; Park and Chung, 2010). PAS users went out more frequently and to a wider variety of places than before. Their physical activities’ function was improved, and they felt more in control over themselves and the environment. They shared positive acceptance of their disability, and their self-esteem was enhanced. Socially, interpersonal relationships improved, and relationships with family members changed from dependent to horizontal, independent relationships (Kim, 2005c). These studies recognise the overall effectiveness of PAS but also highlighted some negative experiences, such as strict eligibility due to the assessment process focusing on medical

standards, the high service fee (service users should pay 0-10% of service fee according to their income level), and insufficient service provision (Lee, 2011).

Besides the PAS, other rehabilitative social services are offered by the e-voucher system (rehabilitation service for people with learning disabilities, speech therapy support services, parent consultation for people with learning disabilities) (Ministry of Health and Welfare, 2018a) or provider support system. These services are delivered by providers, and most of them are private charities. For a long time, these organisations have delivered welfare services to many disabled people and have played a major role in the welfare of disabled people in South Korea. However, after the 2000s, they have been criticised for working under the rehabilitation model based on provider-directed services, which considers disabled people not as active service users but as passive patients (Lim, 2006). Particularly in the case of residential institutions, abuse and oppression of the users and corruption and malpractice in management have been brought into question (Kam et al., 2012; Lim, 2012; Kim, 2010; Lim, 2006). Responding to this criticism, residential institutions are reducing their scales and residents, re-locating from secluded suburbs into larger communities, and rationalising their management by increasing transparency (Lee, 2010b).

Despite the care service noted above, the care for disabled people in South Korea was mainly a burden of the family. The issue of care for disabled people by family members was mainly the experience or care burden of the mother of children with learning disabilities (Kim, 2012b; Lee and Oh, 2006; Oh and Jun, 2004; Lee, 2002b). This tendency has something in common with the care by female family member based on the Confucian traditions noted above (see section 2.2.3).

2.2.5 Employment and Anti-Discrimination

In South Korea, there is an Employment Quota system for disabled people. According to the Employment Promotion and Vocational Rehabilitation for the Disabled People Act 1991 2000, public and private companies larger than a certain scale must employ a percentage of disabled people (Kim and Lee, 2012; Lee and Park, 2012; Kim and Yu, 2001). This system is applied to the central, local governments and organisations employing more than 50 full-time workers. In 2015, the quota was 2.7% for private organisations and 3% for the public, and the government also provides a subsidy to employers who employ disabled workers above the quota and impose charges to those who employ less disabled people (Korea Employment Agency for the Disabled, 2015: unpagged). Along with the quota system, this act also regulates vocational rehabilitation services for disabled people. The services include vocational training, vocational adaptation training, supported employment, and job search services for severely disabled people.

However, despite these policies, the labour force participation rate of disabled people is still relatively low. According to the national survey of disabled people 2011, the labour force participation rate of disabled people was 38.48% (ratio of the working population in the age group of 16-64 currently employed or seeking employment.), the employment rate was 92.2% (ratio of employed out of labour force participation population), and the unemployment rate was 7.8%. While, in the same period, the labour force participation rate of the whole population (disabled and non-disabled people altogether) was 62.1%, the employment rate was 96.8%, and the unemployment rate was 3.2% (Kim et al., 2012: 20). It shows that the exclusion of disabled people from the labour market is relatively high.

Meanwhile, as regards the anti-discrimination in South Korea, the history is not that long. In 2007, the Disability Discrimination Act 2007 was enacted which prohibits discrimination based on disability in all areas of life such as employment, education, use of goods and services, jurisdiction, administration, political rights, maternal and paternal rights, and health rights. The types of discrimination include direct and indirect discrimination, rejection of reasonable accommodation, advertisement, and discrimination of disabled people's companions. Based on this law, disabled people who are discriminated against can make petitions to the National Human Rights Commission (NHRC). Notably, the prohibition of discrimination of health rights includes restrictions of limitation, exclusion, separation, and refusal of disabled people in medical practice (Article 31), aiming to create equal access for disabled people to health services.

2.3 Summary

This chapter presented a contextual background of South Korea. Starting with the welfare regime, the historical circumstances impacting these features and the family culture and attitudes toward disabled people were examined. Social policies related to disabled people were also outlined, and the development process of disability policy, the detailed contents of disability policy such as the registration system, cash benefit, and health and social care policies were described. This overview demonstrated that disability policy in South Korea had quickly developed in a short period, but there is still a considerable lack of substantiality, such as a low level of support.

Chapter 3 Methodology

This chapter will provide an overview of how this study was designed and conducted. First, the aims and objectives of this study will be presented, and an overarching research question and sub-questions will be specified. Then ontological and epistemological consideration of this study will be described and based on this, the adopted methodology - a mixed-method combining quantitative and qualitative data - will be explained and justified. Following this, the detailed research process, including how data were collected, analysed, interpreted, and integrated, will be described and, lastly, study ethical considerations will be reviewed.

3.1 Study aim and research questions

The main objective of this study is to explore the nature of health inequality experienced by disabled people through comparison with non-disabled people in South Korea. Ultimately, this thesis aims to contribute to the realisation of the right to health for disabled people. Therefore, the general and overarching research question of this study is, “How do disabled people in South Korea experience health inequalities?” This general question will be answered through four specified sub-questions as follows:

Research question 1. What is the overall difference in health status between disabled and non-disabled people in South Korea?

This question aims to identify the difference in the health status of disabled and non-disabled people, based on the hypothesis that there is a gap between the two groups. The gap in health status between disabled and non-disabled people was demonstrated empirically through previous studies (Emerson and Hatton, 2013; Emerson et al., 2010; Nocon et al., 2008; Oliver,

1996). Also, the gradient in health by socio-economic status shown in literature (Siegel et al., 2014; Gunasekara et al., 2013; Humphries and Van Doorslaer, 2000) alludes that disabled people as a group with low socio-economic status have poorer health than non-disabled citizens. To answer this question, through descriptive analysis of quantitative data, the overall health status of disabled people and that of the non-disabled people was assessed and compared.

Research question 2. What is the difference in health inequality among the disabled populations and the non-disabled population? How does health inequality within the two populations compare to each other?

This question aims to understand the scale of health inequality according to the socio-economic status within disabled populations. Like in non-disabled people (Costa-I-Font et al., 2011; Konings et al., 2010; McGrail et al., 2009), it is expected that there is an inequality indicating a positive relationship between socio-economic status and health within disabled people. The scale of health inequality by socio-economic status was calculated by a concentration index analysis of quantitative data. This question focused on inequality within disabled people by their socio-economic status, while question 1 focused on the gap between disabled and non-disabled people.

Research question 3. What factors influence health inequality within disabled people, and how are they different from those in the non-disabled population?

This question aims to clarify the key factors impacting health inequality measured from question 2. In previous studies, variables such as gender, age, region of residence, education, and employment status have been analysed as contributing factors (Morasae et al., 2012; McGrail et al., 2009; Hosseinpoor et al., 2006). In this thesis, this was carried out through the decomposition of a concentration index (Clarke et al., 2003), and in this process, the relative

effects of the impact factors were compared to each other. Analysis from qualitative data will supplement the answer as well.

Research question 4. What are the barriers to healthcare service use faced by disabled people?

This question aims to identify the barriers to service use disabled people experience in their lives through their own voices. The meaning of health for disabled people, the difficulties they experience in accessing healthcare, structural, financial, personal, and cultural barriers to equal healthcare use in able-bodied environments and societies, and the methods they use to overcome some of these barriers, were examined. This question required a qualitative approach to data collected through focus groups and interviews.

3.2 Ontological and epistemological considerations

The direction and method of research studies are based on their ontological and epistemological foundations. Though there are variances to a greater or lesser degree among researchers (Ryan, 2018; Carson et al., 2001; Crotty, 1998; Lincoln and Guba, 1985), generally, research paradigms in social science are grouped in three categories: positivism, interpretivism, and critical social science. The ontological and epistemological consideration of these three paradigms can be summarised, as shown in Table 3.1.

[Table 3.1] Ontological and epistemological considerations of research paradigms

	Positivism	Interpretivism	Critical social theory
Ontology	Single external reality or truth	No single reality or truth. Reality is created by individuals in groups	Realities are socially constructed entities that are under constant internal influence.
Epistemology	Reality can be measured and the focus is on reliable and valid tools to obtain it.	Reality is understood through “perceived” knowledge Research focuses on specific and concrete It is used to discover the underlying meaning of event and activities.	Reality and knowledge is both socially constructed and influenced by power relation from within society

Source: Rubin and Babbie (2007: 44-46)

Positivism assumes a single reality and discernible patterns and uniformities in the social world (Alasuutari et al., 2008). Contrary to positivism, interpretivism admits ontological pluralism. It is sceptical about the objective reality free from subjectivity and explores the situation-specific interpretation rather than a causal explanation of social action (Mercer, 2002). Finally, critical social theory treats the conflicts between various social subjects. It considers realities are constructed under social structures in which many troubles embedded, which positivism failed to reveal (Hartley and Muhit, 2003).

This framework is applied to research on disability as well. In disability studies, ontology, an ideological framework about the nature of being and relations, is linked to the question about the nature of disability, and epistemology is about how to approach and gain knowledge. In this thesis, this was addressed partially in chapter one when multiple perspectives on disability were discussed. Various perspectives and models on disability addressed are involved with these ontological and epistemological considerations. For example, the medical model in which disability is regarded as a failure of a body system inherently abnormal and

pathological (Oliver, 1996), is close to the positivist perspective on disability. The cultural model has something to do with interpretivism (Goodley, 2011). The minority model (Goodley, 2011) and the social barrier model (British social model) share the assumptions about power relations in society (Mercieca and Mercieca, 2010). Here, except for the medical model, the rest could belong to the social model in a broad sense (see chapter one). There are various perspectives within the social model in its enlarged sense, but most of these identify themselves in the differentiation from the medical model based on positivism.

Meanwhile, the ontological debate on disability was developed centred on the social model of disability (Riddle, 2013; Goodley, 2011; Tremain, 2001). Most of the time this concluded in the critique or suggestion of alternatives of the social model (Riddle, 2013; Vehmas and Mäkelä, 2008; Bhaskar and Danermark, 2006; Pfeiffer, 2002) (see chapter one). For example, Vehmas and Mäkelä (2008) considered the underlying ontology of the perspectives that distinguish impairment and disability as social constructionism. They criticised that the social model of disability, a materialist research tradition based on social constructionism, did not regard individual properties as crucial, and therefore the study of impairment was marginalised within this approach.

As stated in chapter one, this study embraces the fundamental assumption of a social model based on the distinction of impairment and disability. This study recognises that exclusion and deprivation disabled people face in their lives construct disability and endeavour to grasp their perceived reality. However, it is not appropriate to overlook the criticism upon the social model: as a study on the health of disabled people, this study underlines the significance of impairment and deliberates how to conceptualise disability and health, normally regarded to be antonym relation in the same category.

Furthermore, Mercer (2002) suggested a more specific and practical view on research paradigm as shown in Table 3.2.

[Table 3.2] Comparison of research paradigm

	Positivism	Interpretivism	Critical social theory
Producing Knowledge	Instrumental/ technical knowledge	Practical knowledge	Emancipatory knowledge
Policy making	Engineering/ prediction	Enlightenment	Struggle
Perspective on disability	Individual	Social	Political
Preferable approach	Quantitative	Qualitative	Interactive or dialogic

Source: Mercer (2002)

Though it seems to be a risk of oversimplification, this comparison clarifies the characteristics of research on disability. Research on disability based on positivism was mainly performed quantitatively, a preferable approach by positivism (Terrill et al., 2016; Pahor et al., 2014). Interpretive disability study did not regard disability as a fixed reality and observed it under specific and concrete contexts, adopting a more qualitative method (Shields and Synnot, 2016; Hammel et al., 2015). In critical social theory, the research aims to create knowledge for social transformation and stresses the political and ideological orientation (Toutaine, 1981). Therefore, critical social theory aims at emancipatory research (Barnes, 2014).

Many researchers in the field of disability studies argued that emancipatory research is most appropriate for disability research (Barnes, 2014; Danieli and Woodhams, 2005; Barton, 2005; Mercer, 2002; Stone and Priestley, 1996) and sometimes, emancipatory disability research has been attributed to the social model (Levitt, 2017). Mercer (2002: 245) considered that the ontology and epistemology of the emancipatory paradigm in disability research are located in the social model of disability. Citing Mercer, Levitt (2017) wrote that emancipatory research could be motivated by the social model. Barnes (2014) believed that disability studies aim for an emancipatory discipline intrinsically.

Emancipatory research put emphasis on praxis-oriented research that reveals social injustice and facilitates political action for social transform (Humphries, 1997). Barnes (2003; 2002) presented six core principles characterising emancipatory disability research: i) Research should have accountability to the disability community, ii) The social model of disability fundamentally underpins emancipatory disability research, iii) Researchers must make their standpoint clear at the outset, iv) Emancipatory disability research is predominantly qualitative, v) The experience of disabled people plays an important role, vi) Research should be directly targeted at the practical outcome of empowerment of disabled people. These principles revealed the ontological and epistemological consideration of emancipatory disability research and the underlying social model. However, these principles are not supported by all researchers. For example, Mercieca and Mercieca (2010) said that following these principles does not guarantee the emancipatory nature or ethical faultlessness of research and criticised the over-dependence on these principles. Further, they are concerned that the adherence to the principles would “iron out” and dilute the understanding of the complex reality of disability (Mercieca and Mercieca, 2010: 81).

This thesis, as a study on inequality to be reduced, ultimately aims at emancipatory disability research. It is sceptical about the “principles” above to a certain degree because it can restrict

the researcher's flexibility by leading to preferable conclusions or predetermining the extent of research acceptable. In particular, there was an explicit exclusion of quantitative data in the principles (principle four). There seemed to be a trend in emancipatory research that avoided quantitative research based on positivism seen as representative of the medical model and preferred for qualitative data. However, this simplistic association was criticised to be problematic since there can be no simple causal relation between the use of qualitative data and the removal of disabling barriers (Stone and Priestley, 1996: 705). Stone and Priestley (1996: 705) claimed that the problem is "not the qualitative nature of the data but the theoretical paradigm which guides its collection and analysis."; and they supported the usefulness of quantitative data in identifying disabling barriers. Likewise, if the limitations of quantitative data are recognised and supplemented, the quantitative approach can help to understand the complicated reality of disabled people's lives .

To summarise, this study is based on a broad sense of social model, which has characteristics of interpretive approach in the point that it is anchored in the relativism of context (Fujiura and Rutkowski-Kmitta, 2001) but accepts the criticism of the social model. Also, it emphasises the purpose of emancipatory research but adopted an eclectic method. This attempts to convert the ontological or epistemological limitation into extensions; therefore, this study tries to adopt a mixed-methodology.

3.3 Mixed-methodology

This study adopted a mixed-method that involves collecting, analysing, and mixing quantitative and qualitative data in a single study (Creswell and Plano Clark, 2011). Since this research needs to grasp the nuanced context of reality based on the understanding of the

broader objective situation, a mixed-method is effective in carrying out this study and demonstrating its strong point. In other words, through mixed-method, quantitative and qualitative data can complement each other and make it possible to understand the phenomenon in a more multidimensional way.

Quantitative data are useful to assess and compare the health inequalities between disabled and non-disabled people. However, as just one quantitative data source is insufficient to draw implications about policy approaches and to explore all research questions adequately, especially question four (what are the barriers to healthcare service use faced by disabled people?), which needs the comprehensive and vivid statements of disabled people, qualitative data complement the quantitative data. This approach enables the researcher to answer research questions that cannot be answered by one method alone (Blaikie, 2010: 219).

This adoption of a mixed-method can be supported by a reflective assessment of the prevalent research methodology of disability studies. As seen above, disability studies have identified them as emancipatory studies and find an adequate method for it. More recently, furthermore, criticism of such a qualitative data-oriented emancipatory methodology of disability studies has been raised. Danieli and Woodhams (2005) criticised that excessive involvement in an emancipatory paradigm oppressed the production of knowledge that can be generalised and claimed that more pluralist and eclectic approaches should be applied in disability research. Mercieca and Mercieca (2010) mentioned that adherence to the principles of emancipatory made understanding disability incomplete and advocated the expansion of research methodology. Stone and Priestely (1996: 706), though adhering to the emancipatory research, demanded to adopt plural methods for data collection and analysis regarding the changing needs of disabled people. That is, it is recognised that a variety of methods are needed to investigate the nature of the disability and its world.

Numerous models are suggested as mixed-method research (Martins et al., 2016; Creswell and Plano Clark, 2011; Leech and Onwuegbuzie, 2009; Teddlie and Tashakkori, 2003). Among various models, this thesis adopted the typology suggested by Creswell and Plano Clark (2011). They introduced six models of mixed-methods distinguished by the several components summarised in Table 3.3.

[Table 3.3] The major research designs of mixed-methods types

Design model	Level of interaction of two methods	Priority	Timing of strands	Point of interface
Convergent parallel design	Independent	Equal emphasis	Concurrent	Interpretation if independent Analysis if interactive
Explanatory sequential design	Interactive	Quantitative emphasis	Sequential: quantitative first	Data collection
Exploratory Sequential design	Interactive	Qualitative Emphasis	Sequential: Qualitative first	Data collection
Embedded design	Interactive	Either quantitative or qualitative emphasis	Either concurrent or sequential	Design level
Transformative design	Interactive	Equal, quantitative, or qualitative emphasis	Either concurrent or sequential	Design level
Multiphase design	Interactive	Equal emphasis	Multiphase combination	Design level

Source: Creswell and Plano Clark (2011: 74)

These six models are appropriate for different situations. In this study, the “explanatory sequential design” was used, which is defined as “methods implemented sequentially, starting

with quantitative data collection and analysis in Phase one followed by qualitative data collection and analysis in Phase two, which builds on Phase one” (Creswell and Plano Clark, 2011:73). Creswell and Plano Clark (2011: 82) advised to choose this design when: i) the researcher and research problems are more quantitatively oriented, ii) The researcher knows the important variables and has access to quantitative instruments for measuring the constructs of primary interest, iii) The researcher develops new questions based on quantitative results, and they cannot be answered with quantitative data. The research questions and researcher of this study have the characteristics mentioned above: the research questions are suitable to be investigated through quantitative data, and the researcher is familiar with the quantitative analysis, there is an accessible dataset including validated key variables, and the main purpose of a qualitative data collection is not only to investigate separated research questions, but also to complement quantitative data.

Therefore, this study analysed quantitative data in Phase one. Since the secondary data already collected are used, the data collection stage is unnecessary in Phase one. After the analysis of quantitative data was done, the qualitative data collection was designed considering the quantitative analysis results and then conducted in Phase two.

3.4 Quantitative data collection and analysis

Quantitative data were collected and analysed to comprehend the general health status and health inequality of disabled people and compare it to non-disabled people.

3.4.1 Quantitative data and variables

Secondary quantitative analysis of the Korea National Health and Nutrition Examination Survey (KNHANES) data was conducted. KNHANES is collected annually based on the National Health Promotion Act 1995 (Article 16) since 1998 by the Korean Centre for Disease Control and Prevention (KCDC) (KNHANES, 2015). The purpose of this survey is to investigate the overall health and nutrition status of South Koreans. It is the most representative health-related survey of South Korea, which produces data on health indicators such as smoking, alcohol use, physical activities, and obesity submitted to the WHO and OECD (KNHANES, 2015). The most recent data available at the time of analysis (December 2015) were from 2013 (KNHANES, 2015).

The sampling in this survey was as follows: first, around 300,000 districts of the Population and Housing Census 2010, 192 districts were selected through stratified probability proportionate sampling. Then, 20 households per each district and a total of 3,840 households were extracted as sample households via systematic sampling. The total number of subjects was 10,113, and 7,580 were interviewed with a response rate of 75% (KCDC, 2014: 16).

[Table 3.4] Measurement of Variables

	Category	Variable
General factor	Demographic variables	Gender, Age, Marital Status, Residence
	Socio-economic variables	Monthly household income, Education, Employment status
	Impairment-related variables	Disability type , Disability grade
Health outcome	Perceived health status	Self-assessed health (SAH), EQ-5D

Category		Variable
	Morbidity	Diagnosis of 22 chronic diseases (Cardiovascular disease (Hypertension, Dyslipidemia, Stroke, Myocardial infraction, Angina pectoris), Musculoskeletal disease (Osteoarthritis, Rheumatoid arthritis), Respiratory disease (Pulmonary tuberculosis, asthma, Endocrinology and metabolism disease (Diabetes mellitus, Thyroid gland disease), Cancer (Stomach cancer, liver cancer, Colorectal cancer, Lung cancer), Depression, Atopic dermatitis, Allergic rhinitis, Renal failure, Hepatitis B, Hepatitis C, Liver cirrhosis)
Healthcare service use	Health screening	General health check-up, cancer screening
	Unmet healthcare service needs	

To understand the general characteristics of the study sample, I analysed their demographic and socio-economic variables (see Table 3.4). In the group of disabled people, disability type and grade were also included because the data were collected before the grading system was abolished in 2019. Among socio-economic variables, monthly household income was converted into equivalised household income, which is calculated by dividing household income by the square root of the number of household members (OECD, 2011; OECD, 2008), in order to equalise the income of households with a different number of household members. The household income quintile, which divides all the respondents into five equal-sized groups when ranked by household income, was also estimated based on equivalised household income.

Impairment-related variables were composed of disability type and grade based on the disability registration system. Here I use the term “impairment-related” and “disability” together, since the nature of these variables is close to impairment - the physical and mental dysfunction - although the operational definitions of these variables follow the legal disability registration system and there are already settled English translation in South Korea. Disability

type is a nominal variable of 15 values (disability of limbs, disability of brain lesions, visual disability, hearing disability, speech disability, facial disfigurement, kidney dysfunction, cardiac dysfunction, respiratory dysfunction, liver dysfunction, epilepsy, intestinal/urinary fistular, mental disorder, intellectual disorder, autistic disorder) as seen in chapter two. In the analysis, I re-categorised 15 types into four groups (difficulties in mobility function, difficulties in sense and communication, internal organ dysfunction, and cognitive and psycho-emotional difficulties) according to the nature of the impairments. Disability grade covers six grades from grades one to six, and it was re-categorised into severe (1-2) and moderate (3-6) grade (see chapter two).

Considering the variables used in the previous literature and the purpose of comparison between groups, I chose three variables to measure and compare the collective health of populations. Self-assessed health (SAH) is one of the most frequently used variables when assessing health status. This demands respondents to assess their health with a five-point scale: from very good to very bad (see Box 3.1).

[Box 3.1] Self-assessment health

Q. How is your health in general?

1. Very good
2. Good
3. Fair
4. Bad
5. Very bad

SAH has been assessed as a powerful predictor of mortality and healthcare service use (Bailis et al., 2003; Eriksson et al., 2001; Benyamini and Idler, 1999; Idler and Benyamini, 1997) and reliable to predict morbidity of chronic disease (Molarius and Janson, 2002; Shadbolt, 1997). It is also beneficial when comparing the health status of plural groups because it assesses comprehensive health intuitively with a single item (Noh et al., 2017; Hu et al., 2016; Devaux, 2015).

The second variable is the EQ-5D, a standard instrument used as a measure of health outcome developed by EuroQol Group, a network of international multidisciplinary researchers devoted to measuring health status (EuroQol Research Foundation, 2015). EQ-5D has been included in KNHANES since 2005 (Kang et al., 2006), and studies about the validity to a variety of groups (patients with osteoarthritis, rheumatic disease, and cancer, etc) were performed multiple times (Kim et al., 2016; Kim et al., 2015; Kim et al., 2012b; Lim et al., 2010). That is, it is a tool used stably. Conceptually, this instrument assessing the problems in daily lives is close to the concept of disability, which means the limitation of daily living. From this instrument, it is represented that disability is included in the construct of health outcome. It assesses one's health across five areas, including mobility, self-care, usual activity, pain/discomfort, and depression/anxiety on a three-point scale, as shown in Box 3.2.

[Box 3.2] EQ-5D questionnaire

- Please indicate which statements best describe your own health state today.

Q1 Mobility

1. I have no problem in walking about.
2. I have some problems in walking about
3. I am confined to bed.

Q2. Self-care

1. I have no problems with self-care
2. I have some problems in washing or dressing myself
3. I am unable to wash or dress myself

Q3. Usual activities

1. I have no problems with performing my usual activities

2. I have some problems with performing my usual activities.
3. I am unable to perform my usual activities.

Q4. Pain/discomfort

1. I have no pain or discomfort.
2. I have moderate pain or discomfort.
3. I have extreme pain or discomfort

Q5. Anxiety/Depression

1. I have no anxiety or depression
2. I am moderately anxious or depressed.
3. I am extremely anxious or depressed.

Source: NatCen Social Research (2012: unpagged)

The EQ-5D index score, which indicates the comprehensive health status in one figure by calculating the point of each area of EQ-5D, was analysed as well.

Finally, morbidity was also chosen as the health outcome variable. This was measured by a diagnosis of 22 chronic diseases diagnosed by a doctor (see Table 3.4).

Healthcare service use was measured with the following variables: receipt of general health check-up, cancer screening, and unmet healthcare service needs. In this survey, people were asked if they had received a general health check-up and cancer screening during the last two years, and if they had ever been unwell but could not go to the hospital during the last year. Unmet healthcare service needs and reasons were also asked and analysed.

3.4.2 Analytical strategy for the quantitative data

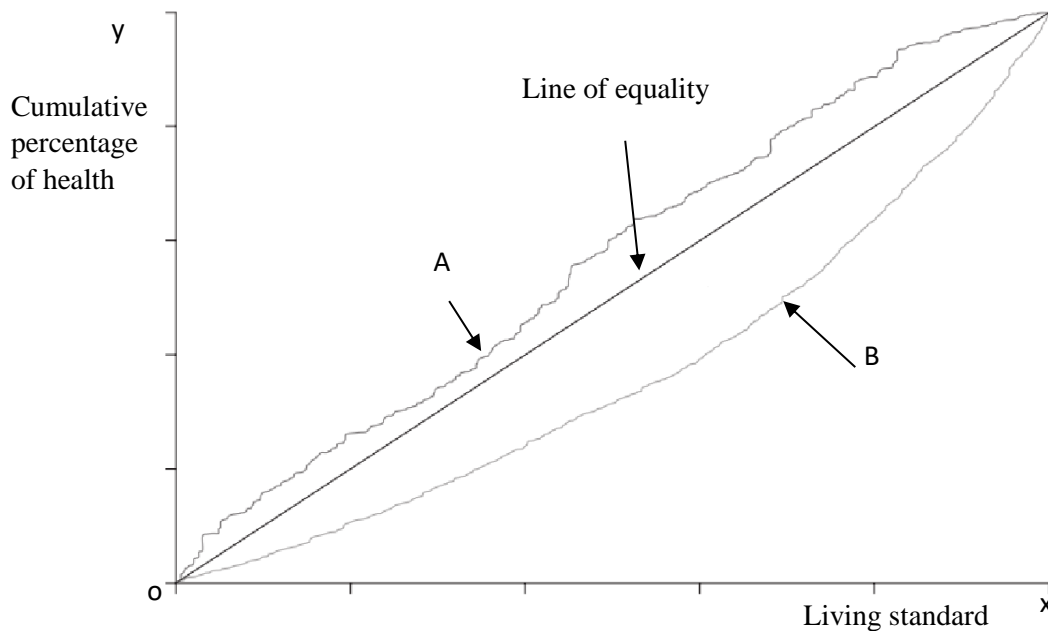
General and health-related factors of the data were analysed using descriptive analysis. For understanding health inequality in each disabled and non-disabled group, the concentration index (CI) analysis and its decomposition were conducted. These analyses were performed using the Stata SE 12.0 package.

The CI is the most commonly used index to calculate health inequalities in various countries (Ataguba et al., 2015; Liu et al., 2014; Gunasekara et al., 2013; Ravaghi et al., 2013; Nedjat et al., 2011; Ziebarth, 2010; Mangalore et al., 2007; Koolman and Van Doorslaer, 2004; Gravelle, 2003; Castillo-Salgado et al., 2001). It has been the global standard tool in health economics for evaluating socio-economic inequalities in health since the 1990s (Kjellsson and Gerdtham, 2013) as one of the most commonly used indices.

To be able to understand the CI, the Gini index must be explained first. The Gini index (also known as the Gini coefficient) (Gini, 1912) is usually defined based on the Lorenz curve. The Lorenz curve is drawn on the x-y axis plane coordinates, plotting the cumulative proportion of the population's total income in the y-axis against the cumulative percentage of the population, ranked by living standards, from the poorest to the richest in the x-axis. The Gini index is the ratio of the area between the line of equality (the line at 45 degrees) and the Lorenz curve over the total area under the line of equality. Theoretically, the Gini index has a value from zero to one. While the smaller number means the higher equality level (zero means the perfect equality), the bigger number means the lower equality. The Gini index can demonstrate the overall level of income equality of one society.

The CI is calculated similarly to the Gini index, but it results from a bivariate distribution of health and social-group ranking (Harper and Lynch, 2006). In the CI, the plotted curve is called a "concentration curve." Like in the Lorenz curve, the x-axis means "income level" or "living standard," but the y-axis means health related variables, e.g., health status instead of the cumulative proportion of total income (see Figure 3.1). Therefore, it is a bivariate distribution of income and health. O'Donnell et al. (2008: 83) explained that the two key variables underlying the concentration curve were health variables and variables capturing living standards ranking individuals from richest to poorest.

Figure 3.1 demonstrates the concentration curve visually. These variables are presented on the x-y coordinate plane, by plotting the cumulative percentage of the health variable in the y-axis against the cumulative percentage of the population, ranked by living standards, from the poorest to richest in the x-axis. Like the Lorenz curve, the more bent concentration curve means more considerable inequality. Also, if the curve bends up (curve A in Figure 3.1 below), it means that people who are within a lower living standard are in better health, and in the case of the curve bending down (curve B in Figure 3.1 below), people within a lower living standard are in worse health. If it is a 45-degree line-which is called the line of equality - then all the people are in the same health outcome variable irrespective of their living standard. O'Donnell et al. (2008) assessed the concentration curve could provide a complete picture of health inequality by displaying the share of health.



Source: Extracted from O'Donnell et al. (2008: 90), modified by the researcher.

[Figure 3.1] Concentration Curve

The CI is twice the area between the concentration curve (curve A or curve B) and the line of equality. Unlike the Gini index, which always has a positive value, the concentration index falls between -1 and 1. If the index takes a positive value, it means that the concentration curve lies under the line of equality, and it exists a pro-rich inequality. In other words, “a disproportionate concentration of the health variable among the rich” exists (O'Donnell et al., 2008: 95). On the contrary, when the index takes a negative value, there is pro-poor inequality. Irrespective of the direction of the sign, the absolute value shows the size of the inequality. The bigger the absolute value, it signifies the larger the health inequality as in the Gini index.

Since there is a limitation of the application of the CI according to the level of measurement, to apply this index into such variables as the SAH or EQ-5D index score, the variables need to be transformed and modified CI should be calculated. For this, the SAH was transformed into a binary variable as “good health” and “poor health.” As the CI varies depending on the cutting point of dichotomisation (Kjellsson and Gerdtham, 2013), three cutting points (good, fair/ordinary, bad) were set, and all the results were analysed. The EQ-5D index score is a continuous variable, so the transformation was unnecessary. For the EQ-5D index score and transformed SAH, the Erreygers CI, developed by Erreygers (2009) as a modified CI was calculated.

The decomposition of the CI is used to identify and quantify the contributions of various determinants of health inequality (van Doorslaer and Jones, 2003). There are two kinds of decomposition of CI. One is a decomposition by dimension (or component), and the other is a decomposition by determinants. Decomposition by dimension is only applied to multi-dimensional variables. According to Clarke et al. (2003), if a health variable is composed of dimensions added together to form an overall measure of health status, the CI can be decomposed into dimensions. The total CI of a multi-dimensional variable is the sum of the

weighted CI of each dimension. On the other hand, decomposition by determinant aims to identify the relative impact of specific determinants of health. O'Donnell et al. (2008: 159) introduced the decomposition of the CI into the contributions of individual factors (such as gender, age, and economic status) to health inequality as a whole, in which each contribution is the product of the sensitivity to health inequality and the degree of income-related inequality in that factor. In this thesis, two kinds of decomposition were applied to the EQ-5D index score, which is a multi-dimensional and continuous variable.

3.5 Qualitative data collection and analysis

The objective of the qualitative data was to explore the barriers to healthcare service use faced by disabled people to be able to explore and interpret the quantitative results. Following the explanatory sequential model, after the analysis of quantitative data, I designed the qualitative data collection to support the interpretation of those quantitative results. I collected qualitative data via four focus groups and six interviews. A focus group is a group discussion on specific topics (Shutt, 2003), enabling the researcher to use group interaction as part of the data-gathering method (Berg, 2006). Through focus groups, researchers can gain deep insights into the context by which certain opinions are held (Blaikie, 2010), expecting that people know and reflect better on their ideas and assumptions after being confronted with contrary views (Millward, 2007). As an interview, semi-structured interviews were carried out face-to-face. A semi-structured interview is considered more advantageous to draw the interviewee's thoughts because the type and order of questions are flexible to clarify the interviewee's response during the interview. The focus groups were conducted first to gain a

general overview of key factors, and subsequently, some issues requiring further depth were explored with individual interviews.

3.5.1 Focus groups

Four focus groups were carried out from April to May 2016 in three cities (Seoul, Daejeon, and Suncheon). Two focus groups were performed in Seoul, while one focus group was conducted in Daejeon and Suncheon each. Considering the size, accessibility, and convenience of sampling, I chose these cities to represent metropolitan city, middle to large-sized city and small town.

I selected participants through purposive sampling. Purposive sampling is to choose samples diversely as much as possible, ensuring all-important values of key factors are selected (Ritchie et al., 2013). For example, if the residential area is a key variable, then samples of both rural and urban area need to be selected. This is based on the assumption that they hold a characteristic expected to be important to the study (Ritchie et al., 2013). Therefore, participants were composed comprehensively considering gender, age, disability type, and socio-economic status.

I sent a request to several acquainted local disability organisations such as a Centre for Independent Living and the support centre for disabled university students to identify possible focus group participants with the following criteria.

[Box 3.3] Focus group participant eligibility criteria

The focus group participants should

- be over 19
- have been using healthcare services for more than one year due to impairment or health problems
- be able to communicate in the Korean language (including sign language, writing, or with any assistance)
- be able to come to the meeting space for a group discussion
- be active in talking about his or her experiences of healthcare service use

The organisations introduced me participants who met the eligibility and were interested in this study. After receiving the contact lists of recommended participants from the organisations, I contacted them to explain the outline of the study and the focus group. The potential participants were given an information sheet, participant consent form, and topic guides via e-mail or in person.

Focus groups were conducted with open and semi-structured questions using a topic guide. I took the role of moderator in all focus groups. It was held in the CILs or a lecture room in the university to facilitate accessibility for physically disabled participants. The focus group composition was relatively homogenous (Stewart and Shamdasani, 2014) in their ages and socio-economic status, but not all the participants in one group had the same type of disability. All focus groups were conducted in the Korean language. Group sizes were four for two groups and five for the other two groups; therefore, finally, there were 18 participants in total. Focus groups lasted from 110 to 135 minutes. The demographic characteristics of participants are shown in Table 3.5.

[Table 3.5] Demographic characteristics of participants of focus group

Group	No.	Pseudonym	Gender	Age	Job	Disability type	Impairment
G1 (Daejun)	1	Min-Soo	M	44	Staff of CIL	Brain lesion	Cerebral palsy
	2	Gina	F	50	Personal assistant	Limbs	Rheumatoid arthritis
	3	Sun-Ho	M	41	Staff of CIL	Brain lesion	Cerebral palsy
	4	In-Hoon	M	43	Staff of CIL	Brain lesion	Cerebral palsy
	5	Ja-Young	F	44	Vice director of CIL	Limbs	Neuromyelitis optica (Devic syndrome)
G2 (Suncheon)	6	Chan-Hee	F	25	IL activist	Brain lesion	Cerebral palsy
	7	Jinu	M	32	IL activist	Limbs	Muscular dystrophy
	8	Seon	M	39	Director of CIL	Limbs	Spinal cord injury
	9	Suji	F	33	Unemployed	Limbs	Spinal cord injury
G3 (Seoul)	10	Yuri	F	19	Student	Limbs	Spinal muscular atrophy
	11	Kyu	M	21	Student	Limbs	Muscular dystrophy
	12	Hyun	M	26	Postgraduate student	Limbs	Spinal muscular atrophy
	13	Ji-Hye	F	31	Staff of Support centre for disabled student in university	Visual disability	Optic atrophy
G4 (Seoul)	14	Kyung-A	F	48	Staff of CIL	Visual disability	Glaucoma
	15	Hye-In	F	42	Staff of CIL	Brain lesion	Cerebral palsy
	16	Jin	M	39	Unemployed	Epilepsy, Intellectual	Epilepsy, Intellectual

Group	No.	Pseudonym	Gender	Age	Job	Disability type	Impairment disorder
	17	Dong-Ho	M	46	Staff of CIL	Limbs	Spinal cord injury
	18	Bomi	F	44	Staff of CIL	Limbs	Polio

3.5.2 Semi-structured interviews

After all the focus groups were completed, to supplement the focus groups' information and make an in-depth exploration of some of the key issues, face-to-face semi-structured interviews were carried out from May to June 2016. The process of recruitment of participants was similar to that of the focus group. I asked disability organisations to recommend suitable participants. To supplement the small number of older participants in the focus groups, I first recruited participants aged over 60. Participants with impairment of internal organs (kidney dysfunction) and dual disability type (Limbs and Kidney dysfunction) were also recruited because it is important to include comprehensive values of the key element in purposive sampling (Ritchie et al., 2013). All interviews were conducted in the disability welfare centre, an interviewee's home or office, or a coffee shop close to their offices in Seoul. They lasted from 80 to 100 minutes. The demographic characteristics of the interview participants are summarised in Table 3.6.

[Table 3.6] Demographic characteristics of interview participants

No.	Pseudonym	Gender	Age	Job	Disability type	Impairment
1	Chul	M	24	Student	Kidney dysfunction	Focal Segmental Glomerulosclerosis
2	Kang-Oh	M	60	Unemployed	Limbs	Amputation, Spinal cord injury
3	Eun-Mi	F	65	Unemployed	Limbs	Aneurysm
4	Young-Min	M	63	Unemployed	Limbs	Spinal cord injury
5	Tae-Yong	M	41	Instructor, counsellor	Limbs	Cerebral palsy
6	Dong-Jin	M	46	Director of CIL	Limbs, Kidney dysfunction	Spina bifida, Chronic renal failure

Although I attempted to recruit disabled participants with various backgrounds for representativeness, it was not easy to avoid the oversampling of physically disabled people among those who willingly talk about their experiences on healthcare service use. That is, the opportunity to listen to the vivid experiences of people with learning disabilities was relatively low. Also, many participants were working in disability organisations, and they were likely to be more sensitive to the disability rights issues than the general disabled population. Although this is advantageous in grasping the problems in accessing healthcare services for disabled people, the knowledge and perceptions of these participants was influenced by their employment in disability organisations, so this can lead to the limitation of generalisation of research results.

3.5.3 Data analysis and interpretation

All focus groups and interviews were recorded under the agreement of the participants. I listened to the record repeatedly and transcribed verbatim records. For the data interpretation, I employed the analysis approach using thematic analysis using qualitative data NVivo 11 software. Thematic analysis is defined as “a method for identifying, analysing and reporting patterns (themes) within data” (Braun and Clarke, 2006), and it is argued to offer an accessible and theoretically flexible approach to analysing qualitative data. I followed the six steps of thematic analysis suggested by Braun and Clarke (2006) (see Box 3.4).

[Box 3.4] Six steps of thematic analysis

Phase 1. Familiarising yourself with your data

Phase 2. Generating initial codes

Phase 3. Searching for themes

Phase 4. Reviewing themes

Phase 5. Defining and naming themes

Phase 6. Producing the report

First, to be familiarised with the data, I reread the transcription of focus groups and interviews multiple times and generated the initial codes for focus groups and interviews together. Before grouping the data into themes, the codes and references were re-read, and initial codes were arranged through combining repeated codes and dividing broad codes. Two main themes were inferred from the data: “secondary impairments,” “the barriers to healthcare service,” respectively. These two themes will be explained in chapters five and six.

3.6 Synthesising quantitative and qualitative results

Synthesis of quantitative and qualitative data is a noticeable feature of a mixed-method (O'Cathain et al., 2007), not found in a mono-method study. By bringing the quantitative and qualitative approaches together, a researcher makes both data interdependent in explaining the research questions (Guetterman et al., 2015; Bazeley, 2012). Fetters and Freshwater (2015:115) believed that the true benefits of mixed-methods are to “produce a whole through integration that is greater than the sum of the individual qualitative and quantitative parts.” (Guetterman et al., 2015: 555) This process enables the researcher to see the theme more deeply and multidimensionally.

In mixed design, a synthesis of quantitative and qualitative data can be conducted at multiple steps of the study according to the model (Teddlie and Tashakkori, 2003). Because this study followed the explanatory sequential design in which the qualitative method is carried out after the completion of quantitative research (Creswell and Plano Clark, 2011), all the processes of collecting, analysing, and interpreting data were performed separately, and the synthesising was conducted at the final step of the study.

In explanatory sequential design, the major objective of qualitative data is to help explain the quantitative results, so there should be a comparison of both results (Creswell and Plano Clark, 2011). According to Erzberger and Kelle (2003), in the combination of both results, there can be three different situations as “convergence,” “complementariness,” and “divergence or contradiction.” The quantitative and qualitative results might be similar or complementary, but they could also be contradictory. This is similar to the case where there is a discrepancy between the research hypothesis and the results of the analysis of the collected data in a mono-method study. In this case, the researcher should try to give some

rational grounds for the situation (Rubin and Babbie, 2007). If the synthesis of a mixed design was in that kind of situation, then a reasonable explanation should be as well. Burt (2010) mentioned that in that case, the researcher should deliberate the cause of the situation: a methodological problem such as a lack of rigour in study conduct, or a misplaced hypothesis or assumption, and so forth.

In this study, to see if there is any conflict between the data results, the qualitative results supplemented or added the nuanced aspects to the quantitative results. Quantitative results were also drawn for a better understanding of the findings from qualitative data. Findings from quantitative and qualitative results generally showed rather convergent or complementary than divergent or contradictory situations. For example, quantitative analysis demonstrated less income and lower health outcome of disabled people, and qualitative analysis supplemented the quantitative results with detailed process and results of their economic and health-related situation. This synthesis brought multifaceted and abundant understanding to the discussion.

3.7 Ethical consideration

Secondary data analysis carries little ethical consideration, and there was no direct contact with the participants. However, according to the data provider's rules, the data were downloaded after the user agreed to confidentially, exclusive usage, and to use the data for statistical purposes only.

There were several considerations regarding the qualitative data, which are summarised below. Before conducting focus groups and interviews, this study received an ethical review committee's approval from ESSL (Education, Social Science, and Law), Environment and

LUBS (Leeds University Business School) (AREA) Faculty Research Ethics Committee of University of Leeds in February 2016 (ethics reference: AREA 15-079).

- Researcher positionality and reflexivity

Researchers' epistemological assumptions affect one's positionality relating to representation of findings, the researcher's role and power relations with others, and especially to the performance of qualitative research (Corlett and Mavix, 2018). In disability studies, it is also said that reflexivity influences the knowledge produced by researchers regardless of their disability (Rinaldi, 2013). Prior to initiating this thesis, I looked back on my position as a researcher and examined how this would affect the conduct of the research. One of my identities is that I am a South Korean. I gaze at the South Korean society, the background of this thesis, as an insider. However, my other identity is that I am not a disabled person. I have been interested in disability issues for 20 years, but my understanding of this issue cannot be that of disabled people themselves. Also, I am highly educated and have been mostly of the middle class and above in my life. There was a gap between my socio-economic situation and that of most disabled people in South Korea. Nevertheless, I think that my marginalised experience as a woman, and as a South Korean in the UK helped me understand part of disabling barriers created by my identity and the group I belong to. I think, that is, I have both an insider view and an outsider view in looking at this issue, and it would bring the possibility and limitation as a researcher at the same time. While carrying out this study, I tried to keep the perspective of emancipatory research, but I cannot but confess that my own reflexive account was not enough due to my unfamiliarity with the issue of reflexivity. Because reflexivity is considered an integral aspect of research, especially in qualitative one (Corlett and Mavix, 2018), I plan to train myself through continuing my study.

-Power imbalance

Power imbalance issues between the researcher and participant have long been discussed in multiple social science studies (Karnieli-Miller et al., 2009; Ochocka et al., 2002; Thomas and O'kane, 1998; Limerick et al., 1996). In particular, from the perspective of a “constructivist grounded theorist,” the relation between the researcher and participant is significant because it influences the overall result of the research. Therefore, equalising the power imbalance between researcher and participant is a priority (Mills et al., 2006). Reinharz (1992) suggested some “consciousness-raising questions” such as “What if this was me?” “How are these similarities and differences being played out in our interaction?” It was required to ask researchers to consider power imbalance and to ensure a conscious, ongoing commitment to participant-driven research (Mills et al., 2006: 10).

To establish an equal power relation, participants were enabled to determine major parts of the interviews. Participants scheduled the time and location of the focus groups, and they were also provided with the interview transcript to review. They were encouraged to contact the interviewer if they were uncomfortable with or want any part of the interview to be omitted. Most of all, I made an effort to have a more reflexive open stance and a proactive plan for the interview (Mills et al., 2006). As a thank you gesture, participants were compensated for their time with a small amount of cash.

-Informed consent

Verbal and written forms of informed consent were obtained from the focus group and interview participants. The written form of consent was prepared in Korean. Participants were informed that they could access and verify the data they provided and that the provided information could be withdrawn at any time. Easy Read consent forms and participation information sheet for people with intellectual disabilities were also provided.

-Protection from Harm

Since personal or sensitive issues were discussed in focus groups and interviews, participants could feel upset by the conversation topics. It was made clear to all participants that they were not obliged to respond to any issues that made them uncomfortable. All participants were reminded of their right to withdraw from the study at any time.

There was the possibility that some participants might get emotional during the course of the study. This is normal, but disability organisations and supervisors were signposted for support in serious situations. An accessible and safe place was chosen by participants as the location for focus groups and interviews.

-Anonymity and Confidentiality

For anonymity and confidentiality, the names of participants were replaced with identifiable pseudonyms. Electronic files were stored on a password protected university computer. Any document containing private information of participants will be destroyed after the research concluded.

-Translation issue

All the focus groups and interviews were conducted in Korean. The researcher is a native Korean speaker; thus, there were no translation issues. One participant of a focus group with cerebral palsy could not speak smoothly; therefore, communication in writing was used. Participants with cerebral palsy in the group interpreted his words if necessary. It was a concern that errors may occur when translating the Korean transcripts of focus groups and interviews into English because, in qualitative research, there is no complete equivalent translation of two different languages (Temple and Young, 2004). Also, the researcher's attribution and bias who translated the transcript might have an impact on the result. To

prevent these problems, I translated the same text in multiple ways and chose the better one after comparisons.

3.8 Summary

This chapter reviewed how this study was conducted. The research aims and objectives were reviewed at first, and then the research questions were presented. Following this, the ontological and epistemological ground of this study was addressed, and the reason for adopting a mixed-methodology, an explanatory sequential model putting the priority on quantitative data was clarified. The procedures of data collection analysed, interpretation and synthesis were presented in detail and, at last, the ethical issues were addressed.

Chapter 4 Health-related characteristics of disabled people in South Korea

In this chapter, the general and health-related characteristics of disabled and non-disabled people in South Korea will be presented. The purpose of this chapter is i) to provide a broad overview of disabled people in South Korea through study sample, ii) to understand the specific health-related characteristics of disabled and non-disabled populations, and iii) to compare the aspects of health inequality of disabled and non-disabled people and the impacts of related variables. To do this, national data will be analysed by quantitative methods. Descriptive analysis, concentration index analysis, and concentration index decomposition will be carried out and these findings will be further explored with qualitative research, which will be presented in chapter five and six.

4.1 General characteristics of respondents

Among 6,040 respondents included in the analysis, using the data of KHNES (see chapter three), the proportion of registered disabled people accounted for 6.5%. According to Statistics Korea and the Ministry of Health and Welfare's statistics, the registered population as of December 2013, when the survey was carried out, was 51,141,463, and the number of registered disabled people was 2,501,112. This means that the proportion of registered disabled people of 2013 was 4.9% (Statistics Korea, 2015; Ministry of Health and Welfare, 2014b), and in the study sample, disabled people were slightly overrepresented.

[Table 4.1] Demographic characteristics

(Unit: %)

Variable		Total	Non-disabled people	Disabled people
Proportion		100	93.5	6.5
Gender	Men	49.7	49.0	60.3
	Women	50.3	51.0	39.7
Age group	16-29	22.3	23.5	6.0
	30-49	39.0	40.1	22.6
	50-69	28.7	27.5	46.0
	70+	10.0	8.9	25.4
Age (unit: year)	Median	44	43	57
	Minimum	16	16	16
	Maximum	96	96	95
Marital status	Single	25.1	25.9	13.7
	Married	64.0	64.0	63.4
	Separated/divorced	3.9	3.7	7.3
	Widowed	7.0	6.4	15.6
Residence area	Urban	81.2	81.4	78.0
	Rural	18.9	18.6	22.0

Data source: Korea National Health and Nutrition Examination Survey (KNHNES) (2015)

The general demographic features of the study sample are shown in table 4.1. First, concerning gender, the proportion of men was much higher in the disabled group (60.3%) than in the non-disabled group (49.0%). This is consistently a trend in the national survey of disabled people (Kim et al., 2014a; Kim et al., 2012; Byun et al., 2006; Byun et al., 2001), but the cause has not been clearly understood. It is assumed that most disabled people were not born with disabilities, but acquired it (88.9%) (Kim et al., 2014a). Men generally benefit from more social participation such as employment, and are therefore more likely to be impaired by the environment than women. For example, injuries due to industrial accidents would be more prevalent among men than women (Rhee et al., 2014; Yi, 2013).

With regard to age, disabled people were generally older than non-disabled people. 40.2% of non-disabled people belonged to the age group of 30-49 years, whereas most disabled people were in the age group of 50-69 years (46.0%). The higher proportion of disabled people in older groups implied that most disabled people were impaired due to acquired conditions such as diseases or accidents rather than hereditary factors, and old age diseases could be a reason for impairment (Kim et al., 2014a; Kim et al., 2012; Byun et al., 2006; Byun et al., 2001). The median age of each group was 43 years for non-disabled people and 57 years for disabled people, which showed a 14 year-gap. Related to this, the low rate of singles (13.7%) and the high rate of widowed people (15.6%) in disabled people could be explained by their older age. The values of non-disabled people were 25.9% (single) and 6.4% (widowed), respectively. In terms of residence area, 81.4% of non-disabled people and 78.0% of non-disabled people lived in urban areas, showing only a small difference between these two groups.

[Table 4.2] Socio-economic and health insurance characteristics

(Unit: %)

Variable		Total	Non-disabled people	Disabled people
Equivalentised household income per month (unit: thousand won)	0-999	22.4	20.7	46.2
	1,000-1,999	35.0	35.4	29.2
	2,000-3,999	34.8	35.8	19.5
	4,000-5,999	6.3	6.4	4.6
	6,000+	1.6	1.6	.4
	Median		1,732	1,750
Education	Below elementary	17.0	15.4	39.9
	Middle school (9 year)	12.6	12.3	17.4
	High school (12 year)	37.8	38.4	29.1
	Higher	32.6	33.9	13.6
Public healthcare system	NHI			
	Self-employed	33.2	33.5	28.8
	Employee	63.7	64.2	56.8
	Medical aid	3.1	2.3	14.5

Variable		Total	Non-disabled people	Disabled people
Insured by private health insurance	Yes	76.7	78.7	48.8
	No	21.7	19.9	47.1
	Don't know	1.6	1.4	4.1

Data source: KNHNES (2015)

Table 4.2 presents the socio-economic characteristics of the study sample. First, the economic status was measured by equivalised household income per month. 46.2% of disabled people were included in the group below 1,000 thousand KRW (656.56 GBP)³ as their monthly equivalised household income. On the other hand, the largest group among non-disabled people was a group with income above 2,000 thousand KRW (1,313.11 GBP) and below 4,000 thousand KRW (2,626.22 GBP) (35.8%). Only 1.5% of disabled people were included in this group. The median value was 1,750 thousand KRW (1,148.97 GBP) in non-disabled people, while 1,172 thousand KRW (769.48 GBP) in disabled people. This shows the low economic status of disabled people in South Korea.

With regard to the education level, the lower rate of highly educated people and the higher rate of lowly educated people in the disabled group could be one indicator of the poor socio-economic status of disabled people. Nevertheless, the low education level of disabled people seemed to be because of their old age alongside disability. Until the 1970s, when South Korea was relatively underdeveloped, the entrance rate to upper educational institution was very low and most people remained at a low level of education (Kwon, 2004). Currently, programmes such as the compulsory education until high school based on the “Special Education for the Disabled People and others Act 2007” and “special admission program for the disabled applicants” introduced in 1995 (Kim, 2009) are expected to decrease the considerable gap between disabled people and non-disabled people in educational level.

³ All the following exchange rates are based on data obtained on September 2020.

Finally, in respect to the medical security, the proportion of recipients of Medical aid - a system consisting of the government pays medical expenses to people with low income, adopted children below 18, and people with rare diseases (see chapter two)- was over six times higher among disabled people, which meant they had much lower income or special healthcare needs. This will be investigated with the qualitative data in chapter six in detail. Also, 78.7% of non-disabled people have private health insurance but in the case of disabled people, this proportion was only 48.8%. To buy private health insurance is an individual choice. However, the low rate of private health insurance of disabled people means that the healthcare cost, which is not covered by public health insurance such as NHI or a Medical Aid programme, can be burdensome to them. The reason for the low rate of disabled people is presumed that many disabled people cannot afford to buy private health insurance; not only because of low income, but also because premiums may be higher, or they are denied coverage because of their impairments. This is supported by the statement of a participant of an interview (see chapter six).

In summary, the results of the demographic and socio-economic characteristics above established that disabled people were more likely to be men, older, in lower income, with lower levels of education than non-disabled people. This illustrated the low socio-economic status of disabled people in South Korea.

[Table 4.3] Employment status (social activity for last week)

(Unit: %)

Value	Total	Non-disabled people	Disabled people
Working in a paid job (or unpaid, working for relatives, more than 18 hours)	57.2	58.2	42.0
Going to school or college full-time (including vacations)	7.5	7.9	2.0
Unemployed/Seeking job	5.3	5.4	4.3
Not working because I feel it was unnecessary	7.1	7.1	6.9
Not working due to health problem	9.8	8.2	34.2
Retired from paid work	1.7	1.6	2.0
Looking after home or family	7.0	7.3	3.6
Others	1.1	1.1	0.6
Did not answer	3.3	3.2	4.4

Data source: KNHNES (2015)

Table 4.3 above illustrates the employment status of the study sample. The question asked for this item in KNHNES was, “In the last week, did you work more than one hour to make money or more than 18 hours as an unpaid worker in the workplace a relative owns? Or were you in a temporal leave for diseases or any other reasons?” If the respondents answered “yes”, then the value was “working,” but if they answered “no”, an additional question about the main reason for not working was asked.

58.2% of non-disabled respondents answered they were “working in a paid job” whereas 42.0% of disabled people were in remunerated employment. When the main reason for the “not-in-paid job” was asked, a noticeable difference between disabled and non-disabled people was found. 7.9% of non-disabled people answered that they went to school or college full-time, while only 2.0% of disabled people did. This means that non-disabled people are more likely

to be in educational courses than disabled people because they are younger, but, partly, it is assumed that this reflects the low opportunity for education for disabled people. “Not working due to the health problem” was over four times higher in disabled people (34.2%) than in non-disabled people (8.2%). Meanwhile, respondents in “unemployed/seeking job” were 5.4% of non-disabled people and 4.3% in disabled people, demonstrating little differentiation. Considering that disabled people over 70 years accounted for around a quarter of disabled people, “retirement” constituted only 2%, while “health problem” accounted for 34.2% of the main reason for not working. They are more likely to be unemployed ever than they are retired from their work.

This result suggested that “involuntary unemployment” is due to the unavailability of jobs, and there was not much difference between the two groups. This could be interpreted as disabled people giving up working voluntarily because of their physical or mental impairments. However, to give up work due to chronic health conditions may imply that little accommodation and numerous barriers are disabling their impairments in working places on the contrary. These social barriers marginalise disabled people and reinforce their poverty (Lee, 2005; Nam, 2005). To promote the employment of disabled people, programmes such as “employment quota system for disabled people” and other support system based on the “Employment Promotion and Vocational Rehabilitation for the Disabled Act 1991 2000” have been implemented and the “Disability Discrimination Act 2007” prohibits discrimination based on disability in employment (see chapter two). These measures are still insufficient, and more policies are needed (Na and Oh, 2015; Lee and Kim, 2013).

At the time of the survey, there were fifteen disability types (disability of limbs, disability of brain lesions, visual disability, hearing disability, speech disability, facial disfigurement, kidney dysfunction, cardiac dysfunction, respiratory dysfunction, liver dysfunction, epilepsy, intestinal/urinary fistular, mental disorder, intellectual disorder, autistic disorder) and six

grades (1-6 grade) in the disability registration system according to “Welfare for the Disabled People Act 2001.” It is supposed to be allocated an disability type and grade when the person registered as disabled. Type is determined based on impaired area and grade is set based on the severity of impairments. The grading system changed into two grades in July 2019: mild and severe grade (see chapter two).

[Table 4.4] Distribution of disability type

(Unit: %)

Category	Type	Proportion	Category	Type	Proportion
Mobility function	Disability of limbs	54.0	Sense & communication	Visual disability	8.4
	Disability of Brain lesions	5.9		Hearing disability	9.9
Internal organ	Kidney dysfunction	3.0		Speech disability	.5
	Cardiac dysfunction	.2	Cognitive and psycho-emotional difficulties	Mental disorder	4.0
	Respiratory dysfunction	1.0		Intellectual disability	4.3
	Liver dysfunction	.4		Autistic disorder	.3
	Epilepsy	.2	Other	Facial disfigurement	0
	Intestinal fistular/urinary fistular	.9	Don't know		7.1

Data source: KNHNES (2015)

Table 4.4 demonstrates the distribution of disability type in the study sample. 92.9% of disabled respondents knew their disability type, while 7.1% were unaware of it. Among the 15 disability types regulated by the “Welfare for the Disabled People Act 2001,” the majority of respondents (54.0%) reported having disability of limbs (amputation, paralysis, etc.), followed by hearing (hearing loss, deafness) (9.9%) and visual (low vision, blindness, and

visual field defect) (8.4%) impairment. The least frequent types were epilepsy and cardiac (heart failure) dysfunction (0.2%) equally, followed by autistic disorder (0.3%) and facial disfigurement (birth-related disfigurements like craniofacial condition and physical injuries as burns, etc.) (0.0%). Though there is a slight difference, these results are similar to the national survey of 2014. i) The proportion of people with disability of limbs is over 50%. ii) The proportion of people with visual and hearing impairment are similar. iii) People with intellectual disabilities are the most prevalent among people with mental disabilities. iv) People with kidney dysfunction are the most prevalent among people with internal organ dysfunctions. v) People with facial disfigurements are the least prevalent (Kim et al., 2014a). This sample of disabled people seemed to reflect the national data closely. Demographic and socio-economic variables by disability type were not analysed due to the small sample size of people with internal organ dysfunctions and mental disabilities.

The characteristics of the disability grade are illustrated in table 4.5.

[Table 4.5] Distribution of disability grade

(Unit: %)

	Grade	Proportion
Severe	1-2	18.1
Mild	3-6	81.9

Data source: KNHNES (2015)

Among the six grades, grades 1-2, eligible for the Disability Benefit are classified as severe grades and grades 3-6 as mild grades (see chapter two). More respondents were distributed in the mild grades (81.9%) than in the severe grades (18.1%).

[Table 4.6] Demographic characteristics by disability grade

(Unit: %)

Variable		Severe	Mild
Proportion		18.1	81.9
Gender	Men	62.0	62.7
	Women	38.0	37.3
Age group	16-29	26.6	1.6
	30-49	21.4	21.0
	50-69	40.7	48.6
	70+	11.3	28.9
Age (unit: year)	Median	51	59
	Minimum	16	21
	Maximum	86	95
Marital status	Single	36.3	8.3
	Married	33.6	70.1
	Separated/divorced	12.5	6.7
	Widowed	17.6	14.9
Residence area	Urban	80.1	77.9
	Rural	19.9	22.1

Data source: KNHNES (2015)

Table 4.6 illustrates the analysis by disability grade. Respondents without grade information were excluded from the analysis. There was no noticeable difference in gender between severe and mild grades. The majority age group was 50-69 years in both severely and mildly impaired people but proportions in the age group of 16-29 years (26.6% in severe grade, 1.6% in mild grade) and 70 years and over (11.3% in severe grade, 28.9% in mild grade) showed significant gaps. This seemed to represent that when people register their disability caused by the geriatric disease in old age, they tend to be given lower grades.

Similarly, disability caused by geriatric illness tends to be given a lower grade (Lee, 2011). As for marital status, while most of the mildly impaired group were married, in severely impaired people, the proportion of singles was the highest, and the proportion of married people was less than half of the mildly impaired group. Also, the proportion of divorced or separated people with severe impairments was even higher than those with mild impairments. It seemed that severely impaired people were less likely to be married, and when they

married, they were less likely to stay married. There was no remarkable difference in the residence area between the two groups.

[Table 4.7] Socio-economic characteristics by disability grade

(Unit: %)

Variable		Severe	Mild
Equivalised household income per month (unit: thousand won)	0-999	54.8	43.6
	1,000-1,999	26.6	30.7
	2,000-3,999	13.4	21.4
	4,000-5,999	3.9	4.0
	6,000+	1.4	0.3
	Median	848.6563	1,250.0
Education	Below elementary	30.8	43.3
	Secondary 1 (middle school) (9 year)	23.3	16.2
	Secondary 2 (high school) (12 year)	25.8	28.4
	Higher	20.1	12.1
Employment status	Working in paid job	27.7	47.3
	Not in paid job	72.3	52.7
Medical security	NHI	31.8	25.9
	Self-employed	40.2	62.4
	Employee	27.8	11.7
Insured by private health insurance	Medical aid	34.1	52.1
	Yes	57.1	46.7
	No	8.7	1.2
	Don't know		

Data source: KNHNES (2015)

Table 4.7 presents the socio-economic characteristics of disabled people by disability grade. Mildly impaired people had higher household income (median = 1,250 thousand KRW) (820.69 GBP) than severely impaired people (median = 848 thousand KRW) (556.76 GBP), which was predictable, since it was reported many times that severely impaired people cannot get paid jobs easily (Kim et al., 2014a; Kim et al., 2012; Byun et al., 2009). These factors aggravate their economic situation. On the contrary, at the educational level, in the severely impaired group, there were fewer people educated below elementary school (30.8%) and

more highly educated people (20.1%) than in the mildly impaired group (43.3%, 12.1%, respectively). This means the severely impaired people were more highly educated than mildly impaired people, and like in other variables, the older age of severely impaired people was one of the reasons for this result.

The proportion of respondents working in paid jobs was considerably higher in those with mild grades (47.3%) than those with severe grades (27.7%). This explains the low income of severely impaired people partially. With regard to the medical security, the proportion of Medical Aid users was over two times higher in severe grades (27.8%) than in mild grades (11.7%). The medical condition of severely impaired people, and their economic status seemed to be the reason for their high reception of Medical Aid. In numerous cases, the rare diseases covered by Medical Aid accompany symptoms recognised as severe impairments. Finally, the proportion of those insured by private health insurance was higher in people with mild grades (52.1%) than in people with severe grades (34.1%). This not only reflected the low income of people with severe impairments but also could be linked to insurance premiums and eligibility criteria to provide cover.

4.2 Health-related characteristics of subjects

Health-related characteristics of disabled people, such as health status and healthcare service use, were analysed compared to non-disabled people. Health status was measured by the variables self-assessed health (SAH), EQ-5D, and morbidity of 22 chronic diseases (see chapter three). Healthcare service use was measured by general health check-up, cancer screening, and unmet healthcare service use.

4.2.1 Health status measured by Self-assessed health (SAH)

Table 4.8 describes how non-disabled and disabled people assessed their health.

[Table 4.8] Self-assessed health (SAH)

(Unit: %)

	Total	Non-disabled people	Disabled people
Very good	5.2	5.3	3.2
Good	29.5	30.4	15.7
Fair/ordinary	49.0	49.3	44.3
Bad	13.0	12.3	23.8
Very bad	3.3	2.7	13.0

Data source: KNHNES (2015)

In both groups, most people assessed their health as “fair/ordinary” (non-disabled people 49.3%, disabled people 44.3%). Still, the proportions of “very good” and “good” were almost two times higher (5.3%, 30.4%) in non-disabled people than in disabled people (3.2%, 15.7%). The proportion of people assessing their health as “very bad” (13.0%) was much higher in disabled people than in non-disabled people (2.7%). This result demonstrated that disabled people report their health status as considerably worse than non-disabled people.

4.2.2 Health status measured by EQ-5D

EQ-5D is a standard validated instrument for measuring health outcomes developed by EuroQol Group (EuroQol Research Foundation, 2015). It assesses one’s health across five areas (mobility, self-care, usual activity, pain, and anxiety) with a three-level scale (no

problem, some problem, and extreme problem) (see chapter three). It was translated into more than 170 languages (Van Reenen and Janssen, 2015) including Korean (Kim et al., 2015). It is widely used internationally, including KNHNES of South Korea and in the “Health Survey England” to assess national health status. Table 4.9 shows the detailed questionnaire.

[Table 4.9] EQ-5D

(Unit: %)

Category	Item	Total	Non-disabled people	Disabled people
Mobility	I have no problems in walking about	87.6	89.5	59.8
	I have some problems in walking about	11.7	9.9	37.2
	I am confined to bed	0.7	0.5	3.0
Self-care	I have no problems with self-care	96.1	97.1	81.7
	I have some problems washing or dressing myself	3.6	2.7	15.8
	I am unable to wash or dress myself	0.3	0.2	2.5
Usual activities	I have no problems with performing my usual activities	91.3	92.8	68.8
	I am unable to perform my usual activities	8.11	6.7	28.0
	I am unable to perform my usual activities	0.6	0.5	3.2
Pain/discomfort	I have no pain or discomfort	77.3	78.5	60.1
	I have moderate pain or discomfort	20.5	19.8	30.5
	I have extreme pain or discomfort	2.2	1.7	9.4
Anxiety/depression	I am not anxious or depressed	88.9	89.6	79.7
	I am moderately anxious or depressed	10.4	9.9	17.41
	I am extremely anxious or depressed	0.7	0.5	2.9

Data source: KNHNES (2015)

The answers to the five dimensions of EQ-5D were analysed by disability, and the result demonstrated that disabled people had more severe problems than non-disabled people in every dimension. In the dimension “mobility,” more than 40% of disabled people responded they have at least some or moderate problems with mobility (moderate 37.2%, extreme 3.0%) while it was around 10% in non-disabled people (moderate 9.9%, extreme 0.5%). In the dimension of “usual activities” and “pain/discomfort,” the proportions of disabled people having problems (moderate 28.0%, extreme 3.2% in usual activities; moderate 30.5%, extreme 9.5% in pain/discomfort) was considerably higher than those of non-disabled people (moderate 6.7%, extreme 0.5% in usual activities; moderate 19.8%, extreme 1.7% in pain/discomfort). The dimension of “pain/discomfort” held the highest proportion of extreme problems in both non-disabled and disabled people. Also, the least proportion of people had functional problems in the dimension of “self-care” in both groups (no problem 97.06% in non-disabled people, 81.67% in disabled people).

The EQ-5D index score was derived from each score in every dimension. In this study, the EQ-5D index score was included in the raw data, calculated according to Nam et al. (2007) (Korea Centres for Disease Control and Prevention, 2014). The EQ-5D index score computed by this method has a value between -.081 and 1, and the larger number means the healthier status (see chapter three). The result of the analysis of the EQ-5D index score by disability is presented in Table 4.10. Based on skewness and kurtosis, the distribution of the EQ-5D index score did not follow a normal distribution (Kim, 2013).⁴

⁴ Skewness is a measure of the asymmetry and kurtosis is a measure of ‘peakedness’ of a distribution.

[Table 4.10] EQ-5D index score

	Total	Non-disabled people	Disabled people
Mean	.9450	.9518	.8473
Skewness	-3.6216	-3.8096	-1.9490
Kurtosis	21.9548	24.6255	8.0357

Data source: KNHNES (2015)

As seen above, the EQ-5D index score of non-disabled people (.9518) is a little higher than that of disabled people (.8473). In other words, non-disabled people are healthier than disabled people.

4.2.3 Health status measured by morbidity

In this section, the health status measure by the morbidity of chronic diseases is analysed. The following table 4.11 indicates the proportion of respondents diagnosed with 22 chronic diseases set by KNHNES.

[Table 4.11] Morbidity of chronic diseases

(Unit: %)

	Non-disabled people	Disabled people		Non-disabled people	Disabled people
Hypertension	15.6	34.9	Stomach cancer	.7	.1
Dyslipidemia	10.0	23.5	Liver cancer	.1	.3

	Non-disabled people	Disabled people		Non-disabled people	Disabled people
Stroke	1.5	11.0	Colorectal cancer	.4	1.8
Myocardial infraction	0.6	1.4	Lung cancer	.1	.5
Angina pectoris	1.3	3.2	Depression	3.1	10.5
Osteoarthritis	8.0	22.4	Atopic dermatitis	3.7	1.3
Rheumatoid arthritis	1.6	3.5	Allergic rhinitis	15.0	6.8
Pulmonary tuberculosis	3.8	7.0	Renal failure	.3	3.9
Asthma	3.0	5.3	Hepatitis B	1.5	3.4
Diabetes mellitus	6.4	19.7	Hepatitis C	.2	.5
Thyroid gland disease	3.0	2.7	Liver cirrhosis	.2	1.7

Data source: KNHNES (2015)

As seen from the table above, the results show that except for four (thyroid gland disease, stomach cancer, atopic dermatitis, allergic rhinitis) out of 22 chronic diseases, the morbidity of disabled people was higher than non-disabled people. Especially, disabled people demonstrated significantly high morbidity than non-disabled people in hypertension (non-disabled people: 15.6%, disabled people: 34.9%), dyslipidaemia (non-disabled people: 10.0%, disabled people: 23.5%), stroke (non-disabled people: 1.5%, disabled people: 11.0%), osteoarthritis (non-disabled people: 8.0%, disabled people: 22.4%), and depression (non-disabled people: 3.1%, disabled people: 10.5%). The rest of diseases' morbidity was too low in both groups, or the difference was too small to be significant.

To sum up, disabled people assessed their health lower than non-disabled people (SAH, EQ-5D), and their morbidity of chronic diseases was higher, as well. Consequently, it seems clear that the health of disabled people was lower than non-disabled people.

4.2.4 Healthcare service use

To investigate healthcare service use of disabled and non-disabled people, the general health check-up and cancer screening rate in the latest two years and unmet healthcare needs were analysed. Unmet healthcare needs were measured by the experience of not being able to go to the healthcare centre despite being unwell for the last one year. The main reason for not receiving healthcare service was inquired as well.

[Table 4.12] General health check-up and cancer screening receiving rate

(Unit: %)

	Total	Non-disabled people	Disabled people
General health check-up	60.7	60.5	64.1
Cancer screening	46.3	45.7	54.9

Data source: KNHNES (2015)

Table 4.12 above presents the receiving rate of general health check-up and cancer screening of disabled and non-disabled people. The receiving rate of the general health check-up of disabled people was 64.1%, while that of non-disabled people was 60.5%. That of cancer

screening was 54.9% in disabled people and 45.7% in non-disabled people. In both values, disabled people demonstrated a higher receiving rate.

Although all respondents were covered by the NHI or Medical Aid programme (see Table 4.2), a considerable population rate did not have general health check-ups or cancer screening for the last two years; This seemed to be related to the type of NHI. As mentioned in chapter two, the NHI programme provides a general health check-up to the self-employed insured over 40, and insured the employee for free at least once every two years. It also provides cancer screening. The subjects of cancer screening vary depending on the kind of cancer, but the most common standard age is over 40 (see chapter two). However, many people did not receive health check-ups because it was not compulsory for the self-employed insured, the dependents of employee insured, and Medical Aid users. In the employee insured cases, based on the Occupational Health and Safety Act 1990, the employers are forced to provide the convenience of designating nearby healthcare centres and helping to receive group check-ups with their colleagues, so the receiving rate is relatively high. The receiving rate of general health check-up and cancer screening by medical security below supports this assumption. The receiving rate was highest in the employee insured, and the self-employed was next, and the Medical Aid user was the lowest.

[Table 4.13] General health check-up and cancer screening receiving rate by the kind of medical security

(Unit: %)

	Total	NHI		Medical Aid
		Self-employed insured	Employee insured	
General health check up	60.7	51.4	66.7	45.2

	Total	NHI		Medical Aid
		Self-employed insured	Employee insured	
Cancer screening	46.3	44.0	48.1	40.3

Data source: KNHNES (2015)

What is notable is that although the proportion of medical aid users was relatively high among disabled people (see Table 4.2), their receiving rate was higher than non-disabled people. This might reflect their older age and higher healthcare needs.

[Table 4.14] Unmet healthcare needs

(Unit: %)

	Total	Non-disabled people	Disabled people
Yes	12.5	12.3	15.2
No	87.5	87.7	84.8

Data source: KNHNES (2015)

The proportion of disabled people who did not have their healthcare service needs met for the last year was 15.2%, and that of non-disabled people was 12.3%. The unmet needs of disabled people were a little bit higher, but the gap was not large.

[Table 4.15] Reasons of unmet healthcare needs

(Unit: %)

I did not go to the healthcare centre...	Total	Non-disabled people	Disabled people
For financial reasons	25.9	23.5	53.6
Due to difficulties in making an appointment	1.9	2.1	-
Due to the poor transportation	4.6	4.4	6.5
Due to the unavailable office hours	31.7	33.0	16.4
Because I did not want to wait too long	4.8	5.1	1.7
Because the symptom was not serious	22.0	23.2	8.6
For other reasons	9.1	8.8	13.2

Data source: KNHNES (2015)

When participants were asked why they did not attend their healthcare centre despite being unwell, 53.6% of disabled people and 23.5% of non-disabled people answered that they did not go due to financial reasons. This answer, which showed a large difference from non-disabled people, implied the low socio-economic status of disabled people. The main reason for not receiving healthcare services in non-disabled people was “unavailable office hours (31.7%),” which was the second most answer among disabled people as well (16.4%). It seemed that working people had difficulties in using healthcare services because of the limitation of the healthcare centres’ office hours.

4.3 Health inequality and concentration index analysis

In this section, health inequality within groups of non-disabled and disabled people will be analysed. Here, health inequality is defined as “differences in health that are unnecessary, avoidable and unfair and unjust (Whitehead, 1992: 431), systematically patterned and socially produced (Whitehead and Dahlgren, 2006)” which had been explained in detail in chapter two. It implies variations in health determined not by biological factors such as heredity but by “social determinants of health” (housing income, etc.) (see chapter two). This phenomenon has been identified as “socio-economic inequality in health” (Morasae et al., 2012).

4.3.1 Concentration index analysis

To understand the health inequality of the study sample, Concentration Index (CI) analysis, the most widely used method to measure socio-economic inequality in health, was applied (see chapter three). With CI, the scale of health inequality will be presented, and by decomposition of CI, the relative importance of the impact factors will be considered.

As the first step of CI analysis, each group to be compared to each other was divided based on income level into five equal subgroups (quintile). In this analysis, the equivalised household income quintile was divided based on the status within their own groups, not the whole population. The health status gap between disabled and non-disabled people was not the focus of this analysis. Instead, a comparison of health inequality within the disabled group and that within the non-disabled group was pursued. In other words, the question “in which

group disabled or non-disabled people, is health inequality more serious?” was asked and answered. Therefore, the quintile means income rank within the group.

The median value of equivalised household income by quintile is shown in Table 4.16.

[Table 4.16] Median household income by quintile within group

(Unit: %/ thousand won)

	Non-disabled people		Disabled people	
	Proportion	Median	Proportion	Median
Lowest quintile	17.0	500	18.92	290
Second quintile	19.6	1,154.7	17.82	552.2159
Third quintile	20.9	1,683.9	19.20	1,000
Fourth quintile	21.8	2,405.7	22.73	1,750
Highest quintile	20.7	3,726.9	21.33	3,050
Income quintile share ratio	-	7.4	-	10.5

Data source: KNHNES (2015)

The median household income of non-disabled and disabled people demonstrated large gaps in each quintile. To compare the income equality within groups, the “income quintile share ratio” was identified. This is the ratio of the median income of the highest quintile to that of the lowest quintile. These values were 7.45 in the non-disabled group and 10.52 in the disabled group, demonstrating that income equality was worse among disabled people. In other words, the wealth was distributed more unequally within disabled people than within non-disabled people.

Next, CI analysis of SAH and EQ-5D was conducted. By nature of variables, Erreygers normalised CI was calculated (see chapter three). Table 4.17 presents three Erreygers

normalised CI calculated by converting SAH into three dichotomous variables according to the cutting point (see Figure 3.3).

[Table 4.17] Erreygers' normalised CI of SAH

	Total	Non-disabled people	Disabled people
SAH 1 (Good health=very good, good, fair/ordinary, bad poor health=very bad)	-.0631780	-.0536314	-.0761662
SAH 2 (Good health=very good, good, fair/ordinary poor health=very bad, bad)	-.1344904	-.1120040	-.2088278
SAH 3 (Good health=very good, good, fair/ordinary poor health:=very bad, bad, fair/ordinary)	-.1335230	-.1163217	-.1924949

Data source: KNHNES (2015)

The Erreygers normalised CI had negative values in both groups regardless of the cutting points. This means there is pro-rich health inequality (health inequality that the rich are healthier than the poor) in both groups because the higher score of SAH means poor health (poor health=1, good health=0). Also, the absolute values of the CI were larger in disabled people. This means pro-rich health inequality is more severe in disabled people than in non-disabled people (see chapter three). In other words, non-disabled people are more equal in health status than disabled people.

Table 4.18 presents the Erreygers normalised CI of EQ-5D index score of both non-disabled and disabled people.

[Table 4.18] Erreygers' normalised CI of EQ-5D index score

	Total	Non-disabled people	Disabled people
EQ-5D	.06206518	.0512451	.11594903

Data source: KNHNES (2015)

Both figures were positive, which means there is pro-rich health inequality in both groups. This is because the higher score of EQ-5D indicates better health. The Erreygers normalised CI of non-disabled people equals .0512 while disabled people, .1159, is larger. This means pro-rich health inequality is more serious in disabled people than in non-disabled people (see chapter three).

To sum up, health inequality analysed through two variables demonstrated similar results. There was pro-rich inequality in health both in non-disabled and disabled people, and this inequality was more severe within disabled people than within non-disabled people.

4.3.2 Decomposition of the concentration index

The relative size of the components of health, decomposed by dimension, was performed. In addition, to identify the relative contribution of the impact factors of health inequality, decomposition by determinants was also conducted. Since SAH is a binary variable, decomposition was carried out only for EQ-5D (see chapter three).

4.3.2.1 Decomposition by dimension

The results of decomposing the CI of EQ-5D by five dimensions are shown in table 4.19.

[Table 4.19] Decomposition of CI by dimension (EQ-5D)

	Non-disabled people			Disabled people		
	CI	Elasticity ⁵	Contribution (%p/%)	CI	Elasticity	Contribution (%p/%)
Mobility	.019446	1.0382539	36.5	.038176	1.1225536	34.5
Self-care	.002897	1.0489731	5.4	.013255	1.1669097	12.4
Usual activities	.007632	1.0459895	14.4	.021313	1.1549008	19.8
Pain/discomfort	.00859	1.0401893	16.1	.021751	1.1494518	20.1
Anxiety/depression	.004966	1.0452406	9.3	.012747	1.1652388	11.9
Residual	-	-	17.9			.9
EQ-5D	.055263	1	100	.124002	1	100

Data source: KNHNES (2015)

The order of contribution rate was similar in both groups. Mobility (non-disabled people: 36.5%, disabled people: 34.5%) was the largest contribution in both groups, followed by pain/discomfort (non-disabled people: 16.1%, disabled people: 20.1%) and usual activities (non-disabled people: 14.4%, disabled people: 19.8%). However, the contribution rate to health inequality among disabled people was more evenly distributed across all dimensions than non-disabled people. In other words, the gaps between dimensions in disabled people were not as large as that of non-disabled people. This can be interpreted as representing the

⁵ Elasticity refers to a measure of a variable's sensitivity to a change in another variable.

complexity of health inequality in disabled people, which presents multiple dimensions instead of only one.

4.3.2.2 Decomposition by determinants

In succession, the CI of EQ-5D was decomposed by determinants and the results are as follows.

[Table 4.20] Decomposition of CI by determinants of non-disabled people (EQ-5D)

		Coefficient	Mean	Elasticity	CI	Contribution (%p/%)
Gender	Men					
	Women	-.019611***	.51010	-.01050	-.06458	1.2665
Age		-.0021083***	43.8643	-.09715	-.11535	20.9133
Education	High school or below	-	-	-	-	-
	Junior college or over	.010187***	.33899	.00362	.293716	1.9884
Employment	Working in paid job	-	-	-	-	-
	Not in paid job	-.0186397***	.39890	-.00781	-.18298	2.6672
Marital status	Married	-	-	-	-	-
	Single, separated, widowed	-.030194***	.35968	-.01140	-.12501	2.6615
Medical security	NHI	-	-	-	-	-
	Medical aid	-.1029016***	.02298	-.00248	-.0633	.2934
Residual		1.072764***				70.2094
						100

* $p < .05$. ** $p < .01$, *** $p < .001$

Data source: KNHNES (2015)

Table 4.20 shows the result of decomposing the Erreygers normalised CI by determinants in non-disabled people. Independent variables were set following the literature review, and the nominal variables such as gender, education, employment, marital status, and medical security were converted as dummy variables (conversion of a categorical variable to a continuous variable for analysis). The results presented coefficient, mean, elasticity, CIs, and contribution of each explanatory variable of EQ-5D inequality. The coefficients demonstrated the impact of each variable on health status measured by EQ-5D. The coefficients of all input variables were significant, but the absolute values were very small. It can be assumed that this significance was due to the large sample size. It can be interpreted that women, rather than men, people of older age, lower education, no paid-job, no spouse, using the Medical Aid programme had lower health status. With regard to the interpretation of CI, being women, of older age, not in a paid job, not married (single, separated, or widowed), in Medical Aid have negative CIs, meaning that they were more concentrated among people with lower income. Conversely, being in a junior college or over, which means higher education has a positive CI and was more concentrated among those of higher income. The characteristics of those in lower-income levels and lower health status correspond to the common socio-economic trends of South Korea. About the contribution to health inequality, age made the largest contribution (20.91%), followed by employment (2.67%), marital status (2.66%), and gender (1.27%).

[Table 4.21] Decomposition of CI by determinants of disabled people (EQ-5D)

		Coefficient	Mean	Elasticity	CI	Contribution (%p/%)
Gender	Men					
	Women	-.0163559	.39721	-.00766315	-.19168	1.1845
Age		-.0043375***	57.01954	-.29172378	-.1627	38.2775
Education	High school or below	-	-	-	-	-
	Junior college or over	-.0493464	.13617	-.00792626	.216251	-1.3822
Employment	Working in paid job	-	-	-	-	-
	Not in paid job	-.0646949**	.56128	-.04283121	-.39114	13.5102
Marital status	Married	-	-	-	-	-
	Single, separated, widowed	-.0280884	.36629	-.01213568	-.27688	2.7097
Medical security	NHI	-	-	-	-	-
	Medical aid	-.1032825***	.14466	-.01762339	-.29852	4.2426
Disability type+	MF	-	-	-	-	-
	SC	.0614708**	.20136	.014600123	-.08534	-1.0047
	IO	.0215054	.06111	.001550347	.066199	.0827
	M	.0443776	.09264	.004849362	-.07081	-.2769
Disability grade	Severe	-	-	-	-	-
	Mild	.0213484	.81777	.020592301	.014279	.2371
Residual		1.14232				42.4193
Total						100

* $p < .05$. ** $p < .01$, *** $p < .001$

MF: mobility function/ SC: sense and communication/ IO: internal organ/ M: mentality

Data source: KNHNES (2015)

For disabled people, additional independent variables such as disability type and disability grade were analysed. The fifteen disability types were re-categorised as four categories, as

seen in table 4.4. Disability grade was considered as either severe or mild grade. Table 4.21 presents the results for disabled people. Unlike non-disabled people, the coefficients were significant in age, employment, medical security, and disability type. The impact of other variables was insignificant. The coefficients implied that disabled people of older age, with no paid job, using the Medical Aid programme and with mobility function difficulties, had lower health status. Like in non-disabled people, the CI demonstrated that women, old-aged, not in paid jobs, not married, Medical Aid users were more concentrated among people with lower income. Highly educated people were concentrated in people with higher incomes. As for disability-related characteristics, people with sensory and communication impairments and mental disability were more concentrated in the lower-income category than those with difficulties in mobility, whereas people with internal organ diseases were at a higher income level than the reference group (MF). When it comes to disability grades, the mild grade group was more concentrated in a higher income group. This revealed that in disabled people, age made the largest contribution to health inequality (38.28%). Employment (13.51%), medical security (4.24%), marital status (2.71%) followed in respective importance. Disability type and grade did not have a large contribution to inequality. The most greatly contributing variable was age and employment. The contribution rates of other variables were less than 5% and insignificant.

4.4 Summary

This chapter investigated the health-related characteristics and health inequality of disabled people of South Korea. National data collected by KNHNES were analysed and the results were presented compared to that of non-disabled people. Disabled people were more likely to

be men, older, in lower income, and in a lower education level than non-disabled people. Also, they were unlikely to be in a paid job compared to non-disabled people.

With respect to health status measured by SAH, EQ-5D, and morbidity of chronic diseases, disabled people presented lower health status than non-disabled people. Disabled people used preventive healthcare services more, but their unmet healthcare needs were higher than non-disabled people. Their internal health inequality was examined by CI analysis and this demonstrated that it was more severe than that of non-disabled people. The decomposition of CI by dimension presented that health inequality among disabled people was constructed by every dimension of health rather than one particular dimension. In the decomposition by determinants, age and employment appeared to be the greatest contribution to health inequality. In the following chapters, based on these findings, the barriers to the healthcare service use of disabled people will be explored by analysing qualitative data collected through focus groups and interviews.

Chapter 5 Living with impairments: developing secondary impairments and how they are related to health outcomes

This chapter addresses the first theme of the two inferred through thematic analysis of qualitative data: secondary impairments. The other theme is “inequality in healthcare utilisation” and it will be addressed in chapter six. In this chapter, first, the various aspects of secondary impairment are represented through participants’ vivid voices. Then the causes and processes of development of these impairments are explored, identifying the impacts of social determinants of health. In addition, the medical treatments for secondary impairments and participants’ satisfaction are reviewed with conflicting cases. Following this, the reasons why people accepted or not when being advised to take medical treatments are described. Finally, the role of Personal Assistant Service as a facilitator of health for disabled people and its relations with independence are presented.

5.1 Impact of various secondary impairment

The main reason why secondary impairments of disabled people matter are that they deteriorate their quality of life (Sezer et al., 2015; Barker et al., 2009; Noreau and Shephard, 1995). When the participants were asked to explain their physical and mental health conditions, they talked about various symptoms. Conditions such as bowel or bladder problems, fatigue, depression, overweight or obesity, pain, and pressure ulcers, referred as common secondary impairments of disabled people by the Centres for Disease Control and Prevention (CDC) of the US (CDC, 2016), were found in the participants. These impairments adversely impact on living normal daily lives and undermine their well-being. Participants

described how these impairments affect their lives.

These secondary impairments have been investigated in previous studies as well (Sezer et al., 2015; Barker et al., 2009; Kinne et al., 2004), however, mostly in medical journals, and instead of describing in detail the experiences of disabled people in their real lives, the state and “diagnosis” of “patients” were described in short. In addition, there was relatively little interest in the social environment. This study seeks to explore secondary impairments in more detail through the voices of disabled people, considering the social-environmental impacts.

An example is presented through Jinu’s story. Jinu, working at a Centre for Independent Living (CIL), is a 30-year-old man with muscular dystrophy, which is a group of degenerative muscle diseases with progressive muscle weakness and atrophy, characterised by necrosis and regeneration of muscular fibre caused by genetic factors (Garfunkel et al., 2007: 386). He explained the impact of his primary impairment:

My legs are spread open because they are too weak. The pelvis is spread often so sometimes I have no choice but to tie my legs when I sleep. It is painful and feels like I have pins and needles in my legs when I wake up, but it is necessary to prevent more severe body transformation. Also, I am always sitting down on a wheelchair so that I cannot lie straight on my back. Then I have a backache and my legs feel tight... As you can see, I’m overweight. It was more (Jinu/M/30)

In Jinu’s case, a weakness in his musculoskeletal system caused by the primary impairment led to a body transformation which brought about chronic pain. He has used a wheelchair for long periods and his body weight pressed over his pelvis, leading to the transformation of his lower body and progressive muscle weakness which in turn aggravated the transformation. He supposed that his overweight seemed to accelerate the transformation. All these body outcomes resulted in chronic pain which is a general symptom among wheelchair users. Their

pelvis tilt, spine crooked, and the balance of the body is lost (Kwon and Chae, 2010; Son, 2009; Ku et al., 2005).

Some of the secondary impairments reported were known as common symptoms of specific primary impairments. 44-year-old Min-soo is an independent living movement activist working at a Centre for Independent Living (CIL). His primary impairment is cerebral palsy, an umbrella term referring to a group of syndromes consisting of non-progressive lesions or impairments generated by an immature brain, leading to movement disorder (Goldsmith et al., 2018). He explained that cervical herniated nucleus pulposus disc is common among people with brain lesions. Other participants with cerebral palsy supported his opinion by saying that they had cervical herniated nucleus pulposus disc, lumbar herniated nucleus pulposus disc, and spinal stenosis, accompanied by chronic pain.

In addition, pressure ulcers were common secondary impairments particularly noticeable among the people with paralysis of their lower body. Pressure ulcers indicate localised injuries of the skin and underlying tissue caused by pressure, shear, friction, or a consolidation of these factors. If a body part is continuously pressed in one position, it causes tissue ischemia, cell deformation, poor drainage of water, and cell death, which generates pressure ulcers (Sonenblum et al., 2014). Several participants talked about difficulties caused by pressure ulcers, which demonstrates implications for the development of secondary impairment and social determinants of health (SDH).

The most common secondary impairment found in the focus groups and interviews were chronic pain and fatigue. Young-min had a spinal cord injury after a car accident in his late twenties. He had fracture-dislocation, which left his whole body paralysed. He has used a wheelchair over 30 years and suffered from multiple secondary impairments besides pain and fatigue, which he described as:

I feel pain on the whole body because of orthostatic hypotension or when my blood pressure lowered when I sit down. When my blood sugar level goes down, I hear something like a mechanical sound in my head for a long time. When my blood pressure goes down, I feel dizzy so I lean my body forward but it makes my pelvis painful. (Young-min/M/63)

Like Young-min, many participants complained of pain and fatigue from a variety of causes. A 24-year-old college student Chul had focal segmental glomerulosclerosis (FSGS), which caused chronic renal failure since he was eleven. He had hemodialysis two or three times a week for four hours and described feeling exhausted after dialysis:

I don't have many physical problems, but the next day after dialysis I feel severe fatigue. At that time, I ache all over my body. (Chul/M/24)

Fatigue is one of the most common symptoms of those who have dialysis experience, which deteriorates their quality of life considerably and affects most areas of life severely (Bossola et al., 2011; Letchmi et al., 2011).

In general, the participants mentioned a wider range of secondary impairments such as osteoporosis, arrhythmia, renal disease, haemorrhoids, respiratory problems, and weak immune systems. Scoliosis was found in many participants with muscular diseases. Heart diseases were also pointed out as a consequence of dialysis. In summary, whatever their impairments were, their daily livings were significantly impacted by these various secondary impairments.

5.2 Cause and treatment of secondary impairments

Participants described how the various secondary impairments mentioned above developed and how they coped with them. The causes, processes, responses, and outcomes of the development of secondary impairments will be presented in this section.

5.2.1 Exploring why secondary impairments happen to disabled people

Secondary impairments are arguably stated as just medical conditions. However, its occurrence and progress were influenced and aggravated by SDH. As seen in chapter one, SDH is defined as “the condition in which people are born, grow, live, work, and age” (WHO, 2015), meaning the environmental factors influential to health status. Dahlgren and Whitehead (1993) suggested five dimensions of SDH as “age, sex, and constitutional factors,” “individual lifestyle factors,” “social and community networks,” “living and working conditions,” and “general socio-economic, cultural, and environmental conditions.” Participants’ narratives described how factors such as the economic condition or others’ support influenced their health and the emergence of secondary impairments.

One significant example is pressure ulcer development. As mentioned above, wheelchair users, without upper limb strength to be able to self-repositioning, seated most of the day and with little mobility, were vulnerable to pressure ulcers (Kim and Kim, 2016). The risk of pressure ulcers increases with ageing because when muscle mass shrinks with ageing, muscles in the buttocks or back decreases, and the muscles acting as a cushion weakens, and the skin faces greater pressure (Jaul, 2010). These ulcers significantly impact people with

negative psychological, physical, and social consequences affecting health-related quality of life (Woodhouse et al., 2015; Lala et al., 2014; Sonenblum et al., 2014).

Pressure ulcers are preventable with appropriate care. Park and Heo (2015) suggested three main dimensions to prevent them: repositioning, skincare, and nutrition care. The recommended methods are: to reposition or use an alternating pressure pad for a wheelchair, chair, or bed mattress to avoid putting pressure on the same region for too long; to keep the skin clean and dry and check it daily; to massage muscles to promote blood circulation; and to improve nutrition status (Park and Heo, 2015). The removal of pressure by repositioning is one of the most important and effective ways to prevent pressure ulcers.

It is not easy, however, to practice the prevention methods (Haesler, 2014). For example, eating healthy food such as fresh vegetables and fruits for better nutrition is expensive and to buy assistive technology like alternating pressure pads is also costly. Those who cannot reposition themselves need an assistant to take care of them. A complex mix of material resources and human support and care is needed for the risk of pressure ulcers to be reduced. Ja-Young, Hyun, and Yuri's stories demonstrate how these factors contributed to this common secondary impairment in disabled people with impaired mobility.

I got a pressure ulcer in November 2014. This disease (Devic syndrome) occurred in 2001 and I've used the wheelchair since 2006. [...] I was too busy with work at that time, so didn't care about the wound and neglected it, then it turned into a pressure ulcer. (Ja-Young/F/44)

Ja-Young, a 44-year-old single woman with Devic's syndrome, working as vice-director of CIL. Devic's syndrome, also known as Devic's disease or neuromyelitis optica is a heterogeneous condition consisting of the simultaneous inflammation and demyelination of

the optic nerve and spinal cord. This syndrome's symptoms are a rapid loss of visual acuity, weakened muscular strength, difficulty in walking, perception-motor disorder of the lower body, hypoesthesia, and incontinence (Farlex Partner Medical Dictionary, 2012).

The initial origin of Ja-Young's pressure ulcer was a wound neglected due to her overwork as a vice-director of CIL, which interfered the healing process and a pressure ulcer developed. Since it is extremely difficult to heal pressure ulcers once they develop, it is crucial to prevent them from the outset (Haesler, 2014). However, Ja-Young did not have sufficient time, finances, and support to prevent and care for her pressure ulcer.

Hyun, a 26-year-old postgraduate student studying particle physics, had a similar condition, but his social support contributed to a different health outcome. His primary impairment is spinal muscular atrophy (SMA), a genetic degenerative neurological disorder characterised by loss of motor neurons and progressive loss of muscle strength (Lunn and Wang, 2008). SMA symptoms are heterogeneous, but they often include loss of deep tendon reflex of limbs, weakness, and hypotonia of symmetrical muscle, hypofunction of facial muscles, and muscle contraction of the tongue (Farlex Partner Medical Dictionary, 2012). Hyun had this impairment since childhood and used a wheelchair for long periods but has never developed a pressure ulcer, and he attributed this to his parents' support. Unlike Ja-Young, he was living with his parents and was able to get help from them. However, while living with parents is common in young people, it is unusual for adults over 40. Even though some disabled people live with their parents because of this care issue and the affirmative support of family has a positive effect on the lives of disabled people (Kim and Bae, 2005; Mant et al., 2000), this involuntary cohabitation was pointed out as a cause of family burden and factor hindering the independence of disabled people (Kim, 2009). This can be used as a ground of the assertion that the public care service for disabled people should be expanded.

Yuri, at 19 years of age, with the same impairment (SMA) but different subtype as Hyun, described a similar situation:

Usually people with this illness suffer from pressure ulcers but my mother cares for me very well and I can reposition myself to some degree so I'm fine. Also, I use an air cushion. (Yuri/F/19)

Yuri is an undergraduate student studying business administration, grown up in a middle - class family, and lives with her family. Like Hyun, she explained how she avoided developing pressure ulcers with her mother's dedicated care and support. An air cushion helped her preventing pressure ulcers as well by dispersing the body pressure. Her parents purchased the air cushion separately from the wheelchair, which cost about 500 thousand KRW (328.28 GBP) when purchased; a burdensome price to be paid. As seen in chapter four, the median of the equivalised household income per month of households, including disabled people, was 1,172 thousand KRW (769.48 GBP) while that of a non-disabled household was 1,750 thousand KRW (1,148.97 GBP) in 2014. In already financially unequal households, this specific assistive technology's cost represents almost half (42.6%) of the total monthly income. Yuri's economic situation, or rather that of Yuri's parents, allowed her to purchase the air cushion, facilitates positive health outcomes preventing secondary impairment.

The difference between Ja-Young and Hyun or Yuri in the development of pressure ulcers represents the impact of SDH, such as financial access to care and equipment for prevention on the process where the primary impairment develops into an additional secondary impairment. The importance of "social and community networks" or "living and working conditions" have been previously described as a key factor affecting health (Braveman and Gottlieb, 2014; Viner et al., 2012; Bambra et al., 2009). In the context of the higher poverty rate of disabled households, this risk is likely to increase.

Other factors illustrated the influences of SDH in disabled people. For example, Bomi is a 44-year-old woman with polio sequelae, working as an admin staff of CIL. Her primary impairment is polio, also known as poliomyelitis or infantile paralysis, which is an infectious disease caused by nervous system infection or another poliovirus (Farlex Partner Medical Dictionary, 2012). This participant related environmental factors with the development of her secondary impairment. She explained how she contracted pleurisy (inflammation of the pleura) at the age of 19 due to the strenuous job of using a manual wheelchair, which increased her fatigue and lowered her immune function, making her body vulnerable to pleurisy. The cost associated with purchasing and maintaining electric wheelchairs restricts their availability for people from low-income households. In South Korea, as of 2020, the standard price of electric wheelchairs is about 1.2 million to 5 million KRW (787.87-3,282.78 GBP), and this exceeded the equivalised household income per month of disabled household mentioned above. Since the purchase of an electric wheelchair is covered by the National Health Insurance (NHI), if an electric wheelchair of about 2 million KRW is purchased, the buyer pays about 200-400 thousand KRW (131.11-262.62 GBP). However, 25 years earlier, when Bomi had pleurisy, there was no such benefit, so the buyer had to pay the full amount. The numerical price of electric wheelchairs would be different from the present due to the value of money, but it would have been a considerably expensive product at that time as well. Therefore, it must have been a considerable financial burden to pay for the electric wheelchair. The need for an electric chair is also related to an inaccessible physical environment. Participants identified the impact of this on their health and wellbeing.

Dong-jin explained how his primary impairment developed into a secondary impairment affected by inaccessible spaces that could support his incontinence needs:

My primary impairment is a spinal cord injury. It is a spina bifida. My spinal nerves have been damaged since I was born due to an unknown cause. It was unknown,

anyway, my kidney was impaired. Because of my urination disorder, my kidney worsened little by little. In 1993, when I studied in the library, I could not go to the toilet very well. It caused a haemorrhage in the kidney and I was diagnosed as having haematuria and proteinuria. [...] I began to use a catheter, but I couldn't insert the catheter unless there was an accessible toilet for disabled people. [...] Maybe I was ashamed because I was young then. Without an accessible toilet around, I held my urine for eight, ten hours... (Dong-jin/M/46)

46-year old Dong-jin works as a director at CIL. He was born with a spina bifida, which is an incomplete closing of the backbone and membranes around the spinal cord (Farlex Partner Medical Dictionary, 2012), resulting in an inability to walk and, consequently, has developed kidney failure. He began to use a catheter, a thin tube inserted in the bladder to drain and collect the urine in the 1990s when the installation of accessible toilets was not common in South Korea. Although the absence of accessible toilets was not the only reason for his renal failure, it seemed to accelerate and aggravate his impairment. This demonstrates how these other secondary impairments can aggravate the health of disabled people caused by a disabling society (Shakespeare, 2017; French and Swain, 2012; Barnes and Mercer, 2005).

This disabling society influences disabled people's health through multiple layers. For Ja-Young, Yuri, and Hyun, the disabling or enabling environments were individual human support or finances. On the other hand, in Dong-jin's case, the secondary impairment was developed by the lack of accessible physical facilities (absence of accessible public toilets) rather than his economic situation. Those with higher income could overcome this architectural barrier with increased human support (i.e., a personal assistant to support toileting). This is related to the multiple layers of SDH (Dahlgren and Whitehead, 1993) in which the effects of each layer of SDH on health are influenced by broader circumstances. Emerson et al. (2011) described the adverse environments disabled people face across their

life courses: poor housing conditions, nutrient-poor diets, economic insecurity due to increasing care costs, and exclusion from the labour market (CSDH, 2008). However, the negative impacts of these factors, which can lead to a greater risk of poor health, can be smaller in high-income countries (Emerson et al., 2009) or less unequal societies. Similarly, disability employment and their inclusions in the labour market are powerfully influenced by welfare programme and national policies (Emerson et al., 2011). This demonstrates the importance of national policy as an upper layer of SDH and why health policy interventions should be considered on the multiple layers of SDH. They also pointed out that discrimination faced by disabled people (disablism) is a deterioration factor in health, which will be discussed in chapter six and subsequent chapters.

5.2.2 Secondary impairments and trade-offs in medical treatments

This section describes how participants responded to the impact of their secondary impairments in their quality of life and well-being. Their responses were different according to their own situations, and sometimes similar choices brought about opposing outcomes.

Some participants needed surgery due to their secondary impairments. These surgeries also had a diverse impact on their health. The cases of Dong-jin and Young-min illustrate two different sides of caring for secondary impairments through surgical intervention:

As I sit too long, I developed a fissure and got haemorrhoids. My wife got worried about it because my underwear was stained with blood due to the chronic haemorrhoids, so I had a haemorrhoidectomy. The haemorrhoids were caused by the spinal cord injury, because the injury caused severe constipation. Well, I might have

given up the treatment just because I'm a disabled person. But the treatment, the surgery was great. I don't bleed any more. (Dong-jin/M/46)

He has used a wheelchair for a long time and developed cracks in the skin or the anal fissure, which led to haemorrhoids. Haemorrhoids are enlarged veins in the anus or lower rectum causing long-lasting discomfort, bleeding and occasionally extreme pain (Farlex Partner Medical Dictionary, 2012). Dong-jin's words implies that he was passive in the treatment of secondary impairment because of his impaired state. He eventually had surgery to ease his wife's anxiety, achieving a satisfactory outcome which had a positive impact on his well-being.

Another participant, Young-min, however, had a very different experience with using surgery to improve quality of life:

I developed a pressure ulcer in 1998-99. It was under the anus... around the hip, left side. [...] Yet it didn't improve so in 2009 I had pressure ulcer surgery. I think that in the process of anesthesia, too much anesthetic drugs went to my waist at that time. Since then my waist weakened and opening my bowels became more agonising. Before the surgery, I could strain my waist to defecate to a certain degree but after I had surgery, it feels like jelly. When I defecate, it takes several hours and perspire heavily all day long. The stools are watery and there is an incontinence problem as well. Sometimes it continues until the next day, even for five days. So it becomes more and more difficult to make plans with somebody or some regular activities. Still, it's the same. (Young-min/M/63)

As mentioned above, Young-min's primary impairment was a spinal cord injury. He developed dyschezia, a problematic and painful defecation (Farlex Partner Medical Dictionary, 2012), which deteriorated since he had surgery. After surgery, to empty his

bowels became more difficult and painful and he developed occasional fecal incontinence. Incontinence not only inflicted his physical suffering but also disturbed his social life considerably because it affected his ability to socialise and prevented him from doing outdoor activities. Incontinence also increases the risk of infections in pressure ulcers (Lachenbruch et al., 2016).

Postsurgical complications were found in other participants as well. Min-soo, whose primary impairment was also cerebral palsy, had surgery due to spinal disease several years ago and since then, he had had a post-surgery sequela consisting of chronic daily pain significantly affecting his wellbeing.

I cannot tolerate pain. Even with tiny pain, I go to the hospital and get an injection or some... treatment. I must relieve the pain. I have been in that kind of condition since I had surgery. The surgery was for spondylolysis of the lumbar spine. The lumbar spines need to be stuck to each other, but in my case, it was separated like this... (stretch fingers apart) So the doctor glued it, and the first surgery was successful. It really was. He placed a pin on my spine. I have focused on the rehabilitation therapy for two years after the surgery. Hydrogymnastics, physical therapy, and exercise therapy... I did nothing but to have therapy for two years. But two years later, I was in urgent need for some fast cash. The youngest baby was born then, so I needed to get a job. Even though the conditions did not permit, I had to work. I earned a high salary for three or four months, and then... while I was working, I could not eat or sleep well and was stressed a lot. This caused an infection on the wound. It was so painful that I couldn't stand it and was told to be admitted in hospital. Finally, the infection spread up one vertebra of the spine, so... I needed an artificial joint fitted. (Min-soo/M/44)

His story illustrates the relationship between material needs, work condition, and negative health outcomes. Min-soo was a recipient of the National Basic Living Security (NBLs)

system, and he was receiving welfare benefits from the government (livelihood benefit) (see chapter two). However, since his benefits remained low for a long time, this income would not have been sufficient to support his family. His employment conditions, such as long hours working without breaks, deteriorated his health. This resulted in chronic pain not well controlled, which made his daily living uncomfortable. Another postsurgical complication was hyperhidrosis, a disorder consisting of excessive sweating. During the focus group, he perspired copiously and explained that this was caused by postsurgical complications demonstrating how post-surgery impact made him feel uneasy and impaired his health outcomes.

50-year-old Gina was another participant who worked as a personal assistant and had rheumatoid arthritis. Her primary impairment was a long-lasting autoimmune disorder that primarily affects joints, typically resulting in swollen and painful joints (Farlex Partner Medical Dictionary, 2012). She had surgery two years ago due to weakness in her neck joint caused by the continuous use of steroid drugs:

I had to go to the hospital for physiotherapy as well. I felt tired and weak because it was an exhausting disease. [...] Definitely, the long-term medication does not seem to have been good for my neck. I heard that the neck is the weakest part among the joints. I've taken steroid for a long time so the neck has been weakened and fractured. Then, the doctor told me that I might be unable to use my lower body if I didn't have surgery. I underwent surgery two years ago. I felt severe pain on the neck, so I had a grimace of pain all the time. It was painful. After the surgery, the pain was so severe that I went to the oriental medical clinic and got a massage, physiotherapy, and acupuncture. It was effective and I recovered a lot. But now I have severe pain on other parts due to the long periods taking medicine. [...] Particularly, my digestive organs are so bad that I come here and there for a cure. (Gina/F/50)

Steroid drugs are widely used in treating chronic inflammatory diseases such as rheumatoid arthritis (Wolfe et al., 2006), and Gina had taken these drugs for a long time. As a side effect of long-term use of steroids, her joints weakened, and surgery was needed. The digestive disorder she mentioned is also a known side effect of steroid drugs (Health Service Executive, 2018). Like Young-Min and Min-soo, Gina suffered from severe pain on the neck because of postsurgical complications. None of these participants mentioned whether these surgeries were effective to the intended purposes, but post-surgery sequela was significant and lowered their quality of life and well-being.

5.2.3 Decision making and risk vs. benefits or medical treatments

Participants refused or abandoned the treatment of secondary impairments for many reasons. Some participants refused or gave up surgery for fear of negative consequences. Most of the time, medical treatment, including surgery, had some gains and losses simultaneously. Benefits of treatment varied: from improved physical function, reduced pain, or reduced risk of future complications. On the other hand, the losses included postsurgical complications and long periods of recovery, and these costs were regarded considerably high by some disabled people. Many participants mentioned this dualism of medical treatment and how this influenced their decisions about whether to start or abandon treatment. Hyun's case presented below illustrates this dualism.

It was not guaranteed to get a satisfying result (with the surgery) with the technique in those days. Also, it was uncertain whether I, the patient, would endure the surgery.

You can get some benefit through the surgery but lose as well. For example, my upper body is very weak but relatively flexible. But they said that if I have surgery, my posture

would be fixed and lose flexibility depending on the result, I should have been hospitalised from 1-2 to 5 years. My doctor said that he would recommend this surgery as a medical professional, but he wouldn't if he were my father. My mother gave up the surgery when she was told that. (Hyun/M/26)

Hyun did not want to spend several years in the hospital and chose a better quality of life rather than to straighten his cervical vertebral at the expense of years of hospitalisation. Equally crucial was the uncertainty of the surgery and how the trade-off between risks and benefits were assessed within the context of an already disabled body.

Participants reported doctors insisting on “fixing” their impairments for little benefit and the resistance to accept this. Kyu is a 21-year-old undergraduate male student with muscular dystrophy, grown up in a middle-class family who developed scoliosis as a secondary impairment. He explained how he resisted the medical solutions to this new impairment. The actual-decision maker for this was his parents, and he agreed to their decision:

I was advised to have the same surgery (correction of scoliosis) but I didn't have it. My doctors suggested it to me a lot of times but in that case, I heard that I had to be hospitalised for several months and it wouldn't be possible to raise my head again when I lower my head. At that time, my parents decided almost everything about me so they decided not to have it, and I agreed with them. I thought that it was not necessary to have surgery. [...] My parents used to take my big brother to the hospital for treatment a lot, but there was no noticeable improvement. So I didn't have too much treatment. (Kyu/M/21)

Although uncertainty was not mentioned explicitly, the benefit of surgery was questioned, and the medical recommendation was unsure. This is about trade-off. People were not ready to trade off decreasing well-being for uncertain outcomes. Although most doctors seemed to

assume and recommend fixing the disability with uncertain risk, one participant reported how a medical professional contrary to the rest suggested not to pursue a medical intervention.

Tae-yong's story illustrates one example of standards disabled people consider when they decide on their treatments. He was a 41-year-old man with cerebral palsy as primary impairment, working at an organisation supporting disabled students and as an instructor on disability rights:

When I was in the first year of my undergraduate course, I went to the hospital and asked the doctor "Which treatment would be better for me, surgery?" The doctor asked, "What year are you in?" "I'm a fresher" I replied. "Fresher? Can you eat for yourself, go to toilet, take a shower, and meet your friends?" "Yes, I can. It is a little bit difficult but I can do it." "Then you don't need to have surgery. If you have medical treatment now, you need to stay in bed for a long time. You can get well a little if you have surgery, but for it, you need to get a lot of physiotherapy. I think it's not a time for treatment but to make friends." He, the rehabilitation doctor, told me so! "If you don't have any particular difficulty in walking right now, then come to me when you're older. Then we can think about this again. Now, for your time and money, the expected improvement wouldn't be significant. It's time to enjoy your life." There are not that many doctors like him. (Tae-yong/M/41)

Considering the high monetary and non-monetary cost of surgery, Tae-yong's doctor regarded "time to enjoy life" as more important than medical treatment. Not only did he recommend to establish and expand social relations rather than concentrate on improving physical functioning for a young undergraduate but implicitly accepted that life with the impairment was equally valuable than life without it (Connor and Gabel, 2010, Edwards,

2005). Further, this story can be an example of reconciliation with the medical profession and demonstrate that there is a “different but good practice”.

The risks of fixing impairments relate to the concept of “iatrogenesis,” conceptualised by Illich (1976), which refers to illnesses created by medical interventions. This relates to the medical model of impairments and the concept of “medicalization” which means that bodily state, mind, and social behaviours are conceptualised and treated in the medical area (Davis, 2015). Disability, regarded as a moral failure for a long time, started to be recognised as a medical issue since the 19th century with the development of modern science because this made possible to escape from unscientific superstitions and moral judgements upon disabled people (Goodley, 2011) (see chapter one). However, since there is no such thing as “human perfection” (Shakespeare, 2017: 6) and the concept of normalcy is fictitious (Davis, 2015), it is neither necessary nor possible to cure or fix all imperfections. From a traditional but pervasive perspective, as disabled people are recognised as deviant human beings (Shakespeare, 2017), and they can be exposed to situations such as the recommendation of excessive or unnecessary treatments.

Finally, for some people, medical interventions brought about positive health outcomes. Yuri’s case demonstrates a different choice under similar circumstances and an increased quality of life post-surgery. Several years ago, Yuri was advised to have the same surgery as Kyu and had it. Satisfied with the result, she thought the surgery made her healthier:

This surgery is very risky. It touches all the vertebra to straighten them, inserts and tightens the screws within them. All the vertebrae have to be touched [...] The results can vary significantly. I had that surgery when I was eleven. Since I was expected to get well soon because of my young age, I decided to have the surgery to correct the vertebra before I had a more crooked spine. [...] As everyone regards their own

experience as the best... so I am pleased with the surgery. If my vertebra had gone crooked more severely, I might have been more vulnerable. I could expect better recovery because I was younger then. I think I'm better now than before the surgery.

(Yuri/F/19)

The financial burden of treatment influenced people's decision to pursue medical solutions, but this was not the only factor impacting decisions. Kang-oh's case illustrates this. 60-year-old Kang-oh was paralysed in the lower body in his early twenties due to an accident. He suffered from a variety of secondary impairments. He had both legs amputated due to pressure ulcers in 1995 and 2010, respectively, and still worries about ill-health due to new pressure ulcers. In the past, his pressure ulcers led to septicaemia, also known as blood poisoning. He also had a urination disorder, which made a hole in his urinary bladder, and needs to insert a catheter to urinate. Kang-oh was advised to have surgery for his bladder expansion, but decided against it:

I refused the surgery because I thought it was no good. If I had enough money, then I would accept the treatment. Since I had little money, once I had listened to the doctor's advice, and then did not accept what I think unnecessary. It's about money. (Kang-oh/M/60)

Although Kang-oh is a recipient of NBLS and can have medical treatment at a low cost (see chapter two), the costs not covered by the social security system influenced his decision. Treatments to "fix" secondary impairments are often considered non-essential and, consequently, not prioritised by those with low income. The financial burden of health will be addressed more in detail in chapter six.

5.3 Prevention, supporting service, and independence

One example of the positive effects of environmental support on preventing secondary impairments is the Personal Assistant Service (PAS). The PAS was introduced in South Korea in 2007 to support the independent living of disabled people and alleviate the caregiving burden of their families (Park and Chung, 2010) (see chapter two). Large numbers of participants were using the service, particularly people with paralysis of the lower body. All the users thought that PAS was greatly helpful, although most of them used it as a support for housework or daily living, and it was not common to associate PAS with improved healthcare needs. However, some participants clearly related PAS with improved healthcare outcomes and wellbeing.

Seon is a 38-year-old director of CIL. He got impaired in the spinal cord due to spinal disease when he was 22. He thought his disease was caused by his job and made an effort to be acknowledged that this impairment was an industrial accident, but it was not successful. Using a wheelchair for 16 years, he was making use of PAS to care for his health and explained the explicit effectiveness of the service:

In my case, my upper motor neuron system was impaired. That is, my cervical vertebra upper than five and six was injured. This impairment makes the muscles stiff and contracted. So I have to take medication, do joint movements, stretch myself, and have massages to prevent muscle's contractions. When there was no PAS, I couldn't do those things. It was a problem. It led to poorer health, much stress, I was more and more nervous ... But now I use medical services, have physiotherapy periodically, and my personal assistant gives me a massage. It helps me release my stress. [...] I depend on my personal assistant pretty much for healthcare. She helps me with stretching myself.

(Seon/M/38)

Some participants like Hyun and Yuri attributed their lack of pressure ulcers to the care of their parents; others, like Seon, relied on his personal assistant for pressure ulcer prevention. Dong-jin also related his improved health with the support of the personal assistant:

With the PAS, basically it is much better in personal hygiene such as having a bath. It is really helpful. Before I use it, I didn't go to the hospital even when I was sick because it was not easy to go out. Now I can go to the hospital with the help of the assistant. (Dong-jin/M/46)

The PAS enabled Dong-jin to care his primary needs but also to access the healthcare centre when needed, including urgent care. The effectiveness of PAS on users' health was reported by previous studies. Disabled people who used PAS reported that their health improved (Lee et al., 2007c), and physical function was improved (Kim, 2005b). Lee (2011a) reported that higher satisfaction with PAS facilitates health promotion behaviour. Early Nosek (1993) claimed that PAS had a positive effect on the health of disabled people. Not everybody related support with improved health outcomes. Sometimes assistive devices and support had negative effects on health like in the case of Kyu, who explained how using a wheelchair had contributed to the decrease in his independent mobility skills:

Because my big brother has the same impairment as me, my parents knew about this disease beforehand and prepared for it. I have muscular dystrophy which is a progressive disease. I was able to walk a little when I was very young but neither very well nor walking upstairs. I could walk until the first grade. Then I took a trip with my family. During the trip, I used a wheelchair because it was too hard to move around. Since then, the impairment got worse and I couldn't but use a wheelchair. In fact, my parents used to let my big brother have rehabilitation therapy, but there was no obvious improvement so in my case, I began to use a wheelchair right away. Before

using the wheelchair, I could use my arms, but since then I got difficulty in moving my arms. And when I was in the 12th grade, my parents helped me focus on studying for a college entrance examination by supporting eating or many other things. This made me move less and aggravated my impairment. (Kyu/M/21)

Kyu's brother's experience affected his parents' attitude to his impairment, letting Kyu use a wheelchair at a younger age than his brother. To provide "an appropriate level of support" that helps maintain or increase one's body function is complex. A similar context was found in other participants' views about the PAS. Although service users reported great satisfaction about the service in many cases, unintended consequences of PAS such as reduced exercise levels and mobility increased weight were also mentioned:

It's just like a joke (laugh), but does it (PAS) make you gain weight, seriously? I saw many cases in which disabled people don't move a lot with PAS. As a result, they gain weight. Anyway, it makes us move less. [...] I started independent living in 1997 and I have never used the PAS yet. I think I need the physical exercise. As a matter of fact, I cannot do lots of things but it's necessary because I don't workout. I know that this kind of housework cannot substitute the exercise, but I'm trying to do cleaning or laundry on purpose to move more. (Bomi/F/44)

Bomi pointed out the negative impact of the support leading to inactivity (even though to gain weight is not necessarily an indicator of poorer health itself). Kyung-a confirmed this duality of PAS outcomes. This 48-year-old woman with a visual impairment caused by glaucoma worked as a PAS coordinator at a CIL, and was a PAS user. She stated the PAS was essential and currently insufficient, but on the other hand, she agreed with Bomi that the PAS could bring about inactivity for some people:

With the PAS, we visually impaired people lose our independence occasionally. I saw those cases. It's kind of dependence... The personal assistants tend to do almost all the things which service users would do on their own before. (Kyung-a/F/48)

Kyu, Bomi, and Kyung-a believed that excessive support for what they could do themselves degenerated their physical function and promoted dependence. This relates to the major strategies of the well-known Social Role Valorisation (SRV) theory of Wolfensberger– the strategies for the enhancement of people's competencies (Osburn, 1998). Wolfensberger (1992) stated that, to enhance the competencies of devalued people, appropriate and effective services should be provided. For this, the level of the material support ought to be appropriate and excessive support can be a barrier to normalisation.

Reablement services can be one example that presents the relationship between support and independence. Reablement is a short and intensive service for disabled or frail people, with the purpose to help people relearn the skills for daily living and improve their ability to live independently (SCIE, 2012). Here, the term “independence” means the capability to perform a specific task by oneself rather than a term focusing on choice, control, and freedom of disabled people and self-determination on their own lives (Morris, 2006). Thus, it is a principle for the carers to focus on the service users' own strengths and help them realise their capacity to recover independence since excessive support can reinforce the dependence of service users.

However, these debates should not be grounds to justify reducing PAS. As illustrated in participants' experiences generally, PAS promote their health and independence and support activities of daily living. PAS should be delivered in effective ways to maintain and/or improve independence. The use of PAS by disabled people is different from dependency, and the emphasis on the performance of bodily task can be a regression to the rehabilitation

model that aims for maximal physical function (DeJong, 1979). This is why the concept of dependence and independence of disabled people was discussed with discretion (Kittay, 2011; Fine and Glendinning, 2005).

5.4 Summary

In this chapter, the diverse aspects related to secondary impairments were examined through the voices of disabled people. Participants described their various secondary impairments, and the causes and processes. External factors were clearly identified as affecting the development of secondary impairments in disabled people. Then, medical treatment of secondary impairments and how people trade-off the benefits and risks of fixing their impairments were explored. Participants were worried about these treatments, and their decision-making process was heterogeneous but mainly linked to quality of life. Finally, PAS' health and social outcomes were identified from the perspective of users of the service, illustrating how unintended consequences of PAS could have an effect on health. These results suggest that disabled people experience multiple barriers that cause secondary impairments, which in turn further deteriorate their health and wellbeing. These barriers are more pronounced for some people than others and financial and care support contribute to preventing secondary impairments.

Chapter 6 Inequality in healthcare utilisation

In the previous chapter, secondary impairments, their causes, and related factors as barriers to the healthy lives of disabled people were investigated. In this chapter, social factors such as physical structure or human attitudes will be explored by examining healthcare service use. This chapter focuses on the barriers to the use of healthcare service as perceived by the research participants, and examines how these social determinants have reinforced health inequality of disabled people. The process of healthcare service use will be presented as follows: before using the service, during the trip to the hospital and healthcare service centre, inside and outside the hospital, during the consultation and in the ward, and after using the service.

6.1 Barriers to healthcare utilisation before using the service

Disabled people encountered barriers before they use healthcare service. One of the key difficulties in using the healthcare service was that they could not find an available hospital nearby. Many participants were going to hospitals located far away from their home address, and Ja-Young was one of them. 44-year-old Ja-Young, vice director of a Centre for Independent Living (CIL), lives in an urban area, Daejun, one of the six metropolitan cities in South Korea (see Table 6.1).

[Table 6.1] Local administrative district of South Korea

First level			Second level
Regional local government	Number	Name	Basic local government
Capital city	1	Seoul	Borough
Metropolitan city	6	Busan, Daegu, Incheon, Gwangju, Daejun , Ulsan	Borough (urban), County (urban+rural)
Province	8	Gyeonggi , Gangwon, Chungbuk, Chungnam, Jeonbuk, Jeonnam , Gyeonbuk, Gyeongnam	City (over 50,000 population, urban) County (below 50,000 population, rural)
Special autonomous province	1	Jeju self-governing province	City
Special autonomous city	1	Sejong self-governing city	-

* Bold fonts are the areas mentioned in this chapter.

Daejun is a metropolitan city with a population of 1.5 million (Daejun metropolitan city hall, 2017), about 160 km away to Seoul's southeast. It is ranked as the fifth-largest city in South Korea according to population size (Statistics Korea, 2018b). Ja-Young was attending two different hospitals that are far away from each other; thus, it took a very long time to reach.

I used to go to two hospitals located far away. I work during the day and the hospitals - one is located in Ilsan, and the other one is in the opposite direction. Those are far from each other and from my workplace. So, I had to go this way, and then come around to go to the hospitals. (Ja-Young/F/44)

She was using two hospitals because one hospital was a general hospital for treatment of her Devic syndrome, and the other one was a rehabilitation hospital for rehabilitation therapy. Like Ja-Young, many participants had to travel long distances to use healthcare services, and some travelled to other cities, most frequently to Seoul, the largest city and the capital of South Korea where most healthcare resources are concentrated (Ministry of Health and

Welfare, 2016a). Some of them used the hospital in Seoul for short periods for diagnosis or surgery, but others continued to travel long distances for a while, and Jinu was one of them. Jinu is a 30-year-old man working at CIL as staff. His job was to investigate the convenient facilities of his community. He was diagnosed with muscular dystrophy when he was a child and went to Seoul for treatment. He moved to Seoul temporarily when his doctor advised his parents to continue to receive treatment long term.

When I was young, I received treatment for two years at a large university hospital located in Seoul. The doctor at the hospital advised me to continue treatment. But I don't live in Seoul, so I had to stay at my grandpa's home. (Jinu /M/30)

Jinu lived in a small-sized city, with a population of 280,000. He needed to move to Seoul, more than 400km away from where he has been living. His father remained where his family lived when he left for Seoul with his mother and stayed at his grandfather's. Participants travelled long distances for healthcare services because they believe hospitals providing good services are concentrated in large cities. Most participants have severe impairments and believed there were not enough healthcare resource to treat them in middle or small-sized cities and rural areas. The gap between metropolitan and provincial areas, especially the difference between Seoul and non-Seoul areas, was noted throughout the focus groups and interviews by many participants.

Gina, a 50-year-old female personal assistant, attended the hospital regularly due to her rheumatoid arthritis. She lived in Daejun like Ja-Young but used the Seoul National University Hospital, one of the biggest and the most renowned hospitals in South Korea. As stated above, Daejun is a relatively big city, but Gina wanted to go to the Seoul National University Hospital because she thought the doctors in that hospital would prescribe the most

modern treatment. She believed that there was a large healthcare gap between Seoul and other areas.

I live in Daejun and it would be convenient for me to go to a nearby hospital. But I go to the Seoul National University Hospital - I can get new medicine there very quickly. It's a better hospital so... so I wouldn't want to change hospital even if it is far away.

(Gina/F/50)

To some participants, the problem was not of distance but of opening times. Chul is a 24-year-old college student in a graduating class. At the time of the interview, he took a leave of absence and worked as an intern at an office for job experience, a common programme among South Korea college students. He had focal segmental glomerulosclerosis (FSGS) since eleven and was registered as a disabled person two years later. Due to this condition, which caused chronic renal failure, he had to have dialysis two or three times a week for four hours each time at the hospital. Since he could not go to the hospital during his office hours, he had to have dialysis after work from nine to six o'clock. To find a hospital available after work was not easy.

Simple access to healthcare services is not difficult for me but my problem is a little different. I want to talk about the limitation of the number of hospitals. Due to my condition, I need to go to the hospital frequently. As I said, the number of hospitals is limited and when I go to rural areas; there are not many available hospitals around there. ... Even in the big city, it is not easy to find a hospital opened after six o'clock. Because I have a full-time job, I need to go to the hospital after work. To find a clinic available during nighttime takes a lot of effort. (Chul/M/24)

The difference between Seoul and the rural areas also appeared in Chul's statement above. The key is, for those who use the hospital frequently and for long periods, both availability of time and distance need to be considered. This lack of availability results in a reduced choice of services and treatment to maintain a lifestyle of work and social activities.

6.2 Barriers to healthcare utilisation during the trip to the healthcare centre

Disabled people encountered a number of barriers during their trip to healthcare centres for treatment. The first issue on the trip was accessibility. Even though the participants found a hospital available, to reach the destination was challenging. The road environment was inadequate to meet disabled people's needs, especially for wheelchair users, and accessible public transportation was not sufficient. Some wheelchair using-participants could not move their upper bodies and were thus unable to drive. For the young participants under 30 years, sometimes parents drove them to the healthcare centre. Though, as it was not possible to use their private vehicles every time, most participants experienced public transportation and encountering barriers within it.

First, participants pointed out the low accessibility of public transportation. Yuri was an electric wheelchair user who lived in Gyeonggi province. Surrounding Seoul, Gyeonggi province has the largest population (over 12 million) among six metropolises and 11 provinces in South Korea (Statistics Korea, 2018b). As Seoul is located in the centre of Gyeonggi province and many cities in this province are functioning as satellite cities of Seoul, Gyeonggi province is known as "the capital area" or "Seoul metropolitan area." With the highest gross regional domestic product (GRDP) in South Korea (Statistics Korea, 2018b),

Gyeonggi Province is considered more developed than other areas. Nevertheless, Yuri mentioned the absence of available public transportation in Gyeonggi province.

Usually I travel by my parents' car. Public transportation for people like me is almost non-existent. If I'd live in Seoul, then it might be better, but I live in Gyeonggi province.

It's quite difficult to use public transportation. (Yuri/F/19)

However, the problem of inaccessible public transportation was found in Seoul as well. Young-min, a resident of Seoul, talked in detail about the inconvenient environment in the subway. The subway is the most popular public transportation system in Seoul, with convenient facilities for disabled people regulated by law. Although, the subway was not experienced as welcoming transportation for disabled people.

I took the subway several times before and felt a height difference between the platform and the train. Sometimes I ask for help from the people close by but it is not easy to get on or off within that short time available, especially on an electric wheelchair. Once in a while, the electric wheelchair can't get on the train due to the height difference. If it was improved, I might go to the city centre but for now, it is not yet ready. It makes many people uncomfortable. (Young-min/M/63)

Even the slightest height difference could be a significant risk and barrier for wheelchair users, and discourage them from using the subway, thereby it narrows the range of movement of disabled people.

Besides the general public transportation barriers mentioned above, like the subway, there is a special transportation service for disabled people stipulated by the "Mobility Facilities Promotion for the Mobility Vulnerable Act 2005" in South Korea (see chapter two). The participants living in middle or small-sized cities with small populations expressed their

discomfort over the scarcity of the service like Yuri did. For example, there is a special taxi service which disabled people can use at a lower cost. Special taxis for this service are equipped with wheelchair boarding devices so that wheelchair users can use this special taxi in their wheelchairs. Being introduced by the central government and run by the local government, it is the most representative transportation service for disabled people. Usually, this service's eligibility is given to the registered disabled people with limbs or brain lesions impairment in grade one or two (see chapter two). The quotes of Seon and Jinu below, both living in Jeonnam province, describe disabled people's reality in rural areas. Jeonnam province, with 1.9 million population, is one of the southernmost provinces of South Korea (see Table 6.1). There are five cities and 17 counties in Jeonnam province (Jeonnam provincial office, 2017) and Seon explained that there is a significant variation in the availability of transportation service for disabled people between areas. Even in certain counties, special taxi services for disabled people had not been introduced at the time of data collection.

The gap between regions is quite large. Of course, there are differences among the neighbourhoods, but even within the same Jeonnam province, the gap between "county" and "city" level is pretty serious. A minute ago, I got a phone call from a disabled friend in Bosung-county saying he wants to run a special taxi for disabled people. For now, there is no special taxi services for disabled people in Bosung-county.
(Seon/M/38)

The special taxi services for disabled people in Bosung county were launched in October 2016 (Lee, 2016); therefore, there was no special transportation service when the focus groups were conducted (June 2016). Seon and Jinu lived in a city where the transport

facilities had been improved recently, but there were many problems due to the lack of a special taxi for disabled people. This situation was described by Jinu:

It is better now with the special taxi for disabled people. At least I can go to the hospital to get treatment. It is much better now, but there were lots of trouble one or two months ago. Many people used the taxi, but the number was insufficient. Hard to book. It was so serious that it was reported on the news. Even I complained about it and gave an interview. (Jinu/M/30)

The lack of a special transportation service is a prevailing situation across the country. Even Seoul was not an exception. Young-min, a resident of Seoul, also had difficulties in using the special taxi. Lack of availability increases badly in the evenings.

I had so much trouble when I called for a special taxi; several times. It is not easy to go out, and in the afternoon, 90% of the taxis withdraw around 4 o'clock. After five, most drivers get off work and only 10% of taxis are left. If I call for a taxi, it doesn't show up. (Young-min/M/63)

This insufficient supply of adequate transportation affects not only visits to the hospital but also other activities directly or indirectly related to health and wellbeing (Giles-Corti et al., 2016; Barton, 2009). Low mobility with inadequate or unavailable transport, bringing about reduced access to social networks, facilities, and goods and services is regarded as a dimension of exclusion (Kenyon et al., 2002). It is associated with all areas of life and impacts on physical health because it imposes restrictions on the social integration of disabled people.

Not only the transportation service but also the road traffic environment was inaccessible to disabled people. Unsafe and unwelcome road traffic environment restricts disabled people's

mobility remarkably (Frank et al., 2006). Jinu talked about the road circumstances, which were not suitable for an electric wheelchair.

I went to a hospital around here to get physiotherapy for two years ... As you see, I can't get around alone. Even with an electric wheelchair, it is really dangerous because of the bumpy road. In that case, I need to use the side of the road. Moreover, it was uphill to the hospital and my arms were not strong enough to drive the wheelchair. It was pretty hard work. So, at that time, I could not get any treatment and just stayed at home. (Jinu/M/30)

The unwelcoming circumstances on roads discouraged Jinu from having treatment and made him stay at home. This environment degrades the accessibility of disabled people, but it is difficult to intervene, because it is not artificially created. In his criticism of the social model of disability, Shakespeare (2006: 201) argued that the barrier-free utopia, in which all externally imposed barriers are removed, is hard to achieve and that is one of the weaknesses of the social model of disability because it does not accord with the belief of social model that external disabilities can be removed. For example, he explained that many parts of the natural world, such as mountains, bogs, and beaches will remain inaccessible to many disabled people (Shakespeare, 2006: 201). Hilly roads can be part of the "natural world," which cannot be removed. Nevertheless, in an urban setting, these barriers can be mitigated by road policies and assistive technologies. We cannot get rid of the hill, which is inaccessible per wheelchair, but an automobile can go up the hill. Also, it can be more accessible with human support. That is, we cannot remove all barriers but we can support disabled people to cross the barriers. Therefore, in Jinu's case, the substantial barrier was the absence of assistance to enable him to overcome the dangerous and hilly road.

These factors such as inaccessible public transportation, poor special transportation service, and inconvenient road environments, prevented the participants from accessing healthcare institutions. Significantly, some participants were left with no choice but to abandon healthcare treatments because of these difficulties. Young-min related the inconvenience of public transportation with his decision to give up the service eventually. This demonstrated how social determinants of health impact disabled people differently since the oppressive society designed for abled bodies contributes to social and health inequalities.

6.3 Barriers for disabled people inside the hospital

Even after disabled people managed to arrive at healthcare facilities, multiple barriers were identified inside hospitals. The internal and external structure of hospitals was not convenient for disabled people to use. Seon, who attended the conflict hospital regularly for rehabilitation therapy, pointed out the inaccessibility of parking areas and toilet facilities:

The accessibility to healthcare centres is improving through the Facilities Promotion Acts, but it is still not enough. Although the legally ruled width of disabled parking space is 3.3 metre, it is often ignored. And the loo? Peace hospital, the one I use, was built recently and it is a leading rehabilitation hospital, yet the accessible toilet sucks. Even an electric wheelchair can't enter. It is only partitioned off part of the general loo! Impossible to access. It is so narrow that a manual wheelchair can hardly enter. To shift from wheelchair to toilet is uneasy. What a barrier! (Seon/M/38)

The lack of accessible toilets in healthcare centres is significant since it can lead to the development of illnesses deteriorating health status and quality of life (Greed, 2006). This

was the case of Dong-jin seen in the previous chapter, who held his urine because he could not use the public toilet and, as a consequence, developed a kidney disease (see chapter five). Inadequate facilities in public toilets have been identified as a barrier to self-catheterisation common in disabled people (Seth et al., 2014). Urinary incontinence issues can contribute to the development of secondary impairments such as pressure ulcers and kidney failure (Allman et al., 1986). Also, it can cause psychosocial problems (Wyman et al., 1990). People with incontinence may have difficulties with lower subjective health, positive relations with others, self-esteem (Heidrich and Wells, 2004), lower quality of life (Sinclair and Ramsay, 2011; Ko et al., 2005), and higher depression scores (Nygaard et al., 2003). The fear of odour and embarrassment can cause an activity restriction (Norton, 1982). Further, it should be remembered that these facilities are necessary, not only for disabled patients but also for staff with impairments. Therefore, the accessibility issue of public toilets available for disabled people should be understood as rights of citizenship (Kitchin and Law, 2001).

Another problem was put on the internal structure of hospitals. Participants talked about the difficulties of moving around in large hospital spaces due to the complicated and labyrinthine layout of their internal structure. However, if adequate personal assistance is available, disabled people move around within the hospital more easily. Ji-hye criticised the lack of support as the reason for the difficulty of internal movement inside the hospital.

Since I have bad sight, I need to keep asking others passing-by for directions while moving within the hospital. The letters on the sign boards are too small for me to read. Even at the supermarkets such as Emart*, if you say to the staff that you're disabled, an assistant helps you out during the shopping. But in hospital, although you tell them about your visual impairment, they provide no assistance. You need to go around with a guardian or a personal assistant. It could be a little bit better with an assistant. But when alone, I have to find my way around too many clinical laboratories. The

laboratories I need to visit are not close to each other. The internal structure is quite complicated. (Ji-hye/F/31) (*- The biggest supermarket in South Korea)

There is a public Personal Assistance Service (PAS) in South Korea, but the users of this service are a small part of the whole disabled community because the eligibility of this service was restricted to people with severe impairments at the time of data collection. In addition, among eligible people, only those who pass the assessment were able to use the service (see chapter two). Therefore, large groups of disabled people are excluded from this service and will not be accompanied by PAS during their hospital appointment. The lack of PAS, thus, is regarded as a problem. However, a more fundamental problem on this issue is that the internal design and signage do not make life easier for disabled people. This is an issue of universal spatial design. According to Ostroff (2011: 1.4), the emergence of the concept of universal design is traced in two major threads: the first one is the legislation including specialised requirements for disabled people (focused on the large-scale built environment), and the second one is market-driven responses to an aging society (focused on the products). Though the primarily related areas of these two threads are different, to design and operate such spaces as public accommodations in a way that disabled people have the same opportunities as others offer convenience to everybody, including the elderly and people with restricted mobility for diverse reasons (Mace et al., 2015: 155-156). Universal design is emphasised in the term such as “better for everyone” or “planning for your family's needs” rather than something for disabled people and the elderly (Mace et al., 2015: 156). This phrase demonstrates that if something is easy for disabled people and the elderly, who are vulnerable in mobility or recognition, then it is easy for everyone to use. Also, this presents the universality of disability imposed by environmental barriers.

6.4 Barriers to healthcare utilisation during consultations and ward admissions

During the consultation and in the ward, disabled people experienced important barriers that could impact health outcomes. These barriers could be categorised into three broad areas: lack of service provision, inaccessible medical equipment, and healthcare staff communication.

6.4.1 Lack of service provision

The problem most frequently mentioned by participants was the lack of service provision. Most participants talked about reduced service provision, which seemed to be a prevalent and chronic situation. In addition, the short time of consultations and rehabilitation services was raised as one of the issues discouraging participants from using healthcare services. Actually, unlike the UK that cut public social spending (Edmiston, 2017) and implemented the policies of austerity recently (Macdonald and Morgan, 2020; Bambra and Garthwaite, 2015), the South Korea government has steadily expanded the welfare expenditure since the late 1980s (Hong, 2017). Though the amount of welfare expenditure was not large compared with the advanced European countries from the beginning (see chapter two), this expansion is not enough to cope with the increasing needs of beneficiaries.

Yuri explained how she needs to spend more than two hours travelling to get to the hospital and another two hours waiting to be seen only for a three-minute consultation. She felt that the gain from such a short interaction was very limited compared to the time involved, and consequently, she decided to give up the service.

I used a distant hospital for a simple check-up for my impairment. It took more than two hours to get there and another two hours' wait. So, it took a whole day to get there. I saw the doctor but actually, the face-to-face consultation took only three minutes. Thus, I asked myself if it was worth it and finally, I stopped going there. (Yuri/F/19)

This situation exemplifies how these aspects operate as barriers to disabled people's health, who have to trade-off many aspects of their lives to attend these visits for little benefit. These short consultation hours are not different for non-disabled people. However, it is a more critical barrier to disabled people because they generally travel a long way due to the scarce healthcare resources, and the long-distance traveling is more difficult for them than for non-disabled people. This is a double exclusion of infrastructure (long drive) and service delivery (three minutes of consultation). Ja-Young had a similar experience. In her case, the reduced service was not a consultation but occupational therapy as part of her rehabilitation treatment. After the duration of the therapy she had for two years, the service time was cut in half she stopped using the service instead of receiving the shortened session. She said that the time reduction was "upsetting," and this emotional response seemed to have affected her decision:

I gave up the service. Because people with nervous system impairment can be supported by the NHI for two years at the longest in this country. After two years, the Health Insurance Review and Assessment Service (HIRA) cut the benefit and the hospital doesn't provide the treatment anymore. They've reduced the treatments one by one. In my case, when I gave up the service last year, I was told that the occupational therapy time, which was thirty minutes before, would be reduced to 15 minutes. It was upsetting. I thought it was the time to quit the rehabilitation service. (Ja-Young/F/44)

Many participants complained about the “long waiting lists” of rehabilitation services. Fundamentally, the long waiting list stems from the supply-and-demand mismatch. In South Korea, the demand exceeds supply is chronic due to the under-funding of healthcare services. A common strategy to manage this problem is that those who have been using the service for a long time must reduce their use to allow new users. This is similar in community rehabilitation centres, which - among other things - often provide rehabilitation services for disabled people. Most rehabilitation services are provided through a voucher system, which is mostly free for recipients of public assistance, and non-recipients can use the service with a small fee (see chapter two), but there are a chronic supply shortage and a long waiting list of up to six months. Eun-Mi explained how the long waiting lists had impacted her accessing rehabilitation therapy services:

I don't do hydrogymnastics right now, but recently I did it for a year. After a year, you must take a break because there are many people waiting for a turn. You need to move to the back of the queue again. Most centres are similar. ... If I use the service for a long time, the service gets reduced little by little - from three or four times a week to two times. And next, they will tell me to make room for others. ... My kind of impairment cannot improve. The centres for treatment are not infinite so they put limitations on the use of service. Simply, I was cut off. Next, I went to the Seoul Rehabilitation Hospital and after a while, I was cut off from there too. Newly impaired patients can get recovered sooner than us, the old patients. (Eun-Mi/F/65)

Eun-Mi's story implies more than a simple insufficient service provision: here is an important subliminal message of “body worth.” She said that she had little chance to “recover” because her impairment lasted for a long time (27 years), and the recently impaired people were prioritised in rehabilitation therapy because of their higher possibility of recovering. According to her, those with ongoing long-term rehabilitation needs (typically disabled

people) are constantly put at the end of the cue to favour more “worthy bodies” (who will recover completely or sooner). Given the situation that rehabilitation services are not enough, the services were allocated based on the assessment of more/lesser worthy bodies, and one of the assessment standards was the “possibility to recover.” It could be considered that those with long-term impairment were pushed back on the priority list because they had received more services than newly impaired people, but this assessment has an interesting health management strategy.

To use the rehabilitation therapy service, Eun-Mi had to stop her rehabilitation for some time and then changed the centres several times, but Yuri gave up the service in this tough process.

I heard that hydrogymnastics was the best way to improve or maintain the status quo, so I used to do it for a while, but there are not that many places that provide hydrogymnastics services so it is too hard to access this therapy. One nearby welfare centre provided this therapy but now it is closed due to maintenance expenses. To do hydrogymnastics, I need to go to a distant university hospital where lots of people gather. The waiting list is too long to wait for my turn. (Yuri/F/19)

Unlike Eun-Mi, who lives in Seoul, Yuri, a Gyeonggi province resident, had mentioned both a long waiting list and a long distance to the rehabilitation centre. Essentially, these two are the same problem: lack of provision, limiting healthcare access to disabled people who are likely to have less material, emotional, or support resources to overcome the barriers. Min-Soo reported a story similar to Ja-Young, but the outcome was different. He accepted the halved service time and continued to use it, because although he also thought that the service time was not enough, he viewed the need to go out for a rehabilitation service as a rehabilitative activity.

Because of the medical fee problem, my healthcare service has halved in time from thirty to fifteen minutes... I thought it was unreasonable to go for a fifteen-minute treatment while it took an hour to get to the hospital. I continued anyway, because even though the treatment time was not very long, I thought getting myself to the treatment and going out was part of the rehabilitation. I take the bus and subway to get there, and it can be kind of rehabilitating. (Min-soo/M/44)

For Min-Soo's "going out" would mean not only to be outdoors literally and to use institutional healthcare services but also to communicate and interact with others, he accepted this process as part of his rehabilitation process and wellbeing improvement.

6.4.2 Inaccessible medical equipment

One of the biggest problems the participants encountered in hospitals was the inaccessibility of medical equipment. It was not easy to use simple medical equipment, with some examination equipment being completely inaccessible for some participants. This inaccessibility to medical equipment such as examination tables and mammography machines was already pointed out as a health promotion barrier (Pharr, 2013; Iezzoni, 2011; Story et al., 2009; Rimmer and Rowland, 2008). As the accessibility to medical equipment is associated with the medical practice itself, this low accessibility can hinder disease and recovery diagnosis (Rimmer and Rowland, 2008). This exclusion from medical equipment was the most direct barrier to smooth and meaningful healthcare services for the study participants.

Bomi illustrated her experience of exclusion caused by the inaccessible equipment when she explained that due to her polio, her body developed differently, and her spine was curved.

This meant that when she attended hospital, she could not sit on the clinical examination chairs:

I've been to dental, eye, and ear, nose and throat (ENT) clinics before. As you know, for treatment, we need to sit on a clinic chair. Of course, I couldn't transfer into the chair by myself, and as you can see, my body is not standard size. I'm so small and my spine is curved a lot so even on the clinic chair, the medical instrument was not fit for me. At the ENT clinic, the ear-looking-device didn't reach my ear. Anyhow the doctor looked into my ear while sweating hard without saying a word. It was so uncomfortable - rather than painful - that although I was told to come again, I didn't. Also, at the eye doctor's, I couldn't use the applanometer while in my wheelchair because it was inaccessible. Anyway, I did it with help from others. But such experiences made me worried about going to the hospital. Even at the regular National Health Insurance check-up, I have nothing but the blood test. When I had an x-ray, I needed to lie down on the x-ray bed, but because of my crooked spine, they didn't know how to take it. They couldn't take my weight, measure my height... Whew, I know nothing about my body at all! [Laughs] Actually, even during the blood test, I couldn't access the test room on my electric wheelchair because the door was too narrow. So, the medical technologist came out from the room and drew my blood at the corridor. Apparently, a hospital is an unpleasant place for me. (Bomi/F/44/Polio)

Bomi's story is suggestive of Kitchin's analysis (1998) of spatialities that work to exclude and marginalise disabled people. Disabled people are kept "in their place" and are treated as if they are "out of place" by spaces designed for non-disabled people: a "spatially-constructed disability" (Kitchin, 1998). As Bomi recognised the hospital as "an unpleasant place," this cumulative experience of exclusion influenced her reluctance to use the hospital. This means that the inaccessible medical equipment makes consultation difficult and generates psychological distance to healthcare service. This reluctance is likely to impact

preventative healthcare practices that can avoid, detect and ensure early treatment of disease or injury.

On a similar note, 21-year-old Kyu had been using a wheelchair for 14 years due to muscular dystrophy. He experienced pain when he lay down for X-rays because his muscles were fragile due to the long-term use of the wheelchair. Kyu described the direct harm (bruises) that the examination procedures caused:

The medical equipment is not well designed. In the ward, the bed I should lie down on is too high, and the X-ray machine is... In my case, sitting on the wheelchair too long, I have little muscles on my hips or my lower back. So, lying down on the X-ray bed, I feel like my bones are exposed to the hard surface. It is painful. I even had a bruise after being x-rayed. (Kyu/M/21)

According to Kyu, although people often only lie down on X-ray beds for short periods, this experience can harm wheelchair users who can have muscle weakness and sensitive skin. In the interview, another participant, Kang-Oh, whose legs already had to be amputated, said that he did not lie down on X-ray beds because of concerns about developing pressure ulcers:

I don't use a usual X-ray machine. If I'd use it, I need to climb into the machine and lie down on it. The surface is so firm that it might make me develop a pressure ulcer. I'm afraid of it. (Kang-oh/M/60)

The experiences of Kyu and Kang-Oh imply that this is not just about accessibility but also a safety issue. Kyu was bruised after being X-rayed, which implies that improper medical equipment can develop secondary impairment, and Kang-Oh was worried about it. Healthcare centres are not only unpleasant and exclusive but also dangerous with safety issues (Story et al., 2009).

Not only the inaccessibility of medical equipment for test or diagnosis but also the lack of assistive devices hindered the smooth use of healthcare service. Some participants take assistive devices from home for their convenience. Young-Min explained why he brought his own hoist to the hospital ward.

I use a hoist at home. With the device, it is much easier to shift my body. But there is no such device in the hospital. I don't go into the hospital quite often but if I need to, I take my hoist to the ward. Without it, to shift my body, you need to hold my body in front and back, under the armpits and legs. When I was hospitalised in Paik Hospital, I asked for help to the people in the ward. My mother held my legs, they caught my upper body and moved up and down. It was a real struggle. It would be much better if a hoist was installed in the ward. (Young-Min/M/63)

This example illustrates the scarcity of basic assistive technology and convenient facilities for dependent users in healthcare institutions in South Korea (Park, 2014b: 414). Young-Min responded to this situation by bringing his own equipment to the ward. According to their material resources and social capital, this kind of individual response cannot be employed by everybody.

Furthermore, inaccessible healthcare centres are more troublesome when there are insufficient healthcare resources available for disabled people. Tae-Yong referred to the lack of choice when accessing hospital care. Neither had he want to use an inaccessible hospital, nor to access low-quality healthcare services closer to him. The limited choice of adequate healthcare providers for disabled people was described as multi-factorial, including distance, accessibility, and quality services:

Even if there was a very good attending doctor, I wouldn't go there if it is not easy to access. If I need to go up the stairs or ride a car, then I wouldn't go there unless I was

sick to death. Large-sized hospitals are too crowded. It is accessible, but the quality of their service is poor. Good clinics are good in quality but they are not big so they are often located on the second floor, or underground, or far away. (Tae-Yong/M/41)

This complex definition of choice for disabled people's health services, particularly, meant that they are less likely to encounter accessible hospital services of good quality, where the medical professionals have the right knowledge of their bodies and attitudes toward disabled people. This issue will be discussed in more detail in section 6.4.3.

6.4.3 Attitudinal barriers: authoritarian attitudes of the medical profession

Attitudinal barriers in healthcare staff have been identified as a factor contributing to health disparities in disabled people (Rimmer and Rowland, 2008). There is a common idea in South Korea that "the healthcare professions are authoritarian to their patients" (Lee, 2012). It is more paternalistic than authoritarian in a clinician-patient interaction model in which healthcare professions position themselves as having full knowledge about the risks and benefits of the decisions made, while the patients only play a very passive role (Charles et al., 1997; Beisecker and Beisecker, 1993; Emanuel and Emanuel, 1992).

In the Korean language, there is a term "Gab-eul relationship," describing the power dynamics between two groups of people. It comes from the legal terminology of a contractual relationship: "Gab" represents the person in the group with more power, while "Eul" is the one who is subjugated. These days this term is commonly used to talk about any relationship with a power imbalance. Several participants used the term "Gab-eul relationship" to illustrate the doctor-patient relationship, as illustrated by Chul's quote.

I don't think it is unfair or discriminative, but basically. it can be the characteristics of doctors. Anyway, the patients are "Eul" and doctors are "Gab" all the time. ... Even with a simple cold, doctors prescribe some specific medication such as Tylenol from the position of "Gab." In that case, I can't tell them that I prefer some other medication because of the atmosphere. But I don't think this is discrimination based on disability.
(Chul/M/24)

Chul recognised the directive attitude of healthcare professionals as a "Gab-eul relationship." Kang-Oh, who was impaired in the 1970s talked about how this paternalistic attitude was worse at that time:

At that time, the doctors were absolute "Gab." Super-gab. They swore or said "If you continue to do that, you're gonna die" without hesitation. (Kang-Oh/M/60)

"Super-gab" implies the extreme power imbalance between the two. This quote about the relationship between the medical profession and patients relates to the "patient role" in the medical model (Newell, 2003). Under the medical model paradigm, the medical professions are experts of illness and disabled people, who are considered as being ignorant of their condition and should follow the professional's instructions. This is involved in the analysis of Foucault (1965). understanding medical knowledge as power, and Freidson's (1970) criticism of medical professionals' excessive influence on patients. This will be discussed below.

During the focus groups and interviews, participants were asked if they were discriminated against or treated unfairly. Although some participants thought that medical staff is paternalistic and assertive, no one directly said that they were "discriminated" against because of being disabled, and some participants appreciated doctors' kindness. They do not believe that the attitude of healthcare professionals is associated with patients' impairment.

Rather, the attitude of the medical staff toward disabled people seems to be close to distancing derived from unfamiliarity, strangeness and ignorance rather than direct discrimination. In South Korea, disabled people are scarcely exposed, and they are not regarded as autonomous and independent. They are seen as aliens perceived only in the context of asking for help (Kim, 2002b). Mass media describe disabled people as dependent and passive or “unknown beings” rather than members of civil society (Chang, 2018). Young-Min described “the atmosphere that neither discriminate against disabled people nor welcome them” as:

I don't think it is a clear discrimination, but often... in the small, private hospitals, doctors do not welcome disabled people that much. It might be a kind of avoidance. It usually takes more time to examine disabled people than non-disabled patients, so in many cases disabled people are tossed to the general hospital. There is no obvious neglect or discrimination toward disabled people these days. But people do not welcome disabled patients. I think it's closer to reality. (Young-Min/M/63)

In addition, the ignorance on how to deal with disabled patients seem to influence their attitude. Bomi, who has polio, has a much smaller body frame than others, and her skinny and bent body was extremely noticeable. She explained how doctors seemed to be troubled by her body:

Yet nobody likes to go to the hospital, I feel the doctors are afraid of treating me. It makes me feel pretty bad. When doctors see me, there is a look of helplessness on their face. (Bomi/F/44)

Hyun, who has spinal muscular atrophy (SMA), has a small body like Bomi and cannot sustain his head due to his weak neck, and he talked about difficulties similar to Bomi's:

As you can see, there is a transformation on my body frame and I look different at a glance. I think it makes doctors feel they can't cure me. Quite often I am advised to go to the large hospital if possible, and even in the large hospital, they told me to go to the hospital previously used. It means, when I go to the hospital, most doctors are embarrassed by my look; some doctors told me "I don't know at all what to do for you."
(Hyun/M/26)

As stated in the Melville (2005)'s study, Seon pointed out the lack of knowledge of the medical profession about disabled bodies:

In many cases, medical professionals have less information or knowledge than we disabled people do. For example, everyone with spinal cord injury urinate in their unique way, depending on the characteristic of their impairments. There are various ways to urinate but not every doctor knows it. [...] Even people with muscular dystrophy, they have a lot of experience and information, but they are ignored quite often by the medical professionals. Of course, it's the same with the people with cerebral palsy, spinal cord injury as well. But not every doctor knows it. (Seon/M/38)

Tae-Yong told a similar story. Moreover, he criticised that some professionals focus on short-term health outcomes instead of long-term benefits:

"Botox" is a remedy for people with brain lesions. It is kind of a neurotoxin. It cannot be a cure itself. After the injection, we should have very intense physiotherapy, occupational therapy and so on to get better. Botox is just an ancillary device. But mothers get their children the Botox shot first because with it, their children walk better. In that case, doctors need to let them know about the effect 20 years later. But in many cases, they don't. If they are not rehabilitation staff or occupational therapists, if they are just physicians or surgeons, they recommend any surgery easily. It might look like

there is some improvement physically. But if we talk about the whole life, it can be different. (Tae-Yong/M/41)

This quote illustrates the importance of an interdisciplinary team approach in the healthcare field when dealing with disabled patients. Also, the healthcare professions depicted above are analogous to the description of Freidson (1970). Freidson argued that the healthcare profession became too autonomous and too powerful for the good of society. He also said that patients had lost the freedom to choose the agencies which pay the bills, and “official medicine” has risen (Freidson, 1989). He did not acknowledge the requirement of esoteric knowledge for clinical practice and argued that lay persons could question it, therefore, he insisted that the autonomy of the healthcare profession must be regulated. (Ford, 1970). His criticism of the medical profession, which is accepted widely, can be supported by the previous examples.

The thoughtless attitude of some medical professionals was also pointed out. During consultations, some doctors do not take the patients’ emotions into account. Yuri referred to the term “human rights sensitivity” when she talked about one doctor’s attitude.

My sister has the same disease as me. Her respiratory system is a little worse than mine, but she is not out of breath when she talks. One day she consulted a doctor who has not seen her before about getting a respirator available while sleeping. With a glimpse at the figures of a simple test result, he said that my sister should insert a tube into her neck and there was no other way. Even though he had never seen my sister before, he talked as if that was the only option. At that time, my sister seemed to be treated as an object and not as a human being. Both my mother and my sister were upset. (Yuri/F/19)

This quote alludes to the lack of human rights sensitivity and a questionable medical practice based on not valuing disabled patients. This is related to a paternalistic model of clinician-patient interaction mentioned above. In this model, the focus is on providing legally required information on available treatment choices and obtaining informed consent for the recommended treatment. It is not on how personal life-related issues may lead the preferences and choice of treatment, to lead to patient autonomy and empowerment. In this decision-making style, the patients play a passive role and their preferences and expertise on their bodies and social life are not a priority (Charles et al., 1999; 1997). Certainly, this is not all medical professionals' attitude; however, participants recognised this attitude by some doctors.

Tae-Yong referred to the relationship between specialist impairment knowledge and the quality of healthcare.

People with brain lesions often have high levels of tension. So basically, we have high blood pressure if measured. If a doctor is ignorant of it, he would tell me I have hypertension. But if he knows about me, he would say "Take it easy, relax, and let's take it again". When I was young, an injection didn't get in my buttock smoothly due to the high tension in my muscles but doctors who knew me could handle the situation. They told me "It's okay, don't worry" and gave an injection while I was distracted so that they made me not worry about it. You can get much better service if you go to a doctor who is well aware of the characteristics of disabled people. (Tae-yong/M/41)

As a consumer of healthcare services, Tae-Yong seemed to be quite an active and expert user. However, it would not be easy for other disabled people to find or access doctors who know their impairment like Tae-Yong. He is highly educated (he completed a master's course) and works as an activist in a disability organisation.

6.5 After using the service

Participants also encountered several barriers after using healthcare services related to social determinants of health and health inequalities. This section will examine the financial burden of medical fees, assistive devices purchases, family conflicts, and private financial responses.

6.5.1 Financial burden of medical fees and the limitation of the NHI coverage

Most participants felt pressured due to the financial burden of subsidising treatments. There is a public medical security system for the whole population in South Korea and the most fundamental system is the NHI programme. Under the NHI, the beneficiaries need to pay premiums regularly. Therefore, those who cannot affiliate themselves to the NHI for economic reasons are funded by the medical aid programme under certain conditions (see chapter two). Despite these programmes, healthcare needs to generate financial assistance to participants because the public security system does not cover services regarded as unnecessary or expensive (Kim, 2014c; Bae, 2010; Heo et al., 2007). One example of this healthcare expenditure paid by the user, is hospital charges. At the time of data collection, the charge for admission to a standard hospital ward (four or six beds wards) was covered by the NHI, but this was not the case for advanced wards (one or three beds wards). (In July 2018, this changed and the charge for an advanced ward was covered by the NHI.) Jinu needed to use a single room due to his impairment because people with paralysis of the lower body may need more spaces to move around, or they may need to empty their bowels in bed which may feel uncomfortable in a shared ward. This generated an additional expense which was not covered by the NHI:

I go into a hospital pretty often. To stay in hospital for long is strenuous due to the hospital charges because I need a private room. As I relieve myself on the bed, if there is anyone else, I cannot do it. Even a double room is so uncomfortable to me that usually I ask for a single room. As you know, there is no discount for a single room. Although an advanced ward cost 100-120 thousand won (69.14-82.96 GBP) per day, I had no choice but to use the single room. It is a lot of pressure and I feel sorry for my parents when I stay there for a long time. (Jinu /M/30)

The lack of or insufficient NHI coverage was a crucial factor affecting the financial stress of participants. This was also described by participants who had benefitted from the programme's expansion over the past few years. Ja-Young stated she felt relieved after the financial burden was eased (but not disappeared) since NHI coverage has been expanded:

I have Devic syndrome. Until recently, last October, the cure for Devic syndrome was not covered by the NHI. It costs 1.6 million won (1,106.18 GBP) for one injection. In addition, it was a wholly private burden. There's a great deal of variability between individuals so some get it three or four times a year, and others six or seven times. In my case, I get the injection once every ten months. Anyway, it was a private financial burden ... I reeled under the burden of 1.6 million won last year. Now it has been covered by the NHI since last October, so the burden has halved to 800 thousand won (553.09 GBP) per injection. Well, it's still burdensome but it has halved anyway. [...]

For disabled people who are not very wealthy, any disabled person will feel considerably burdened (Ja-Young/F/44)

The injection Ja-Young regularly got was rituximab, effective therapy for Devic's syndrome, which reduces the relapse rate of Devic's syndrome and neurological impairments (Damato et al., 2016; Kim et al., 2013). In October 2015, this therapy was covered by the NHI for the first time, since the South Korean government is expanding funding or part-funding to new

services which were not previously (National Health Insurance Service, 2017). The NHI now covers up to 50% of the cost of the injection Ja-Young needs. This initiative is expected to promote the healthcare service use satisfaction by decreasing individual financial burden and healthcare service barriers.

For example, with this new programme, people diagnosed with severe or rare diseases can get a discount through a designated process. Gina explained how this new programme has impacted her own healthcare:

When it comes to rheumatism, there is an expanded benefit coverage programme.

With the programme, the medical fee is discounted a lot. If the original fee was 50 thousand won (GBP 34.57), I then pay only ten thousand won (GBP 6.91). To see a doctor is also discounted. (Gina/F/50)

Chul and Dong-jin were also eligible for this new programme and reflected on the direct impact this has had on their finances. Chul was still a student and financially dependent on his father, who was paying a large amount of money on Chul's health care needs:

Before the expanded benefit coverage programme was applied, I paid 600 thousand won (GBP 414.82) a month for my medical fee; anyway, my father had a reliable job so he was able to afford it. However, 600 thousand won a month ten years ago must have been a huge sum of money. After that, the expanded benefit coverage programme started to cover my disease. It cut the burden in half - 300 thousand won (GBP 207.41) a month. (Chul/M/24)

Dong-jin reminisced a similar experience when he began dialysis for the first time. It cost him 400 thousand won (GBP 276.54) a month (20% of the cost), but a few years later, with the expanded benefit coverage programme for rare diseases began to apply, his contribution

was reduced to 10%. Moreover, after he was diagnosed with cancer, the cancer patient discount began to be applied, and now he pays only 5% of the total dialysis fee, and the rest is covered by the NHI (100 thousand won (69.14 GBP) a month).

However, participants did not talk only about their satisfaction with the system. Although these comments are evidence of reduced burden, they also demonstrate the medical fee's ongoing burden. Seon used the healthcare service when he was eligible for the medical aid programme. (The medical aid programme covers the most medical expenses without premium for people below a certain poverty line) (see chapter two). After becoming a director of a Centre for Independent Living (CIL) and he began to generate an income in 2005, he dropped out of the medical aid programme and affiliated himself to the NHI. In addition, he lost the eligibility of the living allowance of National Basic Living Security (NBLS). The statement below described the financial pressures that he encountered after this change:

The medical fee is somewhat of a pressure on me as well. It could be a small amount of money but the charge for medicine is... Also, I was a recipient of NBLS before I launched this centre in 2005. I received benefits of NBLS from the government then but now I don't. Without the NBLS benefit, even a small amount of money can cause pressure. Although I'm the director in this centre, the salary is pretty low. (Seon/M/38)

His statement showed the limitation of the public assistance system. There are seven benefits in public assistance (living allowances, medical aid, housing benefit, education benefit, childbirth benefit, funeral benefit, self-sufficiency benefit), and in 2005, when he began his work, the eligibility of these benefits was unified as one. If a recipient earns an income above the standard, eligibility for all the benefits was lost. As a result, this system was criticised for disincentivising employment, and then in 2015, the new public assistance system that

diversifies eligibility depending on each benefit was introduced (see chapter two). Under the new system, people with monthly income below 1,807,681 KRW (1,186.84 GBP) for four-member-household as of 2018 can receive the medical benefits and this was a considerable expansion of the benefit. Seon, who is not eligible yet, did not think this standard was reasonable. The system was improved, but it was not enough for disabled people like Seon.

Participants were concerned not only about past and present health expenditures, but they worried about the burden of future medical expenses. The medical expenses Chul spent every month for dialysis was supported by his father, who is the family breadwinner. He expressed the concern on the expected expenses he might need to cover in the future:

Right now, I don't pay the medical fees myself so it is not that burdensome. But I think, "what if my parents retire?" If I should pay for it myself, then it would be a considerable pressure. In the company where I work as an intern right now, even though it might not be my final workplace, the salary is pretty low. A college graduate worker earns below two million won (1,382.72 GBP) a month. When I think of my future, apparently I'll spend about 300 thousand won (207.41 GBP) a month in medical fees. That much expenses every month... It seems to be a burden financially. ... As I told you, my disability is dependent upon money, because money is indispensable to my survival, despite my disability, I should be independent because I need to pay the cost. So I'm trying to work harder at work. (Chul/M/24)

Chul was worried about the dialysis fee, but generally, the medical fee is unpredictable besides this cost. There is no such guarantee that even non-disabled people maintain their condition, but disabled people are vulnerable to various secondary impairments and likely to aggravate their health due to the environmental factors in particular (see chapter five). In many cases, the term "disability" is used in conjunction with the terms "burden" and "cost"

(Wickizer et al., 2011; Stovner et al., 2007; Murray and Lopez, 1996), and predicting and preparing for the costs of disability and disease is an important part of social policy. Although, in some cases, the way “disability” is used is different from that of “people with impairment”, this perspective consequentially implies that “disability” is a social cost, and it reinforces the perception that disabled people are burdensome to society. This financial burden of medical expenses and unmet healthcare needs can cause health inequality (see chapter four).

To sum up, the burden of medical fee expenditure was a pattern in participants’ healthcare use narratives. They benefited from the programmes such as NHI, and some were satisfied with the expansion of NHI, but despite improvements, there was still dissatisfaction with the new system, such as hindering the will to work due to concerns about loss of eligibility of medical benefit. Also, it was found that they were worried about the future expenditure for their treatment.

6.5.2 Purchase and maintenance of assistive devices

Besides medical expenses, disability assistive devices were another cause for extra financial expenditure to participants. Many participants repeatedly talked about the pressure caused by the purchase of electric wheelchairs. Kyu expressed the stress caused by this expenditure and the complicated process of purchasing assistive devices:

Buying the assistive devices is both costly and annoying. In the case of a wheelchair, it can be partly-funded every six years but a doctor’s note on the user’s condition is required each time. Further, the subsidy is much smaller than the real cost of the assistive device. The maximum amount subsidised is two million won (1,382.72 GBP) per one wheelchair. In my case, my wheelchair is much more expensive so it costs 18

million won (12,444.52 GBP). Even with the subsidy, I needed to pay 16 million won (11,061.79 GBP) for the wheelchair. So, I think there is a considerable financial burden to acquire a wheelchair that fits perfectly. (Kyu/M/21)

The purchase of an electric wheelchair is partly covered by the NHI, but the participants explained that this support was insufficient because they needed to supplement it to be able to purchase adequate equipment to fit their changing needs. The 26-year-old Hyun has been using a wheelchair since he was a child, and he had to keep changing assistive devices such as his wheelchair as he grew up:

When we grow, we grow in stature, and the bones grow. We need new devices in accordance to our growth and they need to be personalised to one's body frame. It costs a lot of money but there is little support. (Hyun/M/26)

Hyun's quote reflects that disability expenses are not temporal but long-term. Income inequality was evident in the sample since not everybody could afford this expenditure, and some participants explained how comfort had to be traded, which could deteriorate health outcomes. For example, because of the lack of material resources, Dong-ho accepted to use a wheelchair that was unfit for him:

People with spinal cord injury need to use a personalised wheelchair. Under the NHI programme, the purchase of a manual wheelchair can be supported only with 400 thousand won (276.54 GBP) as an insurance benefit. Usually a manual wheelchair is ten times more expensive so it costs four or five million won (2,765.45-3,456.81 GBP). Once I realized that the new wheelchair didn't fit me well after I bought it. Once purchased, a wheelchair needs to be used at least seven or eight years. [...] I have been using this wheelchair for five years. It is really uncomfortable to use, an unsuitable wheelchair for years. (Dong-ho/M/46)

Not only the initial purchase costs but also the continuing maintenance costs of assistive devices were also a substantial burden imposed on many participants. Kyu talked about the complexity of each supporting process, the unrealistic amount of benefit, and the inconvenience of maintenance:

The maintenance costs are another problem. A lot of assistive devices are imported and are not produced domestically. The tariff policy on the assistive devices are not well designed so most devices are costly. Sometimes the parts of devices are also imported – of course their prices are high so not easy to buy- but other parts are not obtained locally. In that case, I need to order abroad and it means extra cost.

(Kyu/M/21)

To maintain assistive devices, incurs expenses. However, this is more than a simple material problem. For people with difficulties in mobility - to have their own fit assistive devices, would mean more independence (Cook and Polgar, 2014). The results that disabled people who use private modified vehicles such as electric wheelchair or scooter showed greater independence and social participation (Darcy and Burke, 2018; Löfqvist et al., 2012) support this hypothesis. Assistive devices can contribute to creating an enabling environment and enhancing the quality of life of disabled people. If the living spaces of disabled people are reduced due to the high cost of maintenance of assistive devices, it might lead to the lower quality of life of disabled people. It would be more so because most disabled people use their assistive devices lifelong and constant maintenance is necessary.

6.5.3 Family conflicts due to financial burden

One participant mentioned how family conflicts resulted or have been influenced by increased financial expenditure due to their healthcare needs (such as dialysis) or disability (personal assistance, purchase, and maintenance of assistive devices). There are encouraging and inspiring experiences of the family of disabled people reported in previous studies (Paun, 2017). However, the responsibility of care is also a cause of worry to the families of disabled people. Conflicts due to a disabled family member do not emerge only because of medical fees and/or care costs. Sometimes parents who nurture disabled children experience difficult challenges (Gona et al., 2011; Resch et al., 2010) and more fatigue, anxiety, and social isolation (Caicedo, 2014). Parents of disabled children have been reported as more vulnerable regarding their health than parents of non-disabled children (Vonneilich et al., 2016) and these are found in South Korea as well (Lee, 2014b; Bae and Chung, 2008).

Tae-Yong illustrated how financial costs contributed to disabled people's feelings of losing control of their own lives when family members decrease essential support due to the financial difficulties impacting disabled people's identity and social status. He said that the result of this loss was the deterioration of social participation and health of disabled people:

I sometimes think the family is the enemy. Because of the financial limitation, they don't put the disabled person first. "Treatment is useless for you. It doesn't work" "Right now, our life is more important." For instance, you are a disabled person with brain lesions. With an electric wheelchair, now you can lead a daily life, expand your sphere of activity, and stay healthy. But your mother tells you that she has no money to buy a new electric wheelchair. So now you need to walk too much without wheelchair. You put overload on your legs. Then you cannot go out as much. Your social relations decrease, and you will get depressed and die soon. Like this. Sometimes I think the

parents are kind of antagonists. They almost use the similar logic. “For your safety. Electric wheelchair is too dangerous. It’s expensive.” (Tae-Yong/M/41)

With well-fitted (electric) wheelchair, disabled people can reduce secondary impairment (see chapter five) and access healthcare services better. Therefore, even though an electric wheelchair’s cost is not healthcare expenditure, to use assistive devices for mobility is related to health of disabled people. The use of the term “enemy” when referring to a family is controversial because care or assistance for disabled people is still considerably dependent upon private family support. Often family support is essential to disabled people (Kyzar et al., 2012). Nevertheless, the family’s dependence sometimes undermines the independence and health-related quality of life of disabled people in a broad sense (Whiting, 2014). The self-determination of disabled people is likely to be violated by inadequate financial support or, on the other hand, paternalistic decisions. For instance, Baldwin (2015) pointed out that disabled people cared by family members had more difficulty in having control over services than users of paid care service.

In South Korea, with insufficient social (public and private) resources for disabled people, care and support are largely dependent on their families (Kim et al., 2014b). This dependence on the family can be a heavy load to family members, and disabled people who depend on their family for most of their lives are hardly acknowledged as an independent family member. The social support for disabled people is also needed to alleviate family loads and to strengthen the autonomy and independence of disabled people.

6.5.4 Access to health insurance for disabled people

Holzmann and Hinz (2005) suggested a multi-pillar pensions system for old-age income security, composed of the public and private pension systems. As this system, it is common to have private health insurance besides NHI in South Korea. According to Seo (2017), around 87% of South Korean people had private health insurance in 2017. However, it is not easy for disabled people to take out private commercial health insurance because they are often refused by the insurers (Lim, 2017). That is, disabled people have poorer health status and worse environmental conditions, but their health security system is less secure than that of non-disabled people.

From the view of the expansion of public health insurance security, the dependence on the private health insurance might not be desirable (Lee, 2003). Also, there is a criticism that the private health insurance aggravates health inequality because it only alleviates the medical fee burden of those who have purchasing power, but it is not easy for socially vulnerable people to have private insurance (Baek et al., 2012; Bae, 2007). Nevertheless, many disabled people cannot take out private health insurance could be interpreted as disability discrimination (Lim, 2017), and it is prohibited by law (see chapter two). Recently, some private health insurance is accessible to disabled people (Lim, 2017). For example, the private health insurance which only disabled people can purchase was developed, and the “duty of notice of impairment” in making insurance contract (a duty to notify the insurer of the impairment of the insured when purchasing insurance) was abolished in October in 2018 (Cho, 2018). A gradual improvement in the future is expected.

Disabled people have to find strategies to cope with future health care risks. Tae-Yong coped with this insecure situation with instalment savings.

I'm paying a premium of the NHI. Also, because I cannot take up a commercial health insurance, I pay a little each month in instalment savings instead of private insurance. For example, if I get cancer, get a surgery, then it costs me a lot of money not covered by the NHI. Against a rainy day, I made insurance system privately. (Tae-Yong/M/41)

This might be a useful way for Tae-Yong, but it is different from the insurance system, so it is still unstable. Health insurance, no matter if it is public or private, covers medical expenses according to regulations such as insurance terms, regardless of paid premiums, but this kind of personal savings only covers expenses within the amount saved. Moreover, this is not possible for all disabled people. Only those who can afford to save for rainy days can do this.

Some participants responded to financial pressure through the personal support system. As mentioned above, before the NHI covered the cure for Devic syndrome, Ja-Young had to self-fund the expenses. At that time, she received help from a charitable organisation. Dong-Jin had renal cancer surgery six years ago. The NHI covered the cure for renal cancer, but because the cancer surgery is fairly costly, the co-payment that is 30% of the full cost on average was a great amount of money to him, and he had to pay the expenses with help of relatives and acquaintances. Despite the public healthcare security system, he still needed private assistance in case of expensive treatment.

Six years ago, when I got cancer surgery, it cost me six million won (4,148.17 GBP). I realized that it is much better to support financially, even a small amount, than to bring something to eat when I visit a sick person. Almost three million won (2,074.09 GBP) was fundraised by the help of relatives and acquaintances so I could pay the medical fee. (Dong-Jin/M/46)

In-Hoon had a lumbar disc disease and stenosis as well. He had surgery a few years ago, which cost him a lot. At that time, through the information from his disabled colleague Min-

Soo, who was also a research participant, he could be fully funded by the hospital's social work team. In this case, it was not financial support, but informative support.

I decided to have surgery. Min-Soo told me the way to save the hospital bill. [...] About the financial problem... he told me to ask the medical social work team, and I was fully funded. [Min-Soo: They don't fund themselves but match the donator with the needy.] I was worried about the financial problem a lot, but Min-Soo helped me out from beginning to end. (In-Hoon/M/43)

His story suggested the importance of peer support of disabled people. Min-Soo knew about the system in the hospital that supports people who need medical expenses by receiving through a charity organisation to help his friend In-Hoon. As Tae-Yong said, if one meets a doctor who is well aware of the characteristics of disabled people, s/he can use better healthcare services. Information sharing between disabled people can be useful in coping with the difficult problems in healthcare service use.

6.6 Summary

In this chapter, the barriers disabled people encounter when they use healthcare service were investigated. They were facing difficulties in searching available healthcare service centres, getting there, receiving treatment, paying for the healthcare fee and others. Many participants talked about the physical barriers to access and use healthcare centres and medical equipment; human and attitudinal barriers as some medical professionals lacked knowledge and consideration of disabled people; the financial burden due to continued medical expenses; psychological distress and family conflict caused by these barriers. These could be included

in “social determinants of health,” which might be conditions that deteriorate the health of disabled people.

Chapter 7 Integration of quantitative and qualitative results: the multi-dimensionality of health inequality among disabled people

This study adopted a mixed-method of quantitative and qualitative research for a multi-lateral approach to health inequality of disabled people. Data from mixed-methods were analysed in the previous three chapters: in chapter four, information about general characteristics including socio-economic status, health-related variables, and health inequality of disabled people in South Korea were examined by carrying out a secondary analysis of the Korean National Health and Nutrition Examination Survey (KNHNES). In chapters five and six, two main themes derived from the focus groups and interviews were explored: secondary impairments and the barriers to healthcare service use experienced by disabled people.

In this chapter, the findings from the previous chapters will be integrated and synthesised. How these results underpin and supplement each other or whether there is conflicting evidence between them will be explored. The integration of diverse methods generates new knowledge by enabling the researcher to see the results from a new perspective (Schoonenboom and Johnson, 2017). Therefore, this chapter goes beyond a simple summary of the previous chapters, utilising the strength of mixing methods to provide a deeper and multi-dimensional analysis.

7.1 General socio-economic status of disabled people in South Korea

Much data on a national level presented the low socio-economic status of disabled people in South Korea (see chapter two) and quantitative analysis in this study also demonstrated a similar result (see chapter four). First, disabled people had lower income than non-disabled

people. In the analysis of this study, with regards to the household income, 39.01% of disabled people belonged to the lowest income quintile, while 15.2% of non-disabled people were in this group (see chapter four) (All figures in this section are from chapter four). The median of equivalised monthly household income of disabled people was also lower than that of non-disabled people (non-disabled people: 1,750 thousand KRW/ disabled people: 1,172 thousand KRW) (1,148.97 GBP/ 769.48 GBP as the exchange rate of September 2020). In addition, disabled people were less educated than non-disabled people: the proportion of disabled people educated for nine years or less was over twice as many as non-disabled people (non-disabled people: 27.7% / disabled people: 57.3%). Disabled people were also less likely to have paid jobs than non-disabled people (non-disabled people: 58.2% / disabled people: 42.0%). Furthermore, the distribution of wealth was more unequal among disabled people than among non-disabled people. This was found by comparing the income quintile share ratio - the ratio of income for the highest 20% to that of the lowest 20%- of the two groups. The figure of the disabled group was 10.5, while that of non-disabled people was 7.4. This means that among disabled people, the richest 20% earned 10.5 times as much as the poorest 20%, while the richest 20% earned 7.4 times as much as the poorest 20% among non-disabled people (see chapter four).

While the quantitative data showed the objective status of disabled people, the qualitative data revealed several factors generating this lower status. Most participants with paid jobs engaged in work related to disability organisations such as Centres for Independent Living (CIL), while only one participant worked at a workplace where non-disabled people were the majority. This seems to represent that it is difficult for disabled people to get a job in competition with non-disabled people. Interviews demonstrated the economic burdens of disabled people caused mainly by the absence of a stable paid job and the process where their low economic status was being aggravated due to the extra costs of impairments and health

expenditure. For example, Kang-Oh said that he had never had a paid job since he got impaired. Young-Min explained his economic deprivation as below:

I used to be in the middle-class. But it's the 35th year since I got impaired and it has cost a lot of money to use healthcare services, assistive devices, a personal carer and so forth. I am heavily in debt and it is getting worse every day. (Young-Min/M/63)

The loss of ability to work as a paid worker and extra health and social care costs lead to a lower socio-economic status, which brings about aggravation of health and future, even lower economic status. More severe inequalities in the income distribution of disabled people would not be irrelevant to this vicious circle of poverty. This mechanism of double exclusion has been considered as the main aspect of the marginalisation of disabled people (Yeo and Moore, 2003), as found across the globe (Eide and Ingstad, 2017; Hossain et al., 2017; Hughes, 2015. Maart and Jelsma, 2014; Heslop and Gordon, 2014). This study contributes to this literature by verifying the lower status of disabled people and, as it will be explained in the following sections, by demonstrating the role of health in aggravating and perpetuating their poverty.

7.2 Health status of disabled people

The results of the quantitative analysis demonstrated the low health status of disabled people. In this analysis, two fields were adopted to compare the health status of non-disabled and disabled people: comprehensive health status and morbidity rate (the rate of disease in a population).

The comprehensive health status was measured by two indicators: self-assessed health (SAH) and EQ-5D (EuroQoL-5 dimension) index score. SAH is assessed by a five-point scale answer (very good-good-fair/ordinary-bad-very bad) to the question, “how is your health in general?” EQ-5D is a standard instrument to measure health outcomes developed by EuroQol Group, a network of international multidisciplinary researchers measuring health status (EuroQol Research Foundation, 2015). EQ-5D assesses how many problems respondents have in five health-related areas - mobility, self-care, usual activity, pain, and depression and anxiety on a three-point scale (no problem-some problem-extreme problem). The EQ-5D index score is calculated by summing the answers to the five questions. A higher score implies better health outcomes (see chapter three).

Disabled people were found to have lower health status than non-disabled people in both indicators. In SAH, the proportion of disabled respondents assessing their health as “bad” or “very bad” (36.8%) was over twice of non-disabled respondents (15.0%). In the EQ-5D index score, the mean score of disabled people was .84, while that of non-disabled respondents was .95. This showed that non-disabled people reported better health outcomes than disabled people. The morbidity rate was also higher in disabled people. Chronic diseases analysed in this thesis were more prevalent among disabled people except in four diseases: thyroid gland disease, stomach cancer, atopic dermatitis and allergic rhinitis (see Table 4.11).

In some diseases, the morbidity rate was too low in both groups or the difference was too small to be significant, but disabled people represented significantly high morbidity rate than non-disabled people in hypertension (non-disabled people: 15.6%, disabled people: 34.9%), dyslipidaemia (abnormal amount of lipids such as cholesterol in the blood) (non-disabled people: 10.0%, disabled people: 23.5%), stroke (non-disabled people: 1.5%, disabled people: 11.0%), osteoarthritis (non-disabled people: 8.0%, disabled people: 22.4%), and depression

(non-disabled people: 3.1%, disabled people: 10.5%). Consequently, it was identified that disabled people had worse health than non-disabled people in the indicators examined.

In the qualitative study, instead of direct comparison to non-disabled people, the health condition of disabled people was described in detail, and the factors influencing the health status of disabled people were explored through their narratives. Through thematic analysis, two main themes were derived. The first theme, named “secondary impairment,” represented the current health outcomes of participants, causes and related issues. The second theme, “barriers to healthcare service,” identified the influential factors that kept the participants away from the smooth healthcare service use and brought about or worsened ill health. These two themes are associated with the process of aggravation of health of disabled people. This was evident in how the consequences of primary impairments brought about secondary impairments. Secondary impairments were mostly chronic conditions and had a crucial impact on the quality of life of disabled people, but were not necessarily unavoidable if adequate and timely support would have been available. In addition, as it can be seen in section 7.3, many participants experienced decreased health outcomes, which related to numerous “barriers to healthcare service.”

7.3 Health inequalities among disabled people

This section synthesises quantitative and qualitative results related to health inequalities within disabled people.

7.3.1 More unequal health outcome among disabled people

In addition to comparing health characteristics of disabled and non-disabled people, this study compared how severe health inequalities were within both groups. Even though disabled people have poorer health than non-disabled people, it can be assumed that health inequalities by socio-economic class within disabled people groups are less severe than that of non-disabled people. In other words, since disabled people are considered to be at the extreme of poor health, it can be assumed that there is no great variation in their health according to socio-economic status. With regard to this, the impact of economic status on health can be inferred by examining disabled people's health according to their income level. That is to say, the presence of larger health inequality might imply that health status can be improved by improving the social, environmental determinants and material supports (Braveman and Gottlieb, 2014).

In this study, the level of health inequality was quantified through the concentration index (CI) analysis (Wagstaff et al., 1989) (see chapter three). CI analysis for two indicators-SAH and EQ-5D- was performed for both disabled and non-disabled populations. The results of both indicators demonstrated that there was "pro-rich health inequality" (high-income groups have less ill-health than low-income groups) in both disabled and non-disabled populations (see chapter four). In other words, whether disabled or not, wealthy people tend to be healthier than impoverished people. Further, it was found that the absolute value of the CI of disabled people was larger than that of non-disabled people in both indicators (see chapter four). This means that the pro-rich inequality among disabled people is more severe than that of non-disabled people: the gap in health status according to socio-economic status is greater in the disabled population. Based on this, it can be interpreted that when they are poor, disabled people are more vulnerable in health status than non-disabled people: the health status of

disabled people is considered to be more sensitive to their economic power than that of non-disabled people.

The reasons why the health of disabled people in poverty is worse than non-disabled people, and why they are more affected by their economic status than non-disabled people, are complex and could not be answered fairly based on data from this study. However, the qualitative data suggested that disabled people are likely to have higher complicated social conditions, making their health extremely vulnerable. The various secondary impairments mentioned in chapter five (chronic pain and fatigue, pressure ulcers, cervical herniated nucleus pulposus disc, incontinence, and transformation of the body frame) were partially the results of aggravation of health by the lack of social resources to respond to the health risk impacts, which were avoidable. One example is pressure ulcers. Most wheelchair users were exposed to the risk of pressure ulcers and had concerns about them, but not all the users suffered from the pressure ulcers because they can be preventable with proper care such as skincare, repositioning, pressure redistribution, and supply of good nutrition (Park and Heo, 2015). Adequate care requires not only interpersonal but also material support. As seen in chapter five, participants such as Yuri, who were well supported by their caregiver and assistive device, had not developed pressure ulcers, while others without that kind of care and economic support needed to have surgery due to the severity of their pressure ulcers: even Kang-Oh had both legs amputated as a sequela. This example illustrates how the lack of coping resources when disabled people are already exposed to increased health risk can significantly decrease health status.

The narrative of Min-Soo seen in chapter five, whose health was aggravated since he was forced to overwork due to the need for money (due to his youngest baby) when he should have concentrated on the recovery after lumbar disc surgery, supported this finding. He had been occupied with his work for three or four months with a lot of stress but no enough rest

and it caused a surgical site infection. Even though the primary impairments of disabled people do not disable them directly (Oliver, 1990), they may be able to create conditions that are susceptible to deteriorating health. Therefore, economic power, which can deconstruct the condition created like this, is crucial to maintain increased health outcomes in disabled people.

7.3.2 The aspects and causes of health inequality

To find out the influential factors to health inequalities, in both disabled and non-disabled populations, CI of health outcome variables was decomposed by components and determinants (see chapters three and four). A decomposition by components identifies how much each component of health accounts for total health inequality, so it is only performed about the health outcome variable composed of multiple components (Clarke et al., 2003). In the decomposition of CI of EQ-5D by component, the order of contribution to health inequality presented as mobility-pain/discomfort-usual activity was the same in both populations. In other words, health inequality is most severe in mobility, followed by pain/discomfort and usual activity in both populations. However, detailed aspects were different between disabled and non-disabled people: the contribution rate of each component of disabled people was much more equally distributed than that of non-disabled people. Notably, the contribution of self-care in disabled people was more than twice as high as the non-disabled people (non-disabled people: 5.4%, disabled people: 12.4%) (see Table 4.19). It could be interpreted that health inequality among disabled people was found in every dimension of health (mobility, self-care, usual activities, pain/discomfort, and depression/anxiety) evenly rather than one particular dimension constituting the inequality exclusively.

A decomposition by determinants is to compare the relative impact of each cause to health inequality. In the decomposition by determinants of CI of SAH, the most highly contributing variable to health inequality was age (35.6%) in non-disabled people. The next variable was medical security, but the contribution rate (8.7%) was much lower than that of age. On the other hand, in disabled people, the contribution rate to health inequality of employment was the highest (27.7%). The next was medical security (25.7%), and age was high (23.7%). The high contribution rates of these variables were maintained even after the disability type, and grades were additionally introduced in the analysis model (see Table 4.21). This result demonstrated that in disabled people, the contribution of social variables such as employment and medical security were higher than in non-disabled people.

In sum, decompositions of CI by component and determinant implied that health inequalities among disabled people are more multidimensional and affected by social factors than non-disabled people. Further, from the analysis of focus groups and interviews, it is illustrated how the limitation of usual activities brought about depression or anxiety in the end. In chapter six, Tae-Yong described the process in which the impoverished economic situation caused poor health, and the reduction of living space due to low mobility led to aggravated mental health. It implied that the low health status of each dimension of EQ-5D experienced by disabled people with low income was associated with one another, and it can be said that the result of decomposition was taken concrete shape by participant's narrative.

7.3.3 Mental health and disabled people

There were other issues about mental health, which were not mentioned in previous chapters. Young participants like Yuri exposed their anxiety about the future work to be self-sufficient.

I had that kind of anxiety pretty much. What should I do in the future? What about my job? Can I compete with non-disabled people? How should I have much more strength than non-disabled competitor to be chosen? How can I overcome this? I got worried about it. And I thought about the future when my parents are not with me any longer. If they were gone, how can I fend for myself? It made me anxious quite a lot. (Yuri/F/19)

In nearly all cases, anxiety in disabled people was related to their economic instability. In disabled people, the impairments and the absence of coping resources aggravated their anxiety. The specific impact of employment in mental health was a clear finding illustrated by Sun-Ho, a male in his 40s with cerebral palsy, whose unemployment led to his ill health.

I lost my job three years ago. Since then, due to unemployment, I got unwell. I did not quit my job because of my unhealthiness. Rather, the unemployment was a cause and the bad health was an effect. I used to work at a gas station before. But unemployment made me frustrated. It was a mental problem. (Sun-Ho/M/41)

This case seemed to support the theory that employment or job satisfaction is related to the sense of self-esteem (Nosek et al., 2003; Griffin et al., 1996). Since being employed was very important to Sun-Ho, he developed both physical and mental health problems when he lost his job. However, it is too simplistic to infer that employment would positively affect the health of disabled people. Several factors of employment conditions (income, stability, fringe benefits) are necessary to link it to an employee's wellbeing (Graetz, 1993). Ja-Young told her experience of deterioration of health due to job stress.

I'm under a lot of stress recently. Managing and solving the problems makes me exhausted. Due to the overwork and job stress, I'm in poor health now. The stress comes from outside continuously. It's a job stress. (Ja-Young/F/44)

Sun-Ho and Ja-Young suffered mentally from unemployment and job stress, respectively. These opposing cases showed that disabled people experience problems similar to non-disabled people (Lee et al., 2013; Nahar et al., 2013). Work generally has both a positive and negative impact on mental health at the same time. Some long for self-actualisation and economic stability, while others want to quit but cannot do because of their livelihood. Disabled people would be no exception, and this could be a more crucial factor in their health. Nevertheless, it is not actively discussed in South Korea yet. The stress generated by employment has traditionally been regarded as a more micro-level issue than employment policy of disabled people, such as investigating factors impacting on job satisfaction, job performance, or job stress of disabled employees (Lee and Kim, 2012; Kim et al., 2012). However, employment promotion and helping disabled people perform their job and manage their job stress successfully should be considered for their health.

CI Decomposition of EQ-5D by components implied that even health inequality in depression/anxiety was more severe in the disabled group than the non-disabled group (see Table 4.19). This finding demonstrates the vulnerability of poor, disabled people in mental health and implies that there should be a consideration.

7.4 Barriers to healthcare service: environments that make disabled people unhealthy

The interruption to the smooth healthcare service use for disabled people is one of the factors that aggravate their health. These “disabling barriers” are around all disabled people, and therefore hospital environments were no exceptions. Before identifying the barriers, the actual status of healthcare service use by disabled people was investigated.

Two years of general health check-up and cancer screening, provided regularly by the National Health Insurance (NHI, see chapter 2.3), was analysed in chapter four. In both rates, disabled people demonstrated slightly higher values than non-disabled people (general health check-up rate- non-disabled people: 60.5%, disabled people: 64.1% / cancer screening receipt rate- non-disabled people: 45.7%, disabled people: 54.9%). Therefore, it seems that disabled people were included in the basic health check-up schemes for prevention and seem to access these more than non-disabled people. More use of healthcare services by disabled people than non-disabled people was already reported in other studies (Lee, 2013a; Lee, 2004d).

Despite this positive outcome, the unmet needs for access to healthcare services among disabled people were higher than non-disabled people. This was measured by the proportion of positive answers to the question, “Have you ever been sick but not able to go to the hospital? What was the reason?” The result showed that the proportion of disabled people who could not go to the hospital in case of need was higher than that of non-disabled people (non-disabled people: 12.3%, disabled people: 15.2%). Although this may seem a small difference, more than half of disabled respondents (53.6%) stated economic factors as to why they could not go to a hospital, while the proportion was less than one in fourth in non-disabled people (23.5%). That is, disabled people faced much larger financial barriers to healthcare service than non-disabled people. In other words, despite their higher receipt rate of health check-ups, the follow-up or emergency healthcare needs of disabled people could not be met.

The barriers to healthcare service were explored in-depth, and diversely, through qualitative data. Numerous heterogeneous barriers were concretely identified in the participants' accounts of health service encounters. First, the participants had difficulties in finding available hospitals close to their homes. Because most of them had severe impairments, they thought small-scaled clinics were not adequate to treat their impairments but could not find a

large-scaled local hospital specialised for disabled people. This need was even more serious among the residents in rural areas. Even though some of them found adequate hospitals, accessibility was a common barrier to access them. Most participants did not drive; thus, they needed to use public transportation to access healthcare service centres. However, public transportation and road conditions were unavailable or inconvenient for disabled people to use, and the provision of special transportation service (STS) was insufficient.

Once in the hospital, the inaccessibility of medical equipment was also problematic. Participants could not have medical tests because the medical equipment was not accessible to their needs or did not fit their body shape. Even a simple measurement of body stature was not available. Also, there were numerous difficulties during hospitalisation due to the lack of personal assistance and adaptation.

The chronic lack of health service supply was another issue. The total amount of services provided to participants was limited with long waiting lists for rehabilitation therapy, mostly provided in non-medical community-based tertiary care centres. This is significant since physiotherapy ensures mobility recovered or maintained, and therefore, disabled people can benefit from increased independence.

Participants also pointed out the lack of knowledge and experience of medical professions and their attitude. Improper behaviour caused by a lack of clinical expertise in the characteristics of specific disabilities was mentioned, and the paternalistic attitude of medical professionals was also brought into question. According to participants' narratives, some medical professionals expressed their discomfort, especially when they met people with rare diseases or severe transformation. Related to lack of knowledge, participants stated that the information provided about how to access specific healthcare services or support for disabled people was scarce. This is associated with difficulties in self-care and barriers in healthcare

service use: due to the lack of knowledge and information, sometimes they had a hard time taking care of themselves.

Financial burden, the main reason for not using healthcare service in quantitative analysis, was also stated in the focus groups and interviews in more detail. Although all the participants were beneficiaries of public health insurance (NHI) or the Medical aid system, the expenses uncovered by the NHI or other expenditures such as maintenance cost of assistive devices they need to pay for privately were burdensome. Even though NHI's coverage has been expanded gradually, the absence of private health insurance can be a financial barrier.

The barriers to healthcare service use drawn from qualitative data can be broadly classified into financial difficulties, physical inaccessibility, and the ignorance and prejudice toward disabled people of healthcare professions. These categories followed the framework of the Institute of Medicine (1993), which categorised the barriers to healthcare as structural, financial, and personal/cultural barriers (Drainoni et al., 2006). These same factors have also been mentioned in abundant preceding literature (Badu et al., 2016; Merten et al., 2015; Peters and Cotton, 2015; Popplewell et al., 2014; Miller et al., 2013; Drainoni et al., 2006; Kroll et al., 2006). However, all the cited studies are performed abroad, and it was not easy to find the research in which categories the barriers to healthcare service experienced by disabled people based on empirical data in South Korea. Therefore, it can be said that the findings in this study were broadly consistent with preceding research but relatively new in South Korea. The repeatedly mentioned differences between urban and rural areas were also presented in other literature. For instance, Douthit et al., (2015), Aboagye et al., (2014), Montgomery et al., (2014) reported the poor accessibility to healthcare service use of rural residents found in this study. Furthermore, accessibility and health outcomes such as life expectancy were reported to be poor in rural areas (Montgomery et al., 2014; Singh and

Siahpush, 2014; Liu et al., 2013). In the next chapter, this study's findings will be further discussed in comparison with the literature.

7.5 Summary

The main purpose of this chapter was to understand the phenomena related to the health of disabled people multilaterally with focusing on the improvement of their health and health equality. The results derived from quantitative and qualitative data were integrated and synthesized in this chapter. Thus far, disabled people had lower socio-economic status, lower health status, and lay in more severe health inequality situation. Health inequalities among disabled people are more multi-dimensional and affected by social factors than non-disabled people. Also, they experienced plenty of structural, financial, cultural barriers when they used healthcare services. These results were found in quantitative and qualitative data collected according to a mixed-method. In this mixed strategy, qualitative data often represented and supported similar phenomena to quantitative data; or supplemented the complex reality that cannot be known through quantitative research. Sometimes it provided clues to the cause of phenomena that could not be explained by quantitative data alone. The inconsistency or conflicts between quantitative and qualitative data were not remarkable in this study.

Chapter 8 Discussion

In this chapter, three discussions upon the healthy lives of disabled people and health inequality based on the findings of previous literature and synthesis of the results of this study will be provided.

First, the fundamental logic of disability studies of disability and health will be reviewed concerning the method of this study. Second, the perception about the health of disabled people by themselves will be discussed through previous literature, and the participants' words to demonstrate that they can be healthy. Third, the health inequality of disabled people and their social determinants will be discussed alongside quantitative, qualitative results, and synthesis. In the discussion, there will be a deliberate effort to deliver the intended meaning of concepts and expand this study's findings at a theoretical level in association with the preceding research. This discussion will be the procedure to find out the practical implications of this study.

8.1 Disability, health and its metrics

Mentioning the health of disabled people is to disentangle and organise diverse, ambiguous and contested concepts. It is associated with operationalisation of definition, measurement and analysis of quantitative approach alongside performance of qualitative approach.

This study has supported that the concept of "health" has been narrowly applied to disabled people, as pointed out in diverse literature (see chapter one). From time to time, disability (or activity limitation) was recognised as "poor health" in many studies, and disabled people

were considered as “unhealthy people” (Schoeni et al., 2005; Van den Bos et al., 2002; Mendes de Leon et al., 1995). This preconception focused on the limitation of disabled people’s bodily or mental function, and the limitation of function was health outcome. Under this perspective, disabled people are those with an impairment, distinguishing “abled-bodies” and “disabled bodies.” It is regarded as a failure: something deviated from an ideal and normal body (Davis, 2017; Berghs et al., 2016). This assumption is quite far from the social model of disability, reviewed in chapter one, which regards disability as a social construct, and disabled people as an oppressed group by society (Goodley, 2011). In the social model of disability, impairment, which is a physical condition, is distinct from disability to greater or lesser degree.

The perspective of identifying the impaired body with poor health was also reflected in the measurement of health in various quantitative research. Most variables used in my study to measure health equated limitation of bodily function with poor health. For example, in the case of EQ-5D, the respondents were supposed to answer the question on mobility with “I have no problem in walking about,” “I have some problems in walking about,” or “I am confined to bed” (EuroQol Research Foundation, 2015). If somebody answers, “I have some problems in walking about,” or “I am confined to bed,” then s/he is regarded to have worse health than somebody who answers s/he has no problem walking about. However, even those who cannot walk due to the musculoskeletal impairment of the lower body may not have difficulties moving from a bed or wandering around with the help of environmental facilitators such as an assistive device, personal assistant, or convenient facilities. Therefore, without consideration of environmental and social barriers, this question could make it confusing to answer.

Nevertheless, it is not fair to conclude that this questionnaire is wrong because what determines the validity of a question is its purpose. If the purpose of a question is to

understand the body condition without any personnel or material support, the question should be answered without considering assistive devices. For example, the most important objective of an epidemiologic survey is to comprehend the prevalence of a specific disease. On the other hand, regarding the survey related to disabled people, it would be important not only to care about biological impairment but also to identify the obstacles that prevent disabled people from walking. To eliminate disabling barriers and create enabling environments, it is required to figure out how people with impairments perform their everyday lives with or without assistive devices.

This is relevant to the definition of disability and survey design, which has been mentioned in disability studies for a long time (Fujiura and Rutkowski-Kmitta, 2001). The way to inquire about the limitation of physical function and consider this limitation as “poor health” was similar to how disabled people were defined and criticised by previous researchers (Altman, 2001; Fujiura and Rutkowski-Kmitta, 2001; Oliver, 1990). In particular, the subjects of my study included only people registered legally under the “Welfare for Disabled People Act 2007,” which is based on the individual model and limits the range of disabled people very narrowly (see chapter three). This was the case for qualitative sampling as well. It was in order to investigate only those who were officially recognised as disabled people in South Korea, but in this regard, my study can be shown to have substantial weaknesses.

In this regard, Oliver (1990), who defined disabled people not by their characteristics but by barriers in the environment, criticised the way disability was measured in most surveys. He demanded that questions such as “how many difficulties do you have in walking?” should be rephrased as “how many environmental barriers prevent you from walking?” to take into account environmental factors. However, this suggestion did not significantly impact the criticism that the alternative questions were not proper for a survey. For example, Bengtsson (2008) concluded that the social model of disability is an idea about what produces disability

in society, rather than tools for the empirical identification of a group of people in surveys. It (the social model of disability) can show exclusion and oppression against disabled people. However, it is difficult to present to what extent people with specific impairments experience disablement through the questions based on the social model of disability (Molden and Tøssebro, 2010: 177). This is because it is difficult to specify the population according to the environment-dependent conditions. When it comes to the disability issue, defining disabled people within the interaction between individual and environments might be proper. Nevertheless, it cannot be applied to all. This reflects the complexity of the measurement of disability.

From the perspective of disability studies, the attempt to measure the impairment on the disabled body is regarded to be based on the individual model, but more broadly and fundamentally, this can be contemplated with the term “Metric power” (Beer, 2016). In his analysis of the world today, metrics are regarded to play a decisive and intensifying role in organising all areas of contemporary lives. Mau (2019) called this world a “metric society” and offered a critical analysis. Numbers have the power to present complicated information summarised in an easy-to-understand way. It can be very useful to understand the phenomenon, but it leads to the tendency to rank and evaluate everything based on a uniform standard. With this, there is a risk of distorting the essence of the phenomenon by neglecting the context. Contexts such as personal traits and group culture are liable to be overlooked when concentrating on the quantified average and deviation. Since to measure impairment and define disability is context-dependent like above, the metric power of the metric society and its impact are issues to be considered from the critical perspective.

To sum up, regarding impairment as unhealthiness, and consequently, establishing that disabled people are unhealthy is difficult to avoid when assessing and distinguishing people’s functioning in quantitative measurement tools. If we consider the great impact of impairment

on the lives of disabled people (Thomas, 2004), this approach can be necessary. However, to affirm the healthiness in the lives of disabled people, we need to adopt various approaches, which understand health outcomes as constrained under environmental contexts beyond focusing on the limitation of functions. This can be one way to talk about the health of disabled people in the social model of disability.

8.2 Perception of disabled people about their own health

One of the objectives of this study is to enhance the understanding of how healthy life looks like for disabled people, which cannot be carried out without taking into consideration how disabled people experience and understand their own health. Thus, a look back on the relationship between health and disability is required.

The awareness of those limitations and a view of the social world drove the need to include disabled people's voices to explore the further meaning of health. This attempt to understand their subjective experience within the context of their daily lives has been considered an unconventional theoretical and methodological approach in medical sociology (Lawton, 2003). In the study upon the experiences of illnesses, Lawton (2003) considered this as a "shift" from an "outsider's perspective" to focus on their lay experience. This seems like the empowerment of disabled people, instead of experts' authority, which dominated the disability issue for a long time (Oliver, 1996). This is also about empowering disabled people to talk about their health, an area that disability studies have traditionally avoided; disability scholars have identified disability studies as a social, cultural, and political analysis of disability (Goodley, 2011; Barnes, 2003) and an issue about the health of disabled people, which is apprehended to authorise medical profession, was not mentioned actively.

When exploring the meaning of “health” of disabled people through in-depth data, they referred to their health as “adjusted” to their lives, inferring that healthiness standards were adapted. Sometimes they considered themselves unhealthy, but it was mostly due to their secondary impairment rather than primary ones. Participants exemplified their views with examples of their daily lives with illness. Chul, who had dialysis two or three times a week for four hours each time due to his chronic renal failure, considered he had adjusted to his condition and he lived a healthy life because he was carrying out his job without any major trouble. Seon, who had a spinal cord injury, did not consider medical treatment indispensable to improve disabled people’s well-being, and he also claimed that some disabled people could be even healthier than non-disabled people. Chul and Seon explained that a “healthy disabled life” is different from a “healthy non-disabled life” and regarded their impairments as part of their own optimum health status. They definitely cannot represent all disabled people, but there are people like them. As disability is a universal experience in human beings (Marinelli and Orto, 1999) and a kind of continuum, it is illogical to regard two fixed standards of health based on the dichotomy of disabled and non-disabled people. However, it is worthy to emphasise that disabled people do not consider poor health only due to their impairments.

The perception of disabled people like above can be accounted for by “narrative reconstruction” suggested by Williams (1984). It signifies the conceptual strategies people adapt to produce a sense of coherence, stability, and order in the aftermath of the onset of impairment (Lawton, 2003). Williams stated that impaired people employed this strategy to “reconstitute and repair ruptures between body, self and the world by linking and interpreting different aspects of biography in order to realign present and past and self and society” (Williams, 1984: 197). As impairment could be a great shock and a condition to adapt to each individual, the reconstitution was one way of coping with the change. In my study, some participants spent large amounts of money to recover from impairment when they got

impaired the first time, but after they were told there was little possibility to recover, they accepted it and reconstructed their views of health and a healthy body by adjusting it according to their impairments. Furthermore, by reconstructing their own concept of health, they reconciled with their new selves.

However, the concept of “reconstructed health” needs to be interpreted or analysed within the context of the social model of disability framework, focusing not on “removing bodily impairment” but on “eliminating external barriers.” In the reconstructed recognition, disabled people are likely to regard the external environments as larger obstacles to better health than their impairments. This brings the point back to the question, “what is a healthy life?” In this respect, Albrecht and Devlieger (1999) noted the “disability paradox.” In their study, the term “quality of life” was used instead of “health”, but the ultimate intention is similar. The disability paradox means that people with serious and persistent disabilities report that they have good or excellent quality of life, despite observers’ different views (see chapter one). This discordance between actual or perceived health and appearance of health has been identified by previous social science studies. For example, under the strong influence of concrete corporeal manifestation of health (through extreme exercise), some people accept the risk of losing their health to get an appearance of a healthy body (Monaghan, 2001). This demonstrates how the appearance of a healthy body observed on the outside might be far from actual health. This relates to the contested idea of what health is. Hence Albrecht and Devlieger (1999) identified that the core factor of quality of life was “a balance between body, mind, and spirit in the self and the establishment and maintenance of a harmonious set of relationships within the person’s social context and external environment” (Albrecht and Devlieger, 1999: 977). This definition emphasises the reconciliation between individual internal factors and harmony with external conditions.

Albrecht and Devlieger's idea is considerably significant, but it seems to be a little bit biased in the way that it overemphasises a microscopic point. In relation to this, Lawton's (2003) two kinds of influences on lay experiences of health and illness can be presented: social and demographic influences (macro-context) and selves to others (micro-contextual influences). The macro-context corresponded to demographical conditions (age, gender), social class, or self-perception within the social context. For example, gendered norms and stereotypes come under this category. That a scar on a face is regarded as a more severe loss, especially for a young woman (Lee, 2010c), presents that the social role expectation brings differences in the ways body conditions are experienced (Bendelow, 1993). There was also a clue that the social attitudes toward disabled people also affect their self-identities under the perspective of social constructionism (Ville et al., 1994). In a society with an obsession with an "ideal body," physical impairment is a socially great loss. On the other hand, micro-contextual influences are associated with a personal, supportive relationship. Regardless of the social context, if disabled people have inner wellness and good relationships with others, they might think they are in good condition. In this perspective, the concept of disability paradox appears to be biased toward micro-contextual influences.

Furthermore, this expansion of health is a double-edged sword when it comes to disability theory. For example, the components of the ICF (International Classification of Functioning, Disability and Health) include body functions and structures, activity, and participation (WHO, 2001). In this framework, participation is involved in major life areas (education, employment) and community, social and civic life (recreation and leisure, religion and spirituality, political life and citizenship) (WHO, 2001) (see chapter one). ICF has been criticised by disability activists for implying a medical model (Berghs et al., 2016; Cerniauskaite et al., 2011) because it treats body functions and structures in detail as a component of health-related domains. Nevertheless, it is worth noting that it expanded the

concept of health up to civic and religious life and assumed environmental factors. Impairments of body functions and structures are just a part of health, and the concept of health for disabled and non-disabled people needs to be expanded.

8.3 Disabled people and health inequality

In this section, the relations between the socio-economic status of disabled people and their health, the multi-dimensionality of the health inequality of disabled people and the bi-direction of environments affecting disabled people's health will be discussed.

8.3.1 A healthy disabled life: public health, a contested disabled territory

The section above focused on the critical consideration that disabled people are unhealthy simply because of their impairments. By reconstructing the concepts of health adjusted to their own conditions, disabled people reset the standard of good health not only for them but also for non-disabled people. This is not to emphasise the differences between disabled and non-disabled people but highlight that disabled people can have good health, which can be achieved differently. This demonstrates the social construction of "health" and "healthy" lives.

Though, some major variables in general health areas are still crucial to disabled people. Since these variables can demonstrate health inequality between disabled and non-disabled people, the improvement of those indicators could be one of the goals of disability health policies in modern states. For instance, the rate of regular health check-ups is important in

health promotion policy. These indicators are worthy to notice in the paradigm of new public health of which the core variable is a risk management (Petersen, 1997).

Prevention, one of the core objectives of public health policy, is a sensitive issue in disability studies. Mostly this is deeply related to the prevention of an occurrence of impairments, which highlights negative views of disabled people, and also it relates to bioethical issues, such as prenatal tests and eugenics (Shakespeare, 2017; Barnes and Mercer, 2010; Clements and Read, 2008; Hubbard, 1997) (see chapter one). This ongoing debate can be a threat to the right of life of disabled people; hence, it requires a cautious approach.

Nevertheless, the prevention of aggravation of health is directly associated with the quality of life of disabled people. As stated above, those who recognise their impairments as part of their healthy bodies redefine the concept of health. Although the specific meaning of health depends on each person individually, the common area of health includes equal presence and participation in a society beyond a simple minimisation of the negative impact of impairment on life.

The main characteristics of the health status of disabled people found in this thesis are higher morbidity, lower self-assessed health status, lower mobility, and more depression and pain. Their unmet healthcare needs were higher than those of non-disabled people despite the higher usage of preventive healthcare services (see chapter four). Numerous previous studies have shown similar results of poor health and low access to healthcare services of disabled people, not only in South Korea, (Yu, 2016; Yun et al., 2014) but across the globe (Badu et al., 2016; Merten et al., 2016; Peters and Cotton, 2015; Popplewell et al., 2014; Miller et al., 2013; Drainoni et al., 2006; Kroll et al., 2006).

Health screening rates from previous studies did not offer consistent findings: some research showed higher rates of disabled people (Miller et al., 2014) but others identified lower rates

(Rotarou and Sakellariou, 2017; Peters and Cotton, 2014; Yun et al., 2014). In my study, the rate was higher in disabled than non-disabled people. Since the countries where the research was conducted are diverse, such as the United States (Miller et al., 2014), Chile (Rotarou and Sakellariou, 2017), Australia (Peters and Cotton, 2014), and South Korea (Yun et al., 2014), inconsistent results probably reflect the characteristics of each country.

The low socio-economic status and marginalisation of disabled people have consistently been pointed out as one of the associated factors of lower health status (Mithen et al., 2015). If expanded to the whole population, preceding research has demonstrated that the consequences of poor health and the process leading to it are social products (Mackenzie et al., 2017; Emerson et al., 2011; Asthana and Halliday, 2006; Marmot and Wilkinson, 2005). If the poor health of disabled people is a social product, people with biologically similar impairments may have different levels of health outcomes, depending on their socio-economic status. Also, a healthy disabled person with severe impairment but enabling resources will support the possibility of healthy lives of disabled people.

In South Korea, most research on the health of disabled people investigated the actual condition of their health or the relationship between associated variables, including impact factors in quantitative measures (Roh et al., 2017; Yu et al., 2016; Gweon, 2010; Jo, 2010; Jun et al., 2010). My study is relatively innovative in this area by studying not only the health gap between disabled people and non-disabled people but also health inequality among disabled people. The health gap between disabled people and non-disabled people clearly demonstrated the deprivation of disabled people by revealing significant differences between the two groups. What makes some disabled people's health different from other disabled people was explored by analysing the socio-economic inequalities. The status of a disabled person is a broad categorisation that does not reflect disability heterogeneity and acts as a kind of label. It is important to reveal the common experiences of disabled people, but it is

equally crucial to determine the factors that have contributed to the quality of life of disabled people by capturing the diversity within this group. Like gender, age, or ethnicity, impairment is an attribution that can hardly be changed in most cases. If it is effective to enhance disabled people's health by intervening in their primary impairment, it could be allowed. In most cases, however, it is neither possible nor desirable. This means that engagement in another dimension rather than impairments is required to enable disabled people's healthy lives. That is recognition and alleviation of external disabling barriers.

Larger health inequality within disabled people found in this study highlighted the heterogeneity within disabled people who can be seen as homogeneous in health status. The statistical results reported that the health of disabled people was more concentrated in lower status than non-disabled people, but the systematic health inequality according to income level was more serious (see chapter four). This indicated that disabled people with economic difficulties could be more vulnerable in health than non-disabled people. The key issue here can be whether this is because they are poor or they have impairments. The findings in this study demonstrated that these two factors are intertwined in complex ways, and the oppression lay on disabled people in a disabling society aggravates health. The following quote from the focus group illustrates the association between health and finances and the specific health needs of the disabled people who have more trouble in having healthy foods because of their poverty.

Actually, if we [disabled people] eat well three meals a day, then we would have no problem. If we eat enough good food, we would be much healthier than now. But I don't think we can afford it. Sometimes we need supplementary food but it's expensive. [...] The environment that makes us unhealthy is ...the cost. (Seon/M/38)

This finding echoes the debate upon health inequalities in vulnerable populations like ethnic minorities (Lê Cook et al., 2012; D'Anna et al., 2010; Williams and Sternthal, 2010; Nazroo, 2003). Especially, Nazroo (2003, 1998) paid attention to the class disadvantage in studying ethnic inequalities in health, pointing out that most work on this topic focused on genetic and cultural differences. He compared three approaches to the relationship between ethnicity and health – epidemiological approach, structural approach, and identity-based approach. He found out that besides genetic and cultural differences, there was variation in the class position reflecting material disadvantage, the geographical location of residence, recognition of themselves, experience of discrimination, exclusion of everyday life, and psychological situations. This demonstrated that the low socio-economic status of ethnic minorities expanded into the systematic marginalisation of most areas of life, and all these factors intertwined with health intricately. In this context, it is not that unreasonable even if the variable of ethnicity was replaced into disability. There are considerable parallels between these two disadvantaged populations. Like Nazroo (2003) put stress on the centrality of racism in any explanation of ethnic inequalities in health, to account for health inequality of disabled people from the perspective of disablism has great significance for empirical studies and theoretical debates: disablism is an environmental condition that causes poorer health of disabled people, rather than poorer health itself.

The marginalisation of disabled people caused by material conditions is explained by the social model of disability in which disability is a social product based on labour relations. It describes the process and mechanism by which disabled people have been discriminated, excluded, and become a low socio-economic class in capitalist society (Oliver, 1990) (see chapter one). The labour force of impaired people is difficult to be commodified, and health status is aggravated like other groups in low socio-economic status, as stated above in ethnic minorities. In this respect, the low health status of disabled people is both the cause and effect

of their alienation. If, in regards to the group with intersectionality issues such as ethnic minority disabled people or female disabled people, this becomes a farther exclusion.

In a similar but subtly different context, this argument is also found in Sen (2002) who demonstrated the unfairness of health inequality. His capability approach (Sen, 2002) expands the definition of disability and understanding its economic causes and consequences (Mitra, 2006). As seen in chapter one, Sen described the process that a person's capability who cannot access resources is deprived and how his/her functioning is limited as a consequence. This is a representation of the systematic marginalisation of disabled people. The heart of this is that health is functioning as well as capability. Disabled people lost competitiveness in labour market (capability), and as a result, their health is aggravated because of the lack of resources (functioning). The labour market excluding disabled people and the impact is a disabling environment (Mitra, 2006) (see chapter one).

These discussions account for and stress the multiple equality of disabled people. From this point of view, the economic status of disabled people occupies the core of this problem and is the main area that needs to be intervened by social policy. The economic approach alone cannot solve all the problems, but it is illogical to talk about other policies except this. However, this perspective has hardly been highlighted to account for disablism as central to people's experience of health services when it comes to health. My study might provide a clue of disablism in health issues.

It is also worthy of paying attention to the equality of distribution of overall wealth among disabled people rather than their material deprivation. The equity of distribution, not a mere material deprivation, affects overall health levels in society. In other words, the more equitable the distribution of wealth, the higher the health levels in society. Wilkinson (2006) described how inequality in a society made community members' health worse and showed

that the healthiest society is not the richest one but the most equitable society by drawing abundant empirical evidence (see chapter one). This seems to be associated with the analysis that not only disabled people are in low economic status, but also the distribution of income is more unequal among them than that of non-disabled people (see chapter four). Unlike the extreme wealth of the upper economic class that affects the income gap in non-disabled people, this results from the intensified poverty level in disabled people. Therefore, the improvement of the income level of disabled people in extreme poverty leads to their enhanced health level and equal distribution of economic resources. In this point, his recommendation that there is no improvement in health status without removing overall inequality is powerful. To enhance society's health status as a whole, it is necessary to reduce health inequality and improve the overall equality of social structure, and to do so, the support for vulnerable people currently need to be strengthened.

8.3.2 Health inequality and social determinants of health

Health inequality is multi-dimensional. It includes inequalities and imbalance in health status, health behaviour, health knowledge, and healthcare service access and use (Jayaweera and Quigley, 2010; Borrell et al., 2000) (see chapter one). There is a circular causality in health inequalities. Low socio-economic status affects poor health, and their poor health decreases socio-economic status. Health inequalities are intricately intertwined with various forms of multiple inequities. Hence, to reduce health inequalities, it is essential to reduce socio-economic inequalities (Marmot and Allen, 2014). Marmot and Allen (2014: s517) stated that economic inequalities outweighed many other factors that influence health by the overwhelming impact of social and economic factors- material, social, political, and cultural

conditions that shape our lives and behaviours. The results of my study supported this and could provide further details about the health inequality of disabled people.

In my study, the five dimensions of EQ-5D (mobility, self-care, usual activities, pain/discomfort, and depression/anxiety) represent the everyday lives of disabled people. It is not enough to represent the overall social integration or participation of disabled people only with these dimensions, but it is multi-dimensional. In this respect, the smaller difference of contribution rate between dimensions of EQ-5D in disabled than non-disabled people (from the decomposition of health inequality by dimension in the quantitative result) (see chapter four), and the dynamics that poor health in one dimension expands into other dimensions (qualitative result) (see chapter five) demonstrated the complexity of deterioration of health of disabled people. The lack of material resources led to differences in self-care in different ways. For example, without proper assistive devices, suitable care for self was not easy. The purchase and maintenance of assistive devices entailed considerable costs, followed by pain, discomfort, and eventually, a secondary impairment, which increased this discomfort. Increased pain and discomfort decreased performance in usual activities, which developed into depression or decreased mental health.

The contribution rate of pain/discomfort to the entire health inequality presented a considerable value (20.1%) (see chapter four) in this study. This is a significant finding since pain and discomfort are not frequently discussed when studying disabling barriers. Instead, the personal experience of pain referred to in the literature criticising the social model of disability (Thomas, 2004, 1999; Crow, 1996). Thomas devised the term “impairment effect”, which covers pain, to “acknowledge that impairments do have direct and restricting impacts on people’s social lives.” Crow (1996: 217) mentioned the real impact of pain on disabled people’s lives, emphasising that intolerable pain is not “false consciousness that if all the external disabling barriers were removed,” then no longer exist but real. The finding of my

study, as above, can be interpreted to support that the pain cannot be ignored in disabled people's health inequality.

In the decomposition of health inequality by determinants, the finding that the contribution rate of social factors such as employment and medical security was high supports results from similar preceding studies in South Korea (Heo and Hwang, 2014; Kim, 2012d). Although their subjects were not focused on disabled people, the high contribution rate of social factors was significant in many points. In my study, the social impact factors on health status or health inequality, were found not only in quantitative analysis but also overall results, including qualitative analysis. The factors affecting the health of disabled people explored so far in my study can be involved in social determinants of health in Dahlgren and Whitehead (1993).

As noted in chapter two, Dahlgren and Whitehead (1993) suggested the social determinants of health as "age, sex, and constitutional factors," "individual lifestyle factors," "social and community networks," "living and working condition," and "general socio-economic, cultural and environmental conditions." All these factors affect the health of disabled people as well. As summarised in chapters six and seven above, the barriers to healthcare services use encountered by disabled people, demonstrated that these variables were predicted to impact health by impeding smooth access to health services negatively.

The structural, financial, personal, and cultural barriers categorised in the previous chapter can be regarded as "general socio-economic, cultural and environmental conditions;" income level as socio-economic conditions, road, and traffic situation as environmental conditions, and attitudes of healthcare professions as cultural conditions. Also, factors belonging to "living and working conditions," which include factors such as "education," "work environment," "unemployment," "healthcare services," and "housing" (Dahlgren and

Whitehead, 1993) were found by analysing qualitative data. For example, employment conditions and unemployment, job stress, very scarce healthcare service with long waiting lists, and inaccessible medical equipment belong to this category (see chapters six and seven).

Constitutional individual factors such as age or individual lifestyle like health management habits were not explained remarkably in my study. The data showed no clear link between smoking and drinking habits to somatic factors. While, “social and community networks,” considered relatively meagre in disabled people, were mentioned as a means to intervene in their health. A participant of my study said that disabled people who are isolated from normal employment and social life and do not take responsibility of the care of others are likely to neglect to take care of themselves as follows:

I don't have family members who take care of me or whom I need to support. Psychologically, my support system is lower than average and it makes me vulnerable to disease. [...] your social status and whether you are employed or not is important. If you are employed, you should go to your workplace every day. If you're unwell, your superior will tell you to go to hospital and take care of yourself. [...] But if you don't have that kind of social life, that does not happen. [...] Therefore, basically the scope of your social life helps you discover your disease. Even non-disabled people discover their diseases like this. [...] How to get a supportive system? At least, even to own a pet can be helpful. (Tae-Yong/M/41)

Other participants also noted the importance of supporting systems to share information, implying that such networks could positively impact health, which is supported by literature (Berkman, 1995; Bowling, 1991; Kutner, 1987). This is one example of social support and community network, which directly affected healthcare service use.

In the network of disabled people, there are some sub-networks according to type and disease where information is shared. Based on the shared information, you can find a better doctor. I'm that kind of case, too. (Kyu/M/21)

From the quotes above, the positive aspect of a support system or network was highlighted and mentioned to promote good/better health. However, in chapter six, with a somewhat extreme expression of “the enemy,” Tae-Yong described how disregard of healthcare needs of disabled people in their family led to the aggravation of their health. In chapter five, one participant said that his health was aggravated due to the hard work supporting his family. Like this, the family or other social support network can either facilitate or impede health itself or an opportunity to achieve better health. The direction of their effects is not determined. However, disabled people are more likely to be in the lack of such networks and support systems. Some participants have addressed the negative impact of social relations on their independent living, but in situations where such relations are scarce, it will help secure social relations and support network and lead them to function properly.

Since one of the questions of this study was to identify the barriers to healthcare service use, things like the transportation system and healthcare service resources and attitude toward disabled people were mentioned highlighting the negative aspect above. However, there were also examples in which positive aspects of the environment could be shown: someone could reduce the burden of healthcare expense with the help of public and private support systems, and others were able to concentrate on enjoying his life rather than improving bodily function with the advice of a “good doctor” as seen in chapter six. Understandably, like family and social networks mentioned above, other environmental factors can either promote or hinder health. The qualifying rule of the ICF framework demonstrates this bi-direction of environments very well: in ICF, the body functions and structures, activities and participation are qualified in one direction such as “.0=no,” “.1=mild,” “.2=moderate,” “.3=severe,” and

“4=complete” impairment of difficulty. On the other hand, environmental factors are qualified either *facilitator* or a barrier, so there are two directions. “.number” means barrier and “+number” means facilitator. That is, “.0=no,” “.1=mild,” “.2=moderate,” “.3=severe,” “4=complete” facilitator and “+0=no,” “+1=mild,” “+2=moderate,” “+3=severe,” “+4=complete” barrier. This rule is very simple but useful and effective for understanding and presenting the bi-direction of environments. Also, it reminds us that we consider how to make the environment as a facilitator of health.

8.4 Summary

In this chapter, the findings of this study on the health of disabled people were discussed. The concepts and measurement of impairment and health and the perception of the health of disabled people were discussed with the results of this study and previous literature.

The reality related to the health of disabled people was debated alongside the concept of inequality, and it was identified that disabled people are in multiple inequalities, including health inequality. The bidirectionality of the environment as social determinants of health was also discussed. In the next and final chapter of this thesis, some of these findings will be recommended at the policy level.

Chapter 9 Conclusion

The starting point of this study was the concern for the health of disabled people. It can be represented as this question: “how can disabled people live healthy lives?” Identifying the impediments to disabled people’s healthy lives and suggesting solutions was the main point of this study. In this regard, the current health status of disabled people and their healthcare service use were explored.

The study results demonstrated that the poor health experienced by disabled people influenced their lives largely. This suggests that health inequality is a core area involved with the overall marginalisation of disabled people (Mitra, 2006). By implying that disabled people’s health inequality experienced is multi-dimensional and influenced by social determinants, this study suggested how disabled people can live healthy lives. These findings were acquired following the mixed-methodology of quantitative and qualitative data explanatory sequential model (Creswell and Plano Clark, 2011). In this chapter, to organise what this study found better, the overview of the previous chapters will be summarised. The implications of this thesis will be looked back on as well, and finally, policy recommendations will be suggested.

9.1 Thesis Overview

Chapter one started with a brief theoretical review of the core concepts of this study. The distinction between impairment, disability, and health was tried, and the social model of disability and related discussions were identified. The concepts of health inequality and social determinant of health were dealt with as well. Policies to tackle health inequality in South

Korea and across the globe were summarised. Health and health inequality of disabled people in South Korea and recent research on this theme were addressed.

In chapter two, two major topics, the contextual background of South Korea, such as a brief history and cultural background, and disability and health related policies in South Korea, were addressed. To identify the characteristics of South Korea, the welfare regime theory was considered. Societal attitudes toward disabled people and family culture were examined as well as a context. A wide range of social policies for disabled people, including a general health programme was reviewed in this chapter.

Chapter three explained how this study was designed. The research aim and questions and ontology and epistemology of this study were identified, and following this, the method adopted in this study was justified. This study adopted the explanatory sequential model putting the priority on quantitative data. The data collection process (secondary data as a quantitative approach and focus group and interview as a qualitative approach) was addressed. The consideration of the ethical issue of this study was added.

Chapter four delivered the summarised information about the general and health-related status of disabled people in South Korea. The analysis framework of quantitative data compared to disabled and non-disabled people to make the difference clear. Through the secondary analysis of the Korea National Health and Nutrition Examination Survey, both groups' socio-economic status, general health status, and health service use were provided. Health inequality by the income level of both groups, followed by the decomposition of the components and determinants, showed the health inequality of disabled people more in detail.

The thematic analysis of qualitative data, collected by focus groups and interviews, was suggested in chapters five and six. Chapter five's keyword was "secondary impairment," which impacts the health of disabled people greatly. The causes and effects of secondary

impairments were explored through disabled people's voices, expanded into their daily living. Social determinants of health were addressed as the cause of secondary impairments. Other factors impacting secondary impairments such as medical treatment and personal assistant service use were addressed by the participants.

Chapter six focused on the second theme, "inequality in healthcare service use," which consisted of what participants experienced during their healthcare service use. Some of the barriers they encountered were regardless of their impairments; however, it deteriorated the health of disabled people more severely. Social factors such as physical structure or human attitudes are drawn as barriers to equal healthcare service.

Since this thesis adopted a mixed-method, the integration and synthesis of quantitative and qualitative approaches were essential for abundant research implication. In chapter seven, the results from each data were compared, and an attempt was made to describe what quantitative data cannot by qualitative results. This chapter was beyond a simple summary of the previous chapters, presenting the strength of mixing methods for a deeper and multi-dimensional analysis.

Finally, in chapter eight, the finding of this thesis was discussed. The main discussion points were i) the concept of disability-related to the method of this research, ii) perception of healthy lives of disabled people, iii) health inequality of disabled people and social determinants of health. A theoretical review of previous literature and the findings of this study were interlaced in this chapter to understand the health of disabled people.

9.2 Implications of thesis

The theoretical and practical implications of this thesis can be suggested as follows.

First, this thesis can be put in the context of discussions on impairment and health of disabled people in disability studies. As seen in chapter one, the discussions on impairment, disability, and health is generally summarised in two key areas. The first is how to approach impairment and related concepts based on the social model of disability (see chapter 1.1.1), and the second one is prevention of impairment, rehabilitation and related ethical issues (see chapter 1.3.1). I treated these two key areas with preceding debates in chapter one, and discussed these issues again alongside the findings of my thesis in the discussion chapter (see chapter eight). By deliberating the conceptualisation of impairment, impairment effect, disability by external disabling barriers, and health, in terms of concept and measurement, my thesis can contribute to all those the relevant debates.

Second, one significant innovation in this this thesis is the adoption of a mixed-method approach to investigatethe health of disabled people. While studiesrevealing and assessing health inequality are mostly conducted usingquantitative methods (see chapter three), this thesis justified the adoption of a mixed-method strategy by targeting disabled people and bringing the discussion of research methodology to disability studies. Although with the limitation that the qualitative approach was used to explore disabled people's experiences, whereas the quantitative approach was applied for a comparison between disabled people and non-disabled people; the active utilisation of this mixed-method contributes to methodological and theoretical developments in health inequality and disability studies.

Third, this thesis has practical significance in that it reveals the reality and impacting factors of health inequality of disabled people, which can offer clues to solve and alleviate health inequality in this population. Through quantitative analysis, we can establish detailed aspectsof health inequality of disabled people and find that their health inequality is more multidimensional and affected by social factors than that of non-disabled people (see chapter four). The specification of external barriers experienced by disabled people in the process of

using healthcare service through the qualitative analysis revealed which points to intervene in order to improve the health of disabled people and alleviate the inequality (see chapter five, six and seven). Based on this, I present some policy suggestions in the next section.

9.3 Policy recommendations

Since this thesis did not focus on healthcare-related systems, it is not reasonable to draw such specific recommendations upon current disability and health-related systems from my study results. However, several implications can be considered in the area of social policies.

First, the disability registration system and social survey need to be reorganised. The problem of definition of disability in South Korea and social survey based on this definition was mentioned in chapter two, and the quantitative data and variables analysed in my study are not free from that kind of problem. Although there is a transition of abolishing the grading system of disability since July 2019 (see chapter 2), the institutional basis for disability in South Korea is still based on a narrow view of impairment and disability. The social model of disability can have implications in this sense, but discussions on the conceptualisation of health of disabled people is still ongoing and it is not given shape to the level of operationalisation yet. Much more studies on the concept and measurement of disability and health should be carried out in South Korea. As mentioned in chapter one and identified in this chapter through my data, the questionnaires based on the social model of disability cannot apply to the social survey. Nevertheless, it would be useful for the development of theoretical disability studies and practical disability policy.

Second, as many disabled people suffer from preventable secondary impairments, the conditions causing secondary impairments should be controlled through the healthcare

system's daily use. The government developed a programme that reinforces health promotion behaviour and prevents secondary impairments of disabled people in "Health Plan 2020." The main contents of this programme are i) to intensify the visits check-ups for people with severe impairments, ii) to carry out an in-depth analysis on health behaviour (drinking, smoking, diet habits) of disabled people, 3) to provide a suitable health promotion service and thereby 4) to promote the self-healthcare capability of disabled people. This plan focusing on the health management by healthcare professions is significant, but addressing the environments more broadly is needed.

In this regard, the ICF can be referred to since environmental factors were classified into "products and technology," "natural environment and human-made changes to the environment," "support and relationship," "attitudes," and "service, system and policies" (see chapter one). Although to list the environmental factors as a series of codes and to grade the degree of facilitating and hindering seems to be too mechanical and instrumental, the categorisation of environmental factors can help disability activists and policy makers specify the points at which various policy interventions should be made, and help recognise the environment where barriers exist in a multidirectional way. For example, inaccessible medical equipment (products and technology), a steep uphill (natural environment), an oppressive family relationship (support and relationship), discriminative attitude toward disabled people (attitudes), and scarce healthcare service (service, system and policies) can be categorised. The social model of disability, assuming that these disabling barriers can be removed, pays attention to enabling these environmental factors function properly (Swain et al., 2013).

Third, the coverage of public healthcare programme-NHI and Medical aid -for disabled people needs to be expanded. This study demonstrated that the main reason why disabled people could not go to the hospital was economic difficulties (see chapter four). The focus

groups and interview participants expressed their satisfaction with reducing healthcare costs by the coverage expansion but talked about the remaining economic burden (see chapter six). Like this, the coverage of NHI has been expanded continuously, but disabled people still feel burdened. To facilitate the smooth use of healthcare services, it is necessary to reduce the burden by expanding the coverage of NHI. Also, in principle, the expansion of NHI coverage is an essential directivity of social insurance.

Currently, the departments of the central government, including the Ministry of Health and Welfare (MOHW) and local governments, are implementing the healthcare support programme for disabled people and the “coverage rate of healthcare cost of primary centre” and “benefit coverage of NHI of assistive devices” - the outcome indicators of “Health Plan 2020” - are related to this programme (see chapter two). However, this programme is insufficient to mitigate the heavy burden, it is necessary to expand the system more aggressively. In particular, since disabled people are highly dependent upon NHI because of their low rate of private insurance purchase; it is desirable to devise a personalised support programme based on the data on highly used healthcare services according to the characteristics of impairments.

Fourth, physical accessibility throughout our society needs to be raised. It is difficult to improve the health status of disabled people by only modifying systems directly related to healthcare service. Also, it has been found that medical equipment and accessibility around the healthcare centres, general road traffic environment and public transportation are barriers that make it tough for disabled people to access healthcare services. Although the government suggests alternative methods such as telemedicine for people with low mobility, including disabled people (Ministry of Health and Welfare, 2016b), the expansion of this system and to raise the physical accessibility of healthcare centre and all around the society should be combined. In particular, the accessibility of medical equipment needs to be treated as an

urgent issue because it is associated with a diagnosis and treatment of disease directly. The development and supply of medical equipment that can be used by disabled people should be made.

Finally, most basically, it is necessary to reduce the general unequal socio-economic structure. The Commission on Social Determinants for Health (CSDH) recommended to i) improve the conditions of everyday life and ii) relieve the unequal distribution of power, money, and resources as a way to alleviate health inequality (CSDH, 2008). The former recommendation is about the essential conditions for the dignity of life. On the other hand, the latter means alleviating relative inequalities.

To improve the living conditions of disabled people, the conditions in all areas of life should be taken into consideration, beyond the income security reinforcing cash benefit. In addition to education and employment, a long-term plan considering how to promote the integration in the areas where disabled people are excluded and marginalised, including access to information and cultural integration, is needed. Policymakers should accept this recommendation seriously to improve the equal health of all the population.

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Appendix

A.1 Transcripts of focus group

Focus Group 2 (Urban area)

- Date: 21st, April 2016
- Time: 14:00~15:50
- Venue: Daejun OOO Centre for Independent Living
- Participants

ID	Gender	Age	Disease	Public assistance	Education	Marital status
A	F	50	Rheumatoid arthritis	N (recipient of public support for health expenditure)	High school	Married
B	F	44	Devic syndrome	N (recipient of public support to health expenditure)	Attending graduate school	Single
C	M	44	Cerebral palsy	Y	High school	Married
D	M	43	Cerebral palsy	N (recipient of public support to health expenditure)	Middle school	Single
E	M	41	Cerebral palsy	N	Graduate school (master's degree)	Married

M (Moderator): Please introduce yourself to me. You don't need to tell your address in detail. It's fine to say that you live just in Daejun. And your job...

A (Female, 50): Hi. My name is A, I live in OOO, Daejun city. I work as a personal assistant at this centre.

M: Nice to meet you.

C (Male, 44): My name is C. I live in OOO, Daejun city. I live as an activist here but no better than out of work... (Everyone laughter)

M: (Laughter): You're an activist but you don't know what you do...

C: I'm just idle.

M: The sound... Is it okay with you to put the voice recorder here? Nice to meet you, C.

B (Female, 44): Hi, My name is B. I live in OOO and my job is... uh... I am a general secretary of this centre and also want to be a peer counsellor. Nice to meet you.

M: Mr. Oh... Oh sorry, you're not Oh. I changed your family name. Will you be fine without the personal assistant? Then, please introduce yourself.

E (Male, 41): (Because of E's severe language difficulty, I could not dictate what he said) I have no job.

M: Ah, you have no job. Thank you for telling me.

B: No, he's an activist.

M: Ah, activist. Yes, I see.

D: He has retired from a social worker.

M: Ah... retired from a social worker...

C: Social work...

M: I see. Then it is not very long since you lost your job. Sorry, no, since you became an activist. Nice to meet you. I'm a student but I'm as good as unemployed. And lastly...

D (Male, 43): My name is D. I live in OOO, Daejun city. I'm a priest.

M: Priest? What kind of priest?

D: See, I took the tonsure. (Laughter)

M: Ah, you're a bonze? Nice to meet you. Here come the diverse participants. Now we finished the introduction. Let me talk about today's topic, health inequality of disabled people. (Omitted) The first question is about your health status. It's for warm-up. How is your health in general? Is your health status related to... I didn't mean to invite only registered disabled people, but I heard that all of you are registered. Please tell me about how your health status is related to your registered disability.

A: I'm registered as limb disability, grade two. My illness is rheumatoid arthritis. Rheumatoid arthritis of joints of the whole body. I feel pain on rainy days.

M: When were you diagnosed?

A: In 1988.

M: Ah... 18 years ago.

A: Probably...

Many people: No, 28 years ago.

M: 18... no, it's 28 years ago! It's not 2006 but 2016! Sorry, my mistake. I reduce my age 10 years unconsciously.

B: That's what I want, too.

M: Yeah, really... I wish it were 2006.

B: My name is B. Should I talk about health status?

M: Yes, health status of these days. Within one month.

B: I'm in poor health now. Uh... I'm under a lot of stress recently. Managing and solving the problems makes me exhausted. Due to the overwork and job stress, assuming 10 means worst health and 100 means best health, then I'm in around 40.

M: 40 if 10 is the worst? Health status?

B: Yeah, 40.

M: You feel you're in poor health status now... Sorry for the stress I gave you due to this focus group.

B: No, this has nothing to do with the stress. The stress comes from outside continuously.

M: Then your poor health is related to external stress rather than disability.

B: it's job stress.

M: Job stress...

B: If I have to talk about impairment...

M: No, please take it easy to talk what you think. Others, too.

C (Male, 44): My name is C. I have had surgery three times. Three times of spinal surgery...

M: Three times of spinal surgery...

C: Yes. As a result, I feel pain and my muscles stiffened two or three days before rainy or cloudy day. At that time, I take a painkiller or an injection.

M: I see. It's rainy today...

C: Strangely, I'm fine on the very rainy day.

M: Ah? Are you fine on the very day? Then, two days before...

C: I'm sick before it rains.

M: I see. It's new to me.

D: But it's common to disabled people.

M: Is it common?

C: And I have cervical disc disease. I think it's very common within people with brain lesions.

M: Ah, it's common within the people with brain lesions...

B: Cerebral palsy

M: Oh, Cerebral palsy...

C: I have severe muscle stiffness.

M: Thank you. And next...

E: ... (Inaudible)...

D: Neck...

M: I'm sorry, but would you like to talk first?

C: Excuse me. May I translate?

M: Sure.

D: I'll translate what E talks with C.

B: You two are going to translate him?

M: Okay, then I'll listen what you translate as E's words. Thank you for the translation. You are really nice.

E (translated by C): Now I have cervical disc disease, too. I feel pain on the neck.

(Time gap)

M: (Whispering) You may talk a little more slowly.

(C and D are translating E's sign language and talking.)

C: Not yet...

D: Recurrence... I am not diagnosed yet...

C: About the cause of the neck pain.

M: Oh, so you don't know the cause of the neck pain?

C: I am not diagnosed yet, but

M: You are not diagnosed yet, but you have pain on your neck.

C: That's what he told. (Laughter)

M: He is using finger language. Thank you. You may add your answer any time you want. What do you think about my question, D?

D: Two years ago...

M: Two years?

D: I got cervical disc surgery at OO medical centre.

M: OO medical centre?

D: I couldn't work actively for a year after the surgery. It was not easy to have a meal. However, I did light exercise, took rehabilitation therapy such as hydrogymnastics and occupational therapy at the rehabilitation hospital. Also I played boccia at the community welfare centre. It improved my health a lot so now I can eat alone.

M: Wow, you get well a lot.

D: Not completely alone, but if somebody put side dishes on my spoon, then I can eat alone. But it is not easy due to the cervical disc.

M: You suffered from a cervical disc disease. But you recovered thanks to rehabilitation therapy like hydrogymnastics, occupational therapy, and boccia.

D: And last year I got to know about dystonia through the surgery.

M: What?

D: Dystonia.

M: Dystonia?

D: Yes. Almost all the people with cerebral palsy have it. But my case is unique. My muscle is relaxed under the sunshine, so, in this season, still springtime, it is a little... I mean, when the (inaudible) drops, I need to drink something cold such as ice water or iced coffee. It helps me (inaudible). Sometimes I cannot be seated alone. But with something cold to drink, I can sit upright. Yeah it's... unique case.

M: I've never heard of that.

C: He's like a vampire.

M: Vampire! (Laughter) You're so funny. Vampire, diathesis.... Thank you.

C: In the dark...(Laughter)

D: Until last year, I should have been in shady and cool place. (Everyone laughter)

M: Well, then what about the outdoor activity....

D: I was not well last year, but I feel much better physically this year.

M: That's good.

D: Yeah, so I'm in good condition now.

M: Thank you. I feel good you give me a positive, good talk. I feel good you are much better physically than last year. (Explanation about the rest questions for a while) I'll analyse all the answer... (Someone laughter) Why, is there something funny?

B: They always laugh a lot.

M: You are such good friends to each other.

C: I'm so stressed due to the personal assistant service (PAS). Due to the personal assistant...

M: Is anybody stressed due to the PAS? (Everyone laughter) Umm... can this theme be treated here? Of course, I'll keep all the information you provided confidential. But I cannot guarantee other participants will do. You may talk about it as much as you can.

B: Uh... as regards health, I did workout hard till last August.

M: What kind of exercise?

B: Rehabilitation therapy. Like him (Pointing C), I took hydrogymnastics, exercise therapy, and occupational therapy. But since I began to work here as a full time staff, I didn't take treatment any longer. Umm... for my health, these days I stretch for twenty or thirty minutes every morning and evening. Stretch wrist, ankle, knee, pelvis... And an air pressure massage machine for blood circulation... I wear it like rain boots. I have bad blood circulation cause my lower body is paralysed. My feet are often swollen like elephants' feet in the evening time. The massage is good for relaxation and circulation. So... these two things -stretching, air pressure massage - are the only ones I do for my health. Uh... May I keep going?

M: Of course.

B: Then... May I answer the question number 4-2 "Have you ever given up going to the doctor for medical care?"?

M: Oh yes. At first, do you use healthcare service regularly?

B: Uh... At the National Cancer Centre (NCC)... I have Devic syndrome. So I go to the NCC in Ilsan and have a blood test once in ten weeks. Umm... If the result shows specific value, it means recurrence- if it is extremely high or low, then I have an injection to lower the figure. If not, I have another test after ten weeks again. It is direct treatment for my disease. Uh... and I have given up the healthcare service. Because people with nervous system impairment can be supported by National Health Insurance (NHI) for two years at the longest in Korea. After two years, Health Insurance Review and Assessment Service (HIRA) cut the benefit thus the hospital doesn't provide the cure. They've reduce the treatment one by one. In my case, last year, when I gave up the healthcare service, I was told that the occupational therapy time, thirty minutes before, was reduced to 15 minutes.

M: Only half?

B: I was upset then.... (Laughter) so I thought "Yes, now is the time", gave up all the rehabilitation therapy and got this job. But in fact, I am a little anxious. Because the steady treatment means the prevention of the deterioration. As you see, I cannot keep balance because of the scoliosis. My abdominal muscle is so weak that I (Bending) look like this...

C: Isn't it your belly fat?

B: No, it's not. (Laughter) So I'm worried about... How long I can maintain this posture... I expect next year, it will be different from this year just as it's different from last year in this year. Positioning like this (Sitting upright)... is not easy. I need to use abdominal muscles. I'm worried a lot and that kind of thought makes me depressed.

M: Oh, I see. Thank you. It was really detailed answer. Are you using PAS?

B: Yes, I am. It is really helpful to me. If without PAS, then I have to do all the housechore by myself because I'm using the service as housechore support. I have lived where I live now over five years. At the first time, the previous assistant would not support the housechore so I had to do all the housechore by myself. I cleaned with a vacuum cleaner, wiped the floor with a cloth while I'm bending like this. It was really really hard. So now, the second assistant is mostly supporting housechore. It helps me a lot. I would be in such a big trouble without the service.

M: How long do you use?

B: 130-140 hours?

B: 140 hrs? Thank you. It's greatly detailed story.

A: Habit is... My joints stiffened if I don't workout. It makes me so sick. The pain was agonising so I could not do workout, but instead, got some massage when it was too severe. Suddenly I thought "Finally I won't be able to do anything". Shedding tears, I began to do workout little by little. After one or two months later, joints have softened. I was improving more and more. These days I do leg exercise, joint exercise lying down for thirty minutes almost every day. And I receive hydrogymnastics- going into a swimming pool in the gymnasium for the disabled people, and moving joints. I used to do it three or four times a week. When I had no job, I went there even more than three times a week. I couldn't have walked before, but after that I got to be able to walk and do some more exercise. And acupuncture, oriental medical clinic, massage... Getting massage is supported by the government.

M: The government supports massage?

A: About for 10 or 20 months. Anyway, it improved my health a lot. It is not a big deal but as for me, it's really fruitful. And... I have worked here since this January. The job was not hard, but moving around by bus made me burn out. As a result, I couldn't go to the swimming pool and got to feel unwell. Now I know I have to do workout again, and I can do if I ask somebody but it is not easy... Actually, I often lie down on the bed. So I made up my mind to go to the swimming pool from the next month. And... I went to the hospital to be prescribed medicines before, but people around me said "It's not a cure but a just painkiller." and I felt so, too. Thus I went to the oriental medical clinic. The oriental doctor told me to take only the oriental medicine, not the hospital medicine. So I took only the oriental medicine, and got worse. At that time, I ate everything known to be good for health, but now I think there is no way but to take medicine and do exercise. When I get an infection or feel more pain, I take more painkiller or anti-inflammatory. That's the way it goes. As I have gone to the hospital for a long time, it makes me depressed. At home, sometimes I feel depressed. However, I say to myself "No, I should not be discouraged like this!" and try to be encouraged and go outside. Now I'm trying to thank to everybody and live happily, even I need to do workout a little more.

M: Thank you. You're not going to the hospital regularly?

A: I take medicine every day. They told me to come once a month because I went to the hospital for a long time, but I answered that I would go once in three months.

M: Is it enough for the prescription?

A: I go to the OO National University Hospital. Once I go there, I'm sick for a few days. I have been sick a lot when I came back from the hospital. Bothering things, being x-rayed, too many tests... So I told the doctor I was coming once in three months. I take an x-ray, medical tests, medications every three months.

M: Thank you. Ah... Anybody want to talk next?

C: It's me. My health behaviour.... I have a habit. I cannot tolerate pain.

M: You cannot tolerate pain?

C: No, I can't. Even with tiny pain, I go to the hospital and get an injection or some... treatment. I must relieve the pain. I have had that kind of habit since I got a surgery. It was not as it is before.

M: Yeah, you got surgery three times last year? Three times till now?

C: Yes, till now.

M: I see. You cannot stand pain after the surgery. I'm sorry but the surgery was for the cervical disc disease?

C: Spondylolysis of the lumbar spine. The lumbar spine needs to be stuck to each other, but in my case, it was separated like this... So the doctor glued it, and the first surgery was successful. It really was. He placed a pin on my spine. I have focused on the rehabilitation therapy for two years after the surgery. Hydrogymnastics, physical therapy, and exercise therapy... I did nothing but to have therapy for two years. But two years later, I was in bad need for some fast cash. The youngest baby was born then, so I need to get a job. Even though the conditions did not permit, I had to work. I used to work with high salary for three or four months, and then... while I was working, I could not eat or sleep well and have been stressed a lot. It caused an infection on the surgical field. It was so painful that I couldn't stand it and was told to enter hospital. Finally, the infection spoiled up one vertebra of spine, so... it was placed by artificial joint.

M: Ah. So that's why you cannot stand pain.

C: Yes. It was the second surgery, and the third one is... I got a spine disc disorder as a secondary disease.

M: On the lumbar vertebra?

C: Upper part...

M: Upper? Thoracic vertebrae?

C: Probably.

M: Do you go to the hospital regularly?

C: As I told, I cannot stand pain. When doctors prescribe the medication, they are worried about the tolerance. I take it too much. Although I am warned about it...

M: But you cannot tolerate.

C: No I can't.

M: Thank you. Your answer is detailed. I also give you second and third question. Have you ever given up going to the doctor for medical care? Do you use any health related care service such as PAS? How does it influence on your health? If you don't want to talk about PAS, then I'll ask you privately. You don't need to talk about what you don't want to.

C: I have ever given up the healthcare service. It is similar to B. Because of the medical fee problem... The healthcare service I took has halved in time from thirty to fifteen minutes.

M: Then... B gave up the healthcare service because the provider reduced the service, and it offended her. Is it the same reason you gave up the service?

C: I thought it's unreasonable to take fifteen-minute treatment while it took an hour to get the hospital. I used to think so but recently, I think in different way.

A: Here is towel.

M: Ah, you sweat a lot... It is invisible in my position, but once you turn your head, now I can see.

C: A lot of heat in my body...

M: That must be hard for you in summer.

C: Yes. Also this is a sequela of surgery.

M: I beg your pardon?

C: Sequela of the surgical operation...

M: Ah, I see. Thank you.

C: I sweat during the talk...

M: Nevertheless you came here. Thank you so much.

C: Not at all. (Laughter) The reason that I keep going to the hospital is the leader of hydrogymnastics team. I have gone there since it opened, so I know much about him. I have seen him since he was an apprentice.

B: You trained him? (Everyone laughter)

C: No, I didn't. He trained himself on his own. I have seen him for ten years. He is really kind to me. He complies my request.

B: Well, actually you trained him.

D: E and me go to that hospital because C suggested us to do so.

M: You three go to the same hospital? Can I ask the name of the hospital?

B: It's Daejun convalescent hospital.

M: Daejun rehabilitation hospital?

B: No, Daejun convalescent hospital.

M: Daejun convalescent hospital. Then the team leader you just talked is... Oh, I see.

C: I trained him! (Everyone laughter)

M: Aha. Well, I ask you two the question three and four. You talked about your health related habit focused on the workout, but it includes drinking and smoking. Can I ask about it? You drink a lot? Even though you are a priest...

D: I...

M: If you don't want, you don't need to talk about it.

D: Everyone knows it.

M: Then could you let me know?

D: My name is D, and my habit is... I cannot fall asleep at night for recent several years. I make a habit out of falling asleep with a drink. These days, still I drink one and half cup of Soju⁶ every night, with a mug cup.

M: One and half mug cup? Then four-fifths of one bottle of Soju?

C: Generally, it's similar to a beer glass.

M: I see. You drink Soju with a beer glass. By the way, do you have any other habit or use healthcare service?

D: I smoke seven or eight tobaccos a day.

M: Seven or eight... You suffer heavily due to the price increase of tobacco.

D: E smokes, too.

C: But I don't smoke.

M: A-ha-ha, thank you for speaking over the voice recorder. The tobacco... I never mean you should quit smoking. I'm just listening. If you feel uneasy about it, then you may not talk about it.

D: Well... now it's a habit so it is not easy to quit smoking. I've got unwell little by little since ten years ago. Seven or eight years ago, I went to the spine hospital because I had trouble in walking. The doctor told me that I had cervical and lumbar disc disease, and stenosis as well but it is inoperable in this city. I was anxious when he suggested me to go to Seoul. Already I gave up many things including health, but two years ago, the pain was agonising, and my body was being paralysed gradually. At that time C encouraged me to go to Seoul for treatment. He told me I couldn't be cured in Daejun so had to go to Seoul. Therefore I went to OO medical centre...

C: Why do you talk about it now? (Everyone laughter)

D: I mean, you saved my life!

M: Yeah, you're a saviour.

C: You treated your saviour like this? (Laughter)

M: I got it. I'll remember he owed you...

D: So the doctor from the OO hospital...

(Something fell down)

M: Are you all right?

⁶ Traditional Korean alcohol

D: The doctor I met first said that he could not guarantee the result of the surgery. But, I was lucky, he referred me to his senior doctor. At first, I gave up the surgery because the medical team were worried about the effectiveness. But the new doctor told me that if I didn't have a surgical operation, then I couldn't have moved at all, even my finger, in three months. He said he could make me maintain the status... He gave me kind of hope like this, so I got the surgery. And C, also helped me...

M: Ah... you might have been shocked a lot when you heard it from the doctor. "You will not be able to move at all in three months."

D: I was so frightened that determined to have a surgery. C told me the way to save the hospital bill.

M: Wow, did he? He (C) held up the V-sign. (Laughter) I'll ask him later how it was possible.

C: Do you want to really know?

M: Sorry, it's a secret?

C: Not at all. It has to be known widely.

M: Of course. It has to be known... Ah, sorry. You're not finished yet...

D: About the financial problem... He told me to ask the department of welfare...

M: You mean social work team in the hospital?

D: And I was fully funded.

C: They don't fund themselves but match the donator with the needy.

M: They matched the donator. It's their job. Job of the social work team.

D: I was worried about the financial problem a lot, but C helped me out from beginning to end. (Everyone laughter)

M: Wow, is he today's hero?

B: You are worth of the prize.

M: I will never forget it. It's very impressive. Well, can I ask E the same question?

D: He is writing the answer.

M: Ah, he is writing...

C: By the way, I told you that once I gave up the rehabilitation therapy but continued it again. It's because even the treatment time is not very long, but I think getting myself for the treatment and going out is rehabilitation itself. I take bus and subway to get there, and it can be kind of rehabilitation.

B: It's B, I'm.... Sorry, are you finished?

C: Yes.

B: C reminds me of something. The reason I quit the healthcare service is... at that time, I could not decide whether to get treatment or to work here as a full-time worker. Just at that

moment, they reduced the treatment time and I felt bad so... (Laughter) I don't understand why we didn't come across at the hospital, anyway, the hospital we use opened May or April and I have used there since October. I know full story of the hospital. (Laughter) The way they treated me... yeah I understand them, they're just employees. But I didn't feel good. Anyway, I am a paid-worker here so it was not easy to be in hospital for service in duty hours.

M: Well, then the work doesn't seem to have good effect on your health status... as long as in healthcare service. You two said that you didn't have enough time for healthcare service due to the work, and your health got worse because of the job stress.

A: However, if I don't work at all and stay at home, then I lie down on the bed all day long. In that case, I cannot walk long even I want to do some exercise. But now, I have to come here as a worker, I should come out of home, I have to take bus, walk... certainly it makes me move more.

M: That's positive aspect.

D: C lives on the fourth floor of apartment. Going up and down to fourth floor is not easy even for not disabled people, but he doesn't take lift. He uses steps all the time.

M: You used steps to come here?

C: I did. It makes me cry. (Everyone laughter)

M: Then you put your electric wheelchair on the first floor...

D: Yes. It's rehabilitation to him. I could not see him walking for a year, but thanks to the exercise, now he can walk.

C: I think to move more in daily living is rehabilitation as well as hospital care.

M: I agree. Thank you. I could find some points to write in my thesis. E, do you want to do after you finish writing? It is fine to talk now. You prefer to answer later? I see.

D: I use most of PAS among us.

M: How much?

D: From 7 in the morning to 9 in the evening. 450 hours a month.

M: 450 hours. You (??) said your given time is 130 hours. 450 hours.... What about you, C?

C: 156 hours a month. But I use PAS mainly as housechore support.

M: I see. Well... May I read aloud what E wrote? Thank you. Will I...? Okay. "Until three years ago, I used to go to the hospital to cure cold at most once or twice a year. I didn't go to the hospital to cure the impairment. But since three years ago, I have got speech therapy at Eulji university hospital and community welfare centre..." Is this community centre 'OO welfare centre for disabled people'?

B: No, 'Happy rehabilitation welfare centre for the disabled'. It's very close to here.

M: Then, the centre you just told is this, too? I see. "I get exercise therapy at community centre, speech therapy at OO university hospital and community centre, too. Hydrogymnastics at convalescent hospital." Then you three take the hydrogymnastics from

the same team leader in convalescent hospital together. You use a lot of services together. "However, I get worse so I'm worried about the cure and I feel economic burden." Thank you. It's very clear. You two smoke together. (Laughter) This is not a joke, I mean, the health related behaviour is important.

C: I don't smoke at all.

M: Well, I don't think drinking or smoking is shameful. Now I quit but before, I used to smoke, too.

C: But I drink a lot.

M: You drink a lot?

C: Not very often. But once I drink, I drink to the end.

D: Me too, when I go to bed...

E (translated by C): I used to smoke a pack a day.

M: You used to smoke a pack? But you said you smoke six or seven tobaccos a day. When did you reduce smoking?

E (translated by D): When I got unwell...

M: Ah... then three years ago? As you told, you underwent some kind of turning point three years ago, was it that time?

D: Slowly...

M: You may speak slowly.

E (translated by D): To smoke, I had to go outside because there are children at home.

M: Was it tiresome? I see. By the way, I analysed the National Health and Nutrition Survey...

C (Translating): In my opinion, tobacco is...

D: (to E) Please write just one word.

C (Translating): In my thought... He had his own job three years ago, but since three years ago...

M: He has had no job since three years ago

C (Translating): Felt unwell as well. It's because he lost the job. So he tried to work again and he did before...

M: You didn't quit working because you felt unwell, but you got unwell after the unemployment?

E (translated by C): Yes.

M: What did you do before?

E (translated by D): I worked at the gas station.

M: Ah... How did the unemployment influence on your health? Because you got to move less?

E (translated by D): I think so.

E (translated by C): Since last year, I had nothing to do.

E (translated by D): Frustrated...

E (translated by C): It's a mental problem.

M: I see. Thank you. Uh... I want to ask about this a little more but now I'm going to the end, and if I have more time, then I'll ask this. Now I want to talk about your experience of healthcare service use. What kind of barrier do you face? It can be diverse. Physical barrier that hinders accessibility, and... Ah, you sigh and nod your head. And medical profession... In this question, the medical professions include not only doctors but professions working in the hospital setting such as nurse, therapists, and so on. Their knowledge, experience, and the attitude towards you... All these factors can be the barrier to healthcare service use. Or... it can be a facilitator. "Wow, She has a wide knowledge", "She is very sensible when she treats disable patients", I hope that you talk about this kind of experience. And... have you ever felt that you have been discriminated or treated improperly by the medical professional? If so, please tell me in detail. In fact, this is a key question.

D: In my case... the hydrogymnastics therapist is very nice to me. The occupational therapist is doing his best as well. But the physiotherapist is... The occupational therapist doesn't need to carry out other therapy. It isn't his job. But my occupational therapist is nicer to me than the physiotherapist. The physiotherapist is not good. She makes me drowsy. So I quit the therapy.

M: You mean, the physiotherapist also carries out the exercise therapy but she is not expertised? Because she is not an exercise therapist but a physiotherapist...

D: No, originally, the physiotherapist works as an exercise therapist. But the occupational therapist is better.

M: You mean, the occupational therapist is better? Umm..

D: The occupational therapist just needs to help me use chopsticks. But he carries out extra therapy like upper and lower body... He does his best to help me walk a little more. But the physiotherapist- maybe it's because the therapist is a woman- it is tickling when she practices acupressure.

M: Tickling? The acupressure should be pressure...

D: I fall asleep, I awake, and then she says "It's finished."

M: Is it? So you are not happy with the acupressure. I see. If you want to talk about it more, please do it. And... I want to hear your diverse experience. Is it convenient to use the medical equipment installed in the hospital? Some people said that they had difficulty using it. It didn't fit. Some people said they couldn't take even x-ray.

D: It is really difficult to get x-rayed for us in local hospital. I went to a hospital for a medical examination last December. I tried to receive the conscious sedation endoscope, but couldn't.

They didn't allow. So I said that I underwent cervical disc surgery, but they were worried if I did not awake from the anesthetic. I claimed it would be okay but it was useless. They let me go down to downstairs to get x-rayed, but they didn't have a proper equipment for me. I cannot stand up when I get x-rayed, but they had no proper equipment. I told them I couldn't use it. I shot just one photo lying down. It's that kind of barrier...

M: Well, I think it's not unusual. Any other experience?

A: I'm A. When my joint got stiffened, my elder sister helped me a lot so that I could undergo the physiotherapy. She carried me on her back and took me to the hospital to take the treatment. But it burdened me financially. Because of the financial burden, I changed the method. Now I fill the bath with hot water and get into the bath. (Buzzer sounded) And then...

M: Are you all right?

A: And then... I was sceptical about the effectiveness of the physiotherapy, so I searched for the alternative cure. Sometimes I cauterise the skin with moxa. My sister helps me do it and next I do myself. About the hospital... I live in Daejun, and prefer closer hospital. But the reason I go to the OO hospital is- I can use new medicine there very quickly. It's better hospital so... so I didn't change the hospital even it is far. As I have gone there for a long time, the doctor – he is a professor, he is not so kind – he just watched the chart, and told me nonchalantly I should take one more medication. Sure I know there are so many patients waiting. But at first, I thought “Did I come here to hear this short talk?” Sometimes he doesn't even talk about the treatment and just says “It's done. Now go and come later”. At that time, I feel hurt because I get so tired to get there. But as an afterthought... he prescribes medication very well so the medication doesn't cause side effect. That's why I go to the hospital continuously. Well, the nurses are... They are much more friendly than before.

M: Ah... Then the attitude to the medical professions is relatively positive.

C: Medical professions... are they rehabilitation therapists?

M: In fact... probably, only the doctors are subject to the medical law, but I want to know the attitudes of all the other professions allied to medicine.

C: C is talking. When I receive the rehabilitation therapy, the dementia patients...the old dementia patients get treatment from the same therapists with us. I think the therapists should treat the patients according to their own characteristics, but they treat us like dementia patients.

M: Like dementia patients?

C: They shout.

M: Ah, because they think you cannot hear?

C: And their way of speaking is... offensive.

M: You don't like the therapists' way of speaking?

C: No, I don't. It's most of the time. I go there to use the service as a patient, but why do they treat me like I'm weird?

M: Ah... like a weird person.

C: I have an idea, I am well educated enough, and I have family. Why should I be treated like even I'm not a human? In that case, I get angry and ask myself "Do I have to get treatment?"

A: Since the elderly cannot hear clearly, almost all the staffs of hospitals I use have big voices. It's not because they, the staffs, are unkind. They think we can hear more clearly if they speak aloud.

C: But we're different from the elderly. We disabled people have to be treated according to our characteristics.

M: I understand what you talk.

D: Most of the patients... over 70% of the patients are elderly or geriatric patients. About 30% are young people, and disabled people like us are not many. By the way, the hospital focuses on the inpatient...

M: Sorry? General patients?

D: No, the inpatients. The main customers of the hospital are inpatients so we outpatients have difficulty to make an appointment.

M: You have difficulty to make an appointment.

D: I have waited the hydrogymnastics for one year. They told me that there wasn't enough therapist. But C asked the team leader to consider my situation, so I could go to the hospital with E. It was not easy.

M: Well, the process was not easy, but it produced good results. Are you finished, E? Thank you. I'll read aloud. It's E's answer.

E (Read by M): When I go to the hospital, I am asked to come with carer to interpret in some hospital. But mostly, they don't ask. I think it's a problem of disability awareness. I can communicate by writing and many other ways...

M: How do you communicate with staff when you're not with carer? By text? ... I see. Do they make the best use of that method? Thank you, sir.

B: I'm B. I used to use two hospitals and they had poor accessibility. Since I work around here in the daytime, but the hospitals are... One is located in Ilsan, and the other one is in the opposite direction. They are far away from each other and this office. So I had to go this way, and then come around to go to the hospitals. There are available hospitals around here but I feel uneasy to change what I'm accustomed to. I cannot do that. So... I don't go to the nearby hospitals. It's an accessibility problem and... all the medical professions I met are very different. As C said, therapists have just graduated from college, so they know nothing. They just... massage here and there a little, and say "It's done". They are novice. But in the case of therapists with more than three-year's experience, they know how to massage us based on the gender and other things. They have their own knowledge and experience. That kind of practice can improve patients' health, but it is not easy to meet such a good therapist. There is a long waiting line all the time in front of them. (Laughter) Some therapists are really good.

They are well known as best therapist in the hospital. But the patients, who go to the hospital once or twice a week at most like me, cannot meet them easily.

M: If you go to the hospital more, then...

B: Inpatients.

M: Ah, inpatients...

B: Yeah. And... I don't think I have been treated unfairly...

A: It's much better these days. When I was sick at first, the staffs threw tantrum to the patients because they were too busy due to so many people, but now it's much better.

B: But some people still...

M: Some people still throw tantrum?

B: Sure, of course. This just occurred to me, about ten years ago, when H1N1 was prevalent.

M: H1N1? In the year of 2009?

B: Was it 2009? Anyway, I caught the flu and it grew to pneumonia. But I survived! There was a 500-bed general hospital around here. Usually I enter a hospital as a neurology patient, but at that time, I belong to the division of pulmonology. When I left hospital, the bill was much higher than I expected. So I went to the administration team and asked them. They gave me an answer. I paid for it first and demanded the detailed statement. They conducted tests that I didn't ask, such as thyroid test. I don't understand why they did it. You know, it is not covered by health insurance. What is worse, if they conducted the tests, then don't they have to let me know about the result? But they didn't say anything about it. If I didn't check it, I would not know about it at all. After then, at the next visit to pulmonology, I asked the director of the division about it. I heard that the director had approved the hospitalisation. So I asked him why he carried out such tests, why he didn't tell me about the results, and he answered me "Just make an objection to Health Insurance Review and Assessment Service (HIRA), they will return it." So I really made an objection. Right after then, the administration team called me and asked to delete the objection. They told me they would refund all the extra cost. Finally, I got all back.

M: Wow, you handled it very well.

B: Many people don't know about the medical expenses, but I have used the hospital for a long time, and before I got sick, I had worked at hospital. Thus I can expect the amount of the expense approximately. But it was much more than I thought. If it were not me, anybody may pay for the bill without doubt.

M: Yeah, as is often the case. I don't check the detailed statement.

B: It's true. So... the chief administrator said "We will serve you better." I don't need to go to the pulmonology usually, but then... I entered into the hospital due to H1N1. Yeah.... That happened.

M: Thank you. It's really helpful information. Umm... In fact, when I told you about this FG, I said it would take one and half hour. But now, the recording time is over one and half hour.

Anybody has to leave here? You all right? Then, do I speed up? Okay, thank you. I'll preside as quickly as possible.

Now we're talking about barrier in healthcare service use and finance. And then political approach... but I think to talk about political approach is not easy.

“What do you think about the policy improvements for health promotion or equality in the healthcare service of disabled people?” I think ‘equality’ in this question is not easy. You may regard this as quality of healthcare service, or accommodation – that is, convenience. If you don't have answer for this question, then you can just pass it. And question six is about financial barrier. “How is the illness increasing your cost of living?” I wonder if... for example, call taxi for the disabled people is relatively cheap. But it's postcode lottery. There is no enough taxi in some area. The disabled people in that area will spend a lot of transportation expense. Or... the call taxi is more expensive than bus r subway anyway.

Also, cost of equipment, cost of drugs, cost of special diet, cost of therapies.... I wonder how these costs influence on your economic status. And how the government support is helping you to fund for those. In this question, I ask about only central and local government, but you may include private support. Anybody wants to be first...

D: I'm D. The expense for the rehabilitation therapy is... 50 or 60 thousand won a week.

M: Is it patients' sharing?

D: Yes. It used to be. Until last year. At that time, I also paid 200 thousand won a month as PAS sharing fee.

M: Wow, it's a large amount.

D: Yes, it is. And the cost of driving... it was really burdensome. I have no decent income but there are lots of expenditures.

M: Excuse me, but are you the recipient of the National Basic Living Institution (NBLI)?

D: No, I'm not. I'm not eligible for the benefit. It's too rigid. I cannot receive the benefit because I have a house. But I am in near poverty group. C advised me to apply for it... (Everyone laughter)

M: C, again. He is repeated so many times today.

B: He's almost a religious leader (Laughter)

D: He gave me an advice to apply for the near poverty group, and I was passed by a shave. After then, I don't need to pay for the medical fee. I got to take rehabilitation therapy for free, and the private burden of 200 thousand won for PAS was reduced to 20 thousand won. It is really really useful.

M: wow, it's really... it shows the power of information. It's really good.

D: Also E spends a lot of money on healthcare service.

M: Does he?

C: Give E a chance to talk about it.

D: He's writing now.

M: Oh yeah. I'll read aloud what he's going to give me. And you, sir...

C: By the way, the question five... the physical accessibility... I want to talk about it. During the physiotherapy or hydrogymnastics, sometimes I have to ride something or get into the water alone. Then therapists watch it, and say "You cannot do it." I think it's their prejudice.

M: Sorry, I don't understand. What kind of prejudice?

C: They just catch a glimpse of it, and they judge.

M: Ah- you think you can do it, but the therapists say "You can't do it"

C: In my thought, it won't be too late to give up later if I try it at first. If I fail in my attempt, then I'll give up. But they prejudge that I cannot do it. I think it needs to be corrected...

M: I see. The hospital staffs have a tendency to be passive because they are concerned if the patients get hurt.

B: I'm B. "How is the illness increasing your cost of living?" In fact, I have had pressure sore since November 2014. (Laughter) I got this disease in 2001 and have used a wheelchair since 2006. Since then, spinal nerves were not disconnected completely, but connected imperfectly and fade away. It left a trace and the trace disappeared. Sometimes the trace part is paralysed and the sense becomes insensitive. Sitting long time makes me sore and at that time, I move my hips up and down so it was okay. But a scrape... I was so busy that I neglected a scrape and it became a bedsore. Before the surgery, I used to take a bus. There is no subway station around here. I took the lower floor bus with a sense of duty. Because the community changes when we take a bus over and over again. So I took a bus as many as I can even I was blamed. But at that time, when I had bedsore, I couldn't. I had to go to the bus stop from my home. Then the wheelchair rattled. It rattled again when I came back home. It's the same I came here. So after then... I came back to my work last February, and since then I have taken a call taxi for the disabled people. So... I feel sorry when I don't take a bus. I think "I ought to take a bus to change the community, I should not do this..." By the way, the bus fares is a problem too. If there is a subway station around this office, then it won't cost money⁷ and we'll feel easy, but bus or call taxi for the disabled people is not for free, and furthermore, call taxi costs twice as much as the bus. So it's a little but continuous burdensome. And the assistive devices... After I got bedsore, I bought a sitting mat worthy of 480 thousand won. 350 thousand won was supported, and I paid 130 thousand won. That kind of difficulties... And this, the electric wheelchair, is 5.6 million won.

M: Yeah... The electric wheelchair is very expensive.

D: Even in the case of recipient of NBLI, the upper limit of the support is 2.08 million won so the rest 1.5 million won is private burden. That kind of barrier...? It's the same in the case of manual wheel chair. It is so. As I told, I have Devic syndrome. Until recently, until last October, the cure for Devic syndrome was not covered by NHI. It costed 1.6 million won for one injection.

⁷ In Korea, Disabled people can take subway for free.

M: 1.6 million won for one injection?

B: It was wholly private burden. There's a great deal of variability between individuals so some get three or four time a year, and others six or seven times. In my case, I get the injection once in ten months. Anyway, it was private financial burden, but the association of patient of 'Child fund' or social welfare foundation supported me. The guardians of the patients entrust money to the foundation to support the needy. That's how I was supported. Nevertheless, I reeled under the burden of 1.6 million won last year. Now it has been covered by NHI since last October so the burden has halved to 800 thousand won an injection. Well, it's still burdensome but it has halved anyway...

D: Excuse me. May I go to the toilet?

M: Sure. Do you need an assistant?

C: D wants to go to the toilet.

M: Uh, anybody want to go to the toilet?

(Time gap)

M: Ah... B was talking. 800 thousand won was covered by benefit out of 1.6 million won.

B: Yes, that's patients' sharing. The patients' sharing is zero in case of recipients of Medicaid. I got one-time last year and this year, one more time. Because I am still the recipient of Medicaid so I have no burden of patients' sharing. But to disabled people... If he or she is not very wealthy, any disabled person will feel big burden as I just told. I think disabled people including me should be supported by benefits of Medicaid that we can receive treatment, and live a better life. Many disabled people don't go into the community or get a job because they are worried if they lose the eligibility of Medicaid. They make money a little, and spend a little. So those who spend a lot of medical fee say "I don't need to get a job. I earn one or 1.2 million won a month but if I lose eligibility due to this, then I spend more medical fee. Why should I work?" Like this way. So, of course there should be a standard, but considering that kind of policy problem... It would be much better if the government supports...

M: I see. The medical benefit, rather than living benefit inhibits disabled people from getting a job.

A: If once get a job, then you should earn more money than you do not. But if you lose eligibility due to the job, now you have to pay for the medical fee. In that case, you don't need to work.

M: Well, the institution was transformed last year but it doesn't seem to be stabilised yet. There are not much discussion about it. It remains to be seen.

A: I'm A. When I got the illness at first, the hospital bill was really... some medication was not covered by the insurance, and there was much expensive medication. It costed more than 200 thousand (won) per month... it was considerable sum of money at that time, 1988. I was in a lot of pain, had to go to the hospital for physiotherapy as well. I felt tired and weak because it was a wasting disease. Repeatedly, I was hungry and burnout. So I always take oriental medicine even now. It was also a big financial burden. But now, the treatment for rheumatism is subject to co-payment (patients' sharing) decreasing policy so the expense for

cure for rheumatism is reduced a lot. If it is 50 thousand one, then it is reduced to ten thousand won. I can get discount in almost all the cure. It's really good. Even oriental medical clinic. It costed five or six thousand won in one visit before. But since last year, I pay only 1,500 won. It costs 1,500 won to get acupuncture and physiotherapy. Because I'm not a recipient of Medicaid due to my husband's income, I felt burden before, but now I go to the hospital diligently. Certainly, the steady cure was good for my neck. I heard that neck is the weakest part among the joints. I've taken steroid for a long time so the neck has been weakened and fractured. Then, the doctor told me that I could not use the lower body if I didn't have a surgical operation. I underwent the surgery with hipbone two years ago. I felt severe pain on the neck, I gave a grimace of pain. It was really painful. After the surgery, the pain went worse so I went to the oriental medical clinic and got massage, physiotherapy, and acupuncture. It was effective. I got recovered a lot. But now I have severe pain on other part due to the long taking of medicine, the cure for which is not reduced because it is not rheumatism. It's another burden. Particularly, the digestive organs are so bad that I go here and there to cure, but there is no benefit for it. It's a burden.

M: You feel more burdened in medical expenses than living expenses. Is the illness increasing your cost of living?

A: It's... I don't work a lot. Just a few hours. I work to supplement the academy fee of daughter, do exercise...

M: That's why you work. I see. E, you're finished? I'll read it. Thank you. Your answer is very clear so it is helpful.

E (read by M): I spend 3-400 thousand won of medical expense a month. It's economic burden. I didn't spend medical expense due to disability at all, but now it's a really big burden. I hope the government support it. You know, I cannot take out a policy.

B: Insurance for actual expense.

M: Sir, what do you mean with "I didn't spend medical expense due to disability at all"? You mean three years ago? You felt well then so didn't need to go to the hospital, but you lost your job and health. And then you began to go to the hospital for cure, which gives you a big financial burden. Is it? Well, it is not fair that disabled people cannot take out a policy. So you expect the government's support. Support for your medical expense. Thank you. Umm.. 3-400 thousand won a month... and C, what do you want to talk about this?

C: As for the medical fee, I'm the recipient of Medicaid.

M: Ah, Medicaid.

C: But the assistive device is... for example, if I get a flat tyre of my wheelchair along the way, I have to change. I don't know why, but parts of assistive devices are more expensive than other goods. Is it because it is 'rehabilitation assistive device'? It's financial burden.

M: Thank you. Uh, I tried to finish early, but it's over one hour and 52 minutes. Sorry for the delay. Is there anything else you'd like to add before we wrap things up? D is not here. Even he already talked about the medical fee, I want to give him a last chance to talk, but it's too late to let you await...

B: I wish I can take out a policy.

M: An insurance?

B: Insurance for actual expense!

A: We are hospitalised frequently, and it costs us millions won in just one time... It would be no problem if I took out a policy before I got sick, but I have been sick since I was young.

E: Cancer insur...

M: Cancer insurance?

B: Yeah, there is a cancer insurance for disabled people.

M: Do you have a cancer insurance? It covers four-major cancer?

C: No, it covers only liver cancer.

B: There is not much...

M: I see. Now the FG is done. Later I might contact you due to the additional question. If another question arises during analysis, then I will call you. Please cooperate with me. Thank you. Now I'll turn off the recorder.