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Understanding Citizenship and Quality of Life through Disabled Activists in South Korea

Hyunhee Park

A dissertation submitted to the University of Bristol in accordance with the requirements for award of the degree of Doctor of Philosophy in the Faculty of Social Sciences and Law, School for Policy Studies, April, 2020

March, 2021

79,938 words

Abstract

Sixteen disabled activists and leaders in the field of disability in South Korea were interviewed to probe into questions about the concepts of citizenship and quality of life (QOL) of disabled people in South Korea and to share their stories about their involvement in the disability movement. First, drawing on Morris's (2005) concept of citizenship for disabled people and Felce and Perry's (1995) model of QOL, their citizenship and QOL, and by extension the citizenship and QOL of disabled people in general, within South Korean society were examined. Data analysis found that the negative perception of disabled people was the first and the most prevalent barrier within society which prevented disabled people from enjoying their citizenship and a better QOL. The interviewees directly and indirectly emphasised the significance of autonomy as a pre-condition for their citizenship and QOL. They wanted to belong in and contribute to society as autonomous citizens; whilst they described how disabled people's QOL could be improved by enjoying informal relationships, having power and equally distributed opportunities, enjoying leisure time and having a certain kind of attitude to life such as positivity and self-initiative. Disabled people's citizenship and QOL were found to improve each other reciprocally. Data analysis also revealed that some participants found a positive identity through involvement in the disability movement. This resulted in them being empowered and autonomous and, furthermore, affirming their citizenship and enjoying a better QOL. Thematic analysis was utilised as an analytical method, as the participants shared their life stories and experiences, as well as their feelings, thoughts and opinions. This approach helped to identify patterns related to their experiences, opinions, views and behaviours in the stories and was also appropriate in interrogating the meaning of living as citizens and the definition of QOL to the interviewees.

Acknowledgements

First of all, I convey my sincere gratitude to the 16 interviewees who shared their stories, ideas and opinions with me. I am sure that it was not easy for them to talk about their very private stories and to delineate such profound thoughts, so I appreciate their contributions immensely.

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Moreover, I would like to thank Professor Kim Kyungmi for providing such valued insights into the Korean disability field and introducing eight of the interviewees.

Finally, I must thank my dear mother, Kim Soojung, who has supported me with her love and prayers and has always been there for me.

Author’s declaration

I declare that the work in this dissertation was carried out in accordance with the requirements of the University’s Regulations and Code of Practice for Research Degree Programmes and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate’s own work. Work done in collaboration with, or with the assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.

SIGNED: .... DATE:..................

Table of Contents

Chapter 1: Introduction **1**

1.1 Introduction 1

1.2 Conceptualising Disability 2

    1.2.1 The Social Model 2

    1.2.2 The Human Rights Model of Disability 6

1.3 Research Rationale 7

1.4 The Structure of the Thesis 9

Chapter 2: Literature Review **11**

2.1 Introduction 11

2.2 The Concept of Citizenship in Korea 12

    2.2.1 Lack of Democracy 12

    2.2.2 Effect of Nationalism 14

    2.2.3 Citizenship for Minority Groups 14

    2.2.4 Effect of Confucianism 16

    2.2.5 Generational Disparity 17

    2.2.6 The Current Concept of Citizenship in Korea 18

2.3 Disabled People within Korean Society 19

    2.3.1 Perception of Disabled People in Korea 20

    2.3.2 Disability Movements 23

    2.3.3 Anti-Discrimination Act for Disabled People 25

    2.3.4 The UNCRPD in Korea 27

        2.3.4.1 Korean Delegation and Enactment in Korea 27

        2.3.4.2 Concluding Observation and Follow Up 29

        2.3.4.3 Current Status 30

    2.3.5 Need for the Concept of Citizenship for Disabled People in Korea 31

2.4 Korean Literature on Disabled People’s QOL and Citizenship 33

    2.4.1 Definitions of Social Inclusion 33

2.4.2 Limitation of the Meaning of Social Inclusion 34
2.4.3 Studies on Disabled People's QOL and Citizenship (Social Inclusion) 36
2.5 Korean Literature on the QOL of Disabled People 38
2.5.1 Important Domains for Disabled People's QOL 38
2.5.2 Different Views among Different Participation Groups 41
2.6 Studies on Disabled People's QOL in Various Countries 44
2.6.1 Social Inclusion, Rights and Personal Relationships 44
2.6.2 Health Condition and Having Control 45
2.6.3 A Circular Concept of Inclusion and High Quality of Life 46
2.6.4 Section Conclusion 47
2.7 Research Questions 48

Chapter 3: Conceptual Framework **51**

3.1 Citizenship 51
3.1.1 What is Citizenship? 51
3.1.2 Exclusion from Citizenship and Inclusive Citizenship 52
3.1.3 Disability and the Concept of Citizenship 54
3.1.4 Morris's Citizenship for Disabled People 57
3.1.4.1 Self-Determination 58
3.1.4.2 Participation 61
3.1.4.3 Contribution 63
3.1.5 Is the Concept Developed for Disabled People in the UK Suitable for Disabled People in Korea? 65
3.1.6 How Citizenship was Translated into Korean in This Study 66
3.2 Quality of Life 67
3.2.1 Importance of Social Domains 68
3.2.2 Influence of Subjective Views in Determining QOL 69
3.2.3 Why QOL rather than other Terms? 71
3.2.4 Felce and Perry's Model of Quality of Life 74
3.2.5 The Value of Money and QOL 76
3.3 How the Two Concepts Might Relate to Each Other 76

Chapter 4: Methodology **79**

4.1 Methodologies 79
  4.1.1 Philosophical Background of the Study 79
  4.1.2 Qualitative Research 80
  4.1.3 Data Collection: Semi-Structured Interviews 81
  4.1.4 Data Analysis: Thematic Analysis 83
  4.1.5 Trustworthiness 86
4.2 The Research Process 87
  4.2.1 Sample Size 87
  4.2.2 Research Participants and Sampling Process 88
  4.2.3 Interview Protocol 91
    4.2.3.1 Opening Interviews 91
    4.2.3.2 Protocol Questions 91
  4.2.4 Interviews 93
    4.2.4.1 Participants 93
    4.2.4.2 Rapport 93
    4.2.4.3 Order of Protocol Questions 94
    4.2.4.4 Interview Process 95
    4.2.4.5 Additional Questions 96
  4.2.5 Data Analysis 96
    4.2.5.1 Translation 96
    4.2.5.2 Data Analysis with Thematic Analysis 97
  4.2.6 Ethics 100
    4.2.6.1 Asymmetrical Power in Interview 101
    4.2.6.2 Interviewees' Vulnerability 102
    4.2.6.3 Rapport with the Participants 103
    4.2.6.4 Process of Analysis 104
    4.2.6.5 Consent Form 104
  4.2.7 Researcher's Reflexivity 105

Chapter 5: Citizenship **107**

5.1 Introduction 107
5.2 Minsoo's Narrative: Dichotomous Society 109
5.3 Non-Disabled People's Views on Disabled People 111
    5.3.1 Being Different 112
    5.3.2 Beneficiaries/ The Unblessed/ The Vulnerable 115
    5.3.3 Not Existing in Society 119
5.4 Disabled People's Views on Disabled People 121
    5.4.1 Lack of Opportunities to Be Educated 121
    5.4.2 Domestic Abuse of Disabled People 122
5.5 Disabled People's Lives in Mainstream Society 125
    5.5.1 Not Being Valued 125
    5.5.2 Lack of Sense of Belonging 128
5.6 Ways to be Recognised as Citizens 131
    5.6.1 Having a Job and Paying Tax 131
    5.6.2 Re-Imagining of Disabled People in Non-disabled People's Minds 135
5.7 Chapter Summary 138

Chapter 6: Quality of Life 139

6.1 Introduction 139
6.2 Social Relationships for QOL 141
    6.2.1 Emotional Exclusion and Oppression 141
    6.2.2 Collective Solidarity 145
6.3 Power for QOL 149
    6.3.1 Having Agency in Your Own Life 149
    6.3.2 Having Power in Society 152
6.4 Opportunities for QOL 156
    6.4.1 Unequal Opportunities for Disabled People 157
    6.4.2 Lost Opportunities 160
6.5 Attitudes Towards Life and QOL 163
    6.5.1 Being Positive about Life 163
    6.5.2 Having Self-Initiative in Life 164

6.6 Leisure for QOL 168
6.7 Personal Finances 173
6.8 Chapter Summary 176

Chapter 7: Disability Movement **178**

7.1 Introduction 178
7.2 Joining the Disability Movement 180
    7.2.1 Lack of Facilities 180
    7.2.2 Realising Other Disabled People's Needs 182
    7.2.3 Mobilising Other Disabled People 185
7.3 Growth through the Disability Movement 187
    7.3.1 Working for Friends and Working with Others 187
    7.3.2 Solidarity with other Disabled People 190
7.4 Ascertaining Disability Identity in the Movement 193
    7.4.1 Realising Disability Identity 193
    7.4.2 Finding a Positive Self-Image 196
7.5 The Disability Movement in the Past and in the Future 199
    7.5.1 Accomplishments in the Past 199
    7.5.2 Worries for the Future 201
7.6 Chapter Summary 202

Chapter 8: Discussion **203**

8.1 How do Disabled Activists in Korea Speak about, Experience and Conceptualise What It Means to Be a Citizen? 203
    8.1.1 Discrimination against Disabled People and the Idea of Normalisation 203
    8.1.2 How Disabled People Want to Live As Citizens 205
        8.1.2.1 Self-Determination 206
        8.1.2.2 Participation 207
        8.1.2.3 Contribution 209
8.2 How do Disabled Activists in Korea Speak about, Experience and Conceptualise Quality of Life? 213

8.2.1 Differences in the QOL of Disabled People and Non-Disabled People 214

8.2.2 Autonomy for Disabled People's QOL 215

8.2.2.1 Lack of Autonomy in terms of Disabled People's QOL 215

8.2.2.2 Lack of Studies Including the Concept of Autonomy for Korean Disabled People's QOL 217

8.2.3 Importance of Social Context in QOL 218

8.2.4 Personal Finances for QOL 219

8.3 Do the Two Concepts of Citizenship and Quality of Life Speak to Each Other in Everyday Life and Theory? 221

8.3.1 The Role of Citizenship for Disabled People's QOL 221

8.3.2 How Autonomy Links Disabled People's Citizenship and QOL 224

8.4 What is the Impact on Both Citizenship and Quality of Life of Being an Activist and Part of the Disability Movement? 225

8.4.1 Embarking on the Disability Movement 226

8.4.2 Being Citizens in the Disability Movement 227

8.4.3 Realising a Disability Identity 228

8.4.4 Being Empowered as Autonomous Citizens 231

8.5 Chapter Summary 233

Chapter 9: Conclusion 234

9.1 Research Findings 234

9.2 Contribution of This Study to Knowledge 235

9.3 Limitations of the Study and Recommendations for Future Research 237

9.4 Reflection on the Study 238

9.5 Conclusion 240

References 242

Appendix A: Examples of Search Results for Korean Literature 279

Appendix B: Ethics Approval Letter 280

Appendix C: Consent Form (English) 281

Appendix D: Participant Information Sheet (English) 283

Appendix E: Consent Form (Korean) 285
Appendix F: Participant Information Sheet (Korean) 287
Appendix G: Interview Schedule 289
Appendix H: Table of Participants' Information 290

List of Tables and Figures

Table 1: Top 10 components stated by disabled people in the study (Park, 2000) 43

Table 2: Themes and Sub-Themes for Citizenship 109

Table 3: Themes and Sub-Themes for Quality of Life 141

Table 4: Themes and Sub-Themes for Disability Movement 179

Figure 1: A model of Quality of Life (Felce & Perry, 1995, p.62) 75

List of Abbreviations

ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairment, Disability and Handicap
ILO	International Labour Organization
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organisation

Chapter 1: Introduction

> The biggest problem that we, the disabled, have is that you, the non-disabled, are only comfortable when you see us as icons of pity (Shaban, 1990).

1.1 Introduction

This thesis seeks to contribute new knowledge regarding how disabled people in South Korea (hereafter referred to as Korea) conceptualise citizenship for disabled people and their quality of life (QOL) and whether the two concepts are related to each other. As disabled activists were invited to be participants, the thesis also interrogates how their involvement in the movement has contributed to their citizenship and QOL.

This chapter mainly consists of two topics that provide background knowledge to the thesis. The first main topic outlines my understanding of disability, which helps to explain where this thesis originated. Next, is the rationale for the thesis, which explains why this study needs to be conducted, whilst the chapter concludes with the structure of the thesis. Before embarking on the study, I want to open with a personal story which, in fact, led to me studying disability studies and, furthermore, conducting this current study.

One day I encountered a young disabled man, who appeared to be in his early 30s, at an underground station in Seoul, who had a disability affecting his legs. When he walked, he limped heavily, but he did not have crutches with him. He got on and off the next carriage of the same underground train at the same stations as me. I saw him and knew he was there, but he did not catch my attention much while we were waiting for and getting on the underground. When the underground train arrived at the station where we disembarked, I stepped off the train as he was exiting from the adjacent door. I noticed him throwing himself onto the closest wall to the door of the carriage in which he was, instead of walking out. After he threw himself out, he lost his balance and sat crouched in front of the wall on which he was leaning. It seemed that he did not want to cause any delay which might have been caused due to his slow pace of walking. However, he did not have to throw himself: there was enough time to get off the underground by foot. Despite all this, the thing that really seized my attention was his face. His face was more than just still while he was standing up. He looked firm and even elegant, but looked sad from the bottom of his heart. I immediately believed that his sadness was not only due to the difficulties in moving his legs, but also the world he had to face in his everyday life. After this, I lost him. I am not sure whether he used the stairway or the lift at the underground station, but it is clear that this incident triggered my contemplation about disabled people's lives. It was the first time in my life that I thought about disability in depth.

At that time, I had been thinking about changing my career for more than five years, but I was hesitant to make a change. However, several questions, such as why disabled people are so marginalised and excluded from Korean society and what really prevents them from living as equal members of society, and my certainty that this must have an influence on their lives and QOL, inspired me to study the field of disability and, furthermore, gave me the idea for this thesis.

1.2 Conceptualising Disability

This section describes my orientation in understanding disabled people and disability, which informed aspects of this study in addressing my thoughts, forming my research questions and analysing the data.

1.2.1 The Social Model

Disabled people often try to find a way of understanding themselves and identifying their place in society, whilst challenging the widely accepted social perception of disability as personal tragedy (Finkelstein, 2004). The concept of the social model, which rejects the medical/individual model, which perceives disabled people as defective individuals, was first articulated in the early 1980s by Mike Oliver (Oliver, 1983). Oliver (2004, p.21) later summarised the 'social model of disability' as:

> the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment—whether physical, mental or intellectual.

The social model tackles social barriers which take no or little account of disabled people. According to the social model, social barriers cause disabled people to be excluded from mainstream society and prevent them from participating as equal members of society with non-disabled people. As a consequence of this, 'people who are viewed by others as having some form of impairment' become disabled (ibid.). The social model shifted the concept of disability from the range of a biomedical subject to a social context and also empowered disabled people and the disability movement (Campbell & Oliver, 1996; Hurst, 2003). The social model strengthened disabled people's insight into the struggle for emancipation (Finkelstein, 2004, p.16) and supported 'campaigning for anti-discrimination legislation, independent living and a barrier-free society' (Barton, 2004, p.285).

Furthermore, the articulation of the social model challenged the World Health Organisation (WHO) to revise the definition of disability in the International Classification of Impairment, Disability and Handicap (ICIDH) (Hurst, 2003; Schneidert et al., 2003). The ICIDH, which was endorsed in 1980, took a position which understood disability from a linear approach, viewing diseases and impairments as causes and handicap and a person's inability to participate as a member of society in a 'normal' mainstream society as outcomes (Hurst, 2003). The idea which perceived disability as a result of functional limitations in ICIDH was revised in the International Classification of Functioning, Disability and Health (ICF), which was endorsed in 2001 by the WHO. The ICF defines disability as an overarching concept of 'impairments, activity limitations and participation restrictions' and recognises interactions of 'environmental factors' and 'personal factors' with 'health conditions' (McDougall et al., 2010, p.205). The ICF shifted the idea of disability from the medical model of disability to a disabled people's human rights issue (Hurst, 2003; Hammell, 2015). The definition of disability in the ICF model expanded the idea of disability into a wide concept which embraces various perspectives. In addition, the WHO recognised the need for a continuous process of revision and updating the definition of disability (WHO, 2001). This illustrates that the current definition of disability is not definite. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UN, 2018) also does not firmly define a person with disabilities or the definition of disability. Rather, the definitions are open ended (Quinn, 2009). The definition of a person with disabilities is described in article 1 as:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (UN, 2018, Article 1).

The preamble recognises the concept of disability as:

> an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others (UN, 2018, Preamble).

The definitions describe various barriers, including attitudinal and environmental barriers, as the causes hindering disabled people from participation in society. The UNCRPD is against the view of ‘persons with disabilities’ ‘as objects of charity, medical treatment and social protection’ and stated that disabled people are ‘subjects with rights, who are capable of claiming those rights’ as active members of society (UN, 2008, p.8). The UNCRPD was also developed based on the ideology of the social model (De Meulder, 2014; Degener, 2016).

However, although the social model has seen much accomplishment, it still has some limitations and has received criticism. The primary criticism relates to the idea that ‘no body’ or ‘no impairment’ exists within disability theory, as some versions of the social model have over-emphasised the concept of the social barrier and minimised any emphasis on impairment or the body (Abberley, 1987; Morris, 1991; Oliver & Barnes, 2012). Feminist scholars and writers, such as Morris (1991) and Thomas (1999), have claimed that personal experiences related to the relationships, sexuality and motherhood of disabled people are not adequately considered by the social model. Morris (1991, p.181) asserted that, ‘[t]o experience disability is to experience the frailty of the human body’. When this experience is denied, disabled people will ‘commonly feel a sense of personal blame and responsibility’, because their experiences will be ‘something peculiar’ to disabled people ‘as individuals’ (ibid.). Disabled people’s personal experiences are crucial in order to understand their lives and the social world in which they live. A further criticism relates to how intellectual disabilities can be excluded from the social model because social model scholars did not consider people with intellectual disabilities in the discussion of the model (Chappell et al., 2001). As a result, the social model does not adequately take the concerns of people with intellectual disabilities into consideration (Thomas, 1999). Shakespeare (2006) also argued that removing these social barriers may not be the appropriate solution to accommodate all different kinds of disabled people, since different kinds of disabled people have different kinds of concerns regarding their disability.

This research acknowledges that the body and impairment exist and that these are important issues for disabled people, as critics point out. Furthermore, the limitations which exist within disabled people’s lives as a consequence of their impairment cannot simply be ignored. It would be ineffective to overlook the body in discussions on disability. However, in spite of all these contentions about the social model, Morris (1991) pointed out that it is clear that the social model is a practical tool in the process of demanding rights for disabled people. This study also takes the standpoint that the social model has helped society to recognise and view disabled people differently to how it did before—specifically, in a more positive light. The model has also helped disabled people to address the lack or absence of certain rights and citizenship. It has helped them to realise the need to raise their voices to gain these rights. Thus, the social model shifted the focus of disability onto the next step regarding disabled people's QOL (Oliver & Barnes, 1998). Furthermore, it is clear that the social model has helped to shift the idea of disability away from its early conception as a biomedical issue to a human rights perspective (Thomas, 2004).

1.2.2 The Human Rights Model of Disability

The human rights model of disability first 'appeared in an article on international and comparative disability law reform' written by Theresia Degener and Gerard Quinn between 1999 and 2000 (Degener, 2016, p.34). In 2016, Theresia Degener reviewed the human rights model of disability in comparison with the social model in a chapter of a book—*Routledge Handbook of Disability Law and Human Rights*—although she asserted that she did not want to claim ownership of the terminology. Degener (2016) argued that the focus of the human rights model of disability is on recognising 'the inherent dignity of the human being' and contended that the model provides a moral imperative: everyone is a human rights subject; thus, this is an unconditional right. Stein (2007, p.76) also developed a 'disability human rights approach' to examine a theoretical implication for the UNCRPD. He also observed that society needs to acknowledge the value of human beings based on inherent human worth, instead of an individual's functional ability. Indeed, disability can be understood 'as a universal variation rather than as an aberration' (p.77). Thus, Degener (2016) stated that 'the absence of impairment' is not required for the human rights model of disability, since disabled people need to be respected as they are human beings. When the universality of human rights for disabled people is claimed, all disabled people who need additional support also have the right to claim this. This ideology is well expressed in the purpose of the UNCRPD and embedded within it. The human rights model of disability has not been reviewed or elaborated upon by many scholars and has not gained much criticism yet. However, I agree with the idea that disability needs to be recognised from the human rights perspective, which understands disabled people as equal human beings whose inherent dignity needs to be respected as it is.

This study takes the standpoints of both the social model and the human rights model of disability. The social model shifted the perception of disabled people from a medical model and is a practical tool in the process of demanding rights for disabled people. The social model helped disabled people to address the lack or absence of certain rights and citizenship. Furthermore, the arguments claimed by disabled people based on the social model are legitimate because all disabled people are equal human beings who should be respected based on their inherent dignity, as the human rights model of disability articulates.

1.3 Research Rationale

Hughes (2007, p.673) asserted that, 'formal, bureaucratic quality of life measures, almost by definition, assume disability to be ontologically problematic' and claimed that disabled people are often treated by non-disabled people as if they are 'invisible', 'repulsive' or 'not all there' in everyday interactive situations within society. Thomas (1999, p.60) argued that disabled people's 'psycho-emotional well-being' is routinely undermined by the social distance between non-disabled people and disabled people and insisted that disability is about 'barriers', not only in the way of 'doing', but also in the way of 'being'. Hughes's claim and Thomas's arguments present how the existence of disabled people within mainstream society is often denied and how disabled people are not recognised as equal citizens in society and, ultimately, how these social attitudes can undermine disabled people's QOL.

Survey data shows strong discrimination against disabled people within Korean society (RIDRIK, 2003; Kim et al., 2014). In addition, people with differences are not easily accepted within Korean society due to the influences of Confucianism and nationalism (Koo, 1993; Armstrong, 2002). Thus, disabled people are routinely marginalised, discriminated against and excluded from society in Korea (Jang, 2005; Kim, 2008; Yoo, 2011; Lee & Park, 2012). Even within Korean disability policies and legislation, disabled people are often perceived as people who have medical problems or deficiencies and who need care and to be rehabilitated instead of people who can live as full citizens equal to non-disabled people (Nam, 2007; Park, 2008; Yoo, 2011; Park, 2014). It is evident that disabled people in Korea are not often perceived and also do not live as equal citizens. The assumption of this research is that this must have an adverse effect on their QOL and the assumption led me to conduct this study, as I discussed at the beginning of this chapter.

However, the QOL of disabled people has received very little attention as a subject of research in Korea (Kim, 2007a; Park, 2009b; Lee, 2014b). Even amongst the studies on the QOL of disabled people conducted in Korea, disabled people in the studies have not often had the opportunity to discuss their QOL directly, since most of the studies on disabled people's QOL in Korea have used questionnaires (this issue is discussed in the 'Literature Review' chapter). Therefore, I first explicitly asked the interviewees to define the concept of QOL and to describe their QOL. Furthermore, I also explicitly asked the interviewees about the meaning of citizenship to them and how they live as citizens. The concept of citizenship for disabled people is not firmly established within Korean society (Kwon, 2012), since there has long been a lack of awareness in Korea in terms of how disabled people are excluded as members of society (Kim & Fox, 2011; Kwon, 2012). Whilst I was establishing the two concepts, I was also interested to explore any relationship between them.

A total of 16 disability activists and leaders working in Seoul, Korea were interviewed between 10th June 2015 and 19th August 2015. My interviewees were all disabled people who worked to address and acted to obtain disabled people's citizenship and equal rights on the front line. The interviewees meet disabled people from various circumstances and backgrounds, listen to them and discuss and examine issues related to disabled people and disability, which includes disabled people’s citizenship and QOL. Additionally, the interviewees have more opportunities to address and articulate their ideas in public as disability representatives. Therefore, the interviewees were expected to have more comprehensive and detailed ideas concerning disabled people’s citizenship and QOL. As this study is the very first to examine disabled people’s citizenship and to listen to disabled people speak directly about QOL in Korea, I thought it would be beneficial to illustrate a more comprehensive picture of how disabled people perceive their status and position within Korean society and how they illustrate their QOL in Korea. This does not mean that the opinions of disabled individuals who are not involved in the disability movement or who do not work as leaders in the disability field are not important or should not be heard. Their opinions are also equally valuable. It would be favourable to build studies on these issues by interviewing disabled people from different backgrounds and in various circumstances in the future. However, for the purpose of this study, I chose disabled activists and leaders as the interviewees. Furthermore, having disability activists as the participants of the current study also brought the advantage of discovering how their activities in the disability movement had impacted upon their citizenship and QOL.

1.4 The Structure of the Thesis

Chapter 2 locates this thesis within the Korean context. The first part of the chapter reviews Korean literature to outline how the concept of citizenship is understood in Korean society and extends to sections which present how disabled people are positioned and live within Korean society to describe the background of the study and provide additional context. This section also includes the history of the Korean disability movement, the process of how disabled people have supported the UNCRPD to be enacted and stories right up to the current status of how the UNCRPD is applied within Korea. The next part of the chapter focuses on empirical studies on the QOL of disabled people in Korea and other countries. At the end of the chapter, the research questions are presented. Chapter 3 forms a framework to explain how the concept of citizenship and the concept of QOL can be understood and define the two concepts for the current study. Thereafter, chapter 4, which is a methodology chapter, comprises two parts. The first part describes the rationale behind using semi-structured interviews and a thematic analysis for this study. The second part of this chapter describes every step of the process in executing the research, while ethical issues are also discussed. Chapters 5, 6 and 7 are analysis chapters named ‘Citizenship’, ‘Quality of Life’ and ‘Disability Movement’ respectively. These chapters present my findings for each topic. These are followed by the ‘Discussion’ chapter (chapter 8), which answers each of my research questions in light of theoretical ideas and empirical studies. In chapter 9, I reflect on the findings from the study and clarify the understandings presented in this thesis before making some comments and putting forward some recommendations for the future.

Chapter 2: Literature Review

2.1 Introduction

This literature review chapter locates the study within the Korean context; thus, it first outlines the concept of citizenship in Korea and then extends to sections which present how disabled people are perceived and live in Korea. In the following sections a review of empirical studies on the QOL of disabled people in Korea describes how the concept of citizenship is defined in the studies, what the important areas are for disabled people's QOL and how the studies have been approached and conducted in Korea. Empirical studies on the QOL of disabled people in other countries are also reviewed and the differences between Korean literature and literature in other countries are examined. At the end of the chapter, the research questions of the study are discussed.

Before embarking on the main part of the literature review, I briefly explain how both Korean and English literature was researched and which criteria were used to select the relevant literature. Given the nature of this thesis, literature in two languages (Korean and English) has been reviewed. For Korean literature, the Research Information Sharing Service (RISS) provided by the Korean Education and Research Information Service (KERIS), the Koreanstudies Information Service System (KISS) and DBpia were utilised in order to search for literature of interest. Research was a constant undertaking during my PhD. The search focused on literature from the 1990s up until the time of the search.

The following terms were used in Korean for the literature search: disabled people, QOL, citizenship, Korean citizenship, Korean history, disability movement, disability policies, social inclusion, social participation and social integration. As there has not been much literature published on the citizenship of disabled people, literature on social inclusion, social participation and social integration was also searched for. The word 'disability' alone was not used when searching Korean literature, since ‘disability’ in Korean is applied to instances when something fails to function. Had disability alone been included in the search, too much literature that was not relevant to disabled people would have emerged. There was some duplication within the literature when it came to social inclusion, social participation and social integration. A table showing the amount of literature found and the key words used for the research is presented in Appendix A. The ‘key word’, ‘title of literature’ and ‘abstract’ guided the selection of literature which was relevant to this thesis. I also followed up references from previous literature which I had read. This helped to expand the search, as did using books.

For English literature, the research process was relatively similar. It was not particularly difficult to find English-language literature on the QOL and citizenship of disabled people, although social inclusion was also used in the search along with citizenship to enrich the content of the search. Meanwhile, well-being and happiness were added to the English literature search on QOL. For empirical studies, the search focused on literature from the late 1990s up until the time of the search. Literature on the QOL of disabled people from various approaches, including those more focused on social approaches, was also considered. The main search engines used for English literature were Web of Science, the University of Bristol’s Library Service and Google Scholar.

2.2 The Concept of Citizenship in Korea

2.2.1 Lack of Democracy

Many scholars argue that citizenship is the main concept within the ideology and system of democracy and the concept and practice of citizenship cannot be developed properly in nations where democracy is not fully established (Smith, 1995; Turner, 1997; Pierson, 1998).

In Korea, strong anti-communist[1] authoritarian regimes, which were succeeded by different military coups, held power in Korea from 1963 until February 1988 (Koo, 1993). During the subsequent authoritarian regimes, a system of democracy in Korea was not firmly established: the constitution was revised to strengthen the president's power, while media material had to pass censorship under the government-controlled administration (Oh, 1999). The regimes created by the coups damaged citizenship, not only in terms of political citizenship, but also in terms of social citizenship under the guise of 'development' (Chang, 2012a). The anti-communist authoritarian regimes focused on national economic development and drove the country to become industrialised and the economy grew (Park, 2009a; Joo, 2017). The neglect of people's rights was compensated for by a dramatic rise in the nation's wealth, which the government used as vindication for its society being undemocratic.

Spectacular economic growth raised issues concerning distribution and economic justice and the number of exploited citizens increased from the early 1960s (Koo, 1993; Chang, 2012a). In the 1970s, inequality became more severe, especially in the industrial sector where exploitation of workers and despotism among employers became acute. This economic injustice and exploitation of workers was raised as a social issue by intellectuals and understood as a consequence of a lack of democracy instead of economic inequality (Eun, 2005). The Korean labour movement was supported by the democratic movement, organisationally and ideologically led by students who struggled for democratisation (Koo, 1993). The democratic movement merged with the ideology of *minjung* (the people or the masses) and nationalist sentiment against the authoritarian state was amplified and expanded into political, economic and cultural movements in the 1980s (Koo, 2008). Tensions between state and society boiled over in June 1987 (*Yuwol Hangjaeng*—The June Struggle). It is indisputable that *Yuwol Hangjaeng* prompted a dramatic transformation into a new era of Korean democracy (Koo, 1993; Oh, 1999; Armstrong, 2002). A new regime elected by the people launched in February 1988 and that Korean society became more

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[1] Due to the existence of two Koreas, South Korea and North Korea, military power in South Korea

settled in terms of its ideology and politics. Given the country's history, it is perhaps not surprising that the concept of citizenship was not developed in a proper manner in Korea until 1988 (Kim, 2006). After the June Struggle in 1987 and the ensuing democratic developments in the 1990s, the concept of citizenship began to be developed and expanded within Korean society (Choe, 2006).

2.2.2 Effect of Nationalism

Korean citizens began to be provided with legal citizens' rights and required to conform with citizens' obligations by the constitution and related legislation in 1948 (Cho, 2007). The concept of citizenship in Korea is often considered based on nationality (Park, 2008; Kim, 2011). This could be a result of a strong sense of nationalism in Korea. All Korean students were taught in school that they were one ethnic group (*Danil Minjock*—sole ethnicity), with a similar appearance and sharing one common language (Mo, 2009). This was clearly written in social studies textbooks until February 2007 and was articulated as a strength of the nation (Lee, 2012b). Kim (2006) argued that the concept of citizenship in Korea has been developed based on nations which showed loyalty to anti-communism. Previous Korean constitutions stated that sovereign power resides with nations. The nations in the constitution are Koreans who have Korean parents or a Korean father (ibid.). Korean nationality is based on blood relationships. Jang (2005) also claimed that the concept of citizenship is understood as rights for people who carry out their citizens' duties in sole ethnicity nations such as Korea. Furthermore, she argued that the concept of human rights is compatible with the concept of citizenship in a one ethnicity nation such as Korea, since the concept of human rights is perceived as an inherent right for all human beings. In the case of Korea, all human beings are all Korean (ibid.).

2.2.3 Citizenship for Minority Groups

Jang, however, asserted that there have always been minority groups who have been excluded and differentiated by various categories such as nationality, race, class and disability (p.216). Kim (2013, p.45) also claimed that citizenship refers to a person's relationship with a state, but the Cold War, which finally led to the Korean War (1950–1953), and the current neoliberalism, have excluded special groups of people in Korea from a nation state and located them at the periphery of society. According to Choe (2006), the concept of citizenship entails two aspects: legally secured citizens' status and citizens' ability to take part in public activities and responsibilities. However, Choe's definition also implies that there are some people who are excluded from his concept of citizenship in Korea, since some people who do not have the ability to take part in public activities and responsibilities are inevitably excluded from the discourse of citizenship.

Kang (2016) contended that the occurrence of various movements in Korea, such as the labour movement, the democratic movement, the feminist movement and the disability movement, which have claimed their citizenship, reflect that equal citizenship has not been guaranteed to all citizens in Korea for a long time. Furthermore, intentionally or unintentionally, Korean society often categorises some citizens based on their 'differences', such as gender, religion, disability, social status, region of origin and ethnicity, as minorities (Yoo, 2004). People who are different from 'normalised' people often appear at the fringe and are routinely excluded and discriminated against in discourse and practice of citizenship within Korean society (Yoon, 2002).

Jang (2005) categorised minority groups in Korea into four different groups depending on whether the aspiration of the minority group is to establish/re-establish their identity or to access social rights or both in claiming their citizenship. According to her, disabled people are the only minority group within Korean society that has accomplished both the establishment of a 'new identity', defining their differences as a different personality, and pursuing their rights adequately. However, disabled people are still discriminated against, excluded and struggling for access to citizenship in Korea. Kang (2016) claimed that the slogan used by disabled people—'disabled people are citizens too'—is a meaningless rhetoric for disabled people within current Korean society whose substantive citizenship is not guaranteed. However, this is not only the case for disabled people, but also various minority groups whose citizenship is fragile in Korean society, such as groups of particular ethnicities (Kim, 2009; Kim, 2011; Lim & Lee, 2014), North Korean defectors (Bae, 2017; Yoon, 2019), immigrant workers (Seol, 2007; Cho, 2009) and workers whose citizenship is fragile within Korean society (Choe, 2010; Jang, 2017). Seok et al. (2005) claimed that the introduction of social rights in Korea is still in its early stages, while civil rights and political rights have been applied and exercised since 1987. Minorities are not recognised and their existence is sometimes even denied within Korean society. They may exercise their civil rights and political rights, but their economic, social and cultural rights are not secured (ibid.), whilst inequality and conflict among members of civil society has got worse in Korea (Lee, 2015).

2.2.4 Effect of Confucianism

It is often claimed that individual differences are easily rejected within Korean society (Koo, 1993). This could be a result of Confucianism, which is pervasive and embedded within Korean society, along with a strong sense of nationalism. The last Korean[2] dynasty (1392–1910) was a Confucian monarchy, which promoted Confucianism as an essential social philosophy in understanding Korean society. Confucianism has long been prevalent and embedded within every aspect of Korean culture, politics, ethics, language and education and its significance prevails to this day (Kim, 1993; Armstrong, 2002). Accordingly, it would be unwise to attempt to comprehend either Korean or Korea without bearing Confucianism in mind. One of the strongest arguments of Confucianism is about social harmony and unity (Moon, 2010). As a consequence, people who challenge this harmony or break the unity of society are considered abnormal, so individual differences are not often accepted (Yoon, 2008). People who are different from the majority are regarded as 'wrong' (Wang, 2004). It

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[2] This was before the current Korea was divided into South Korea and North Korea.

is not difficult to assume that Korea is a collectivist society (Lee, 2012a; Park, 2016). Park (2016) claimed that collectivist societies, such as Korea, understand individuals within 'interdependent relationships' with other members and emphasise 'mutual sympathy'. However, non-cooperation between members of different groups is another characteristic of collectivist society (Greif, 1994). The ideas of Confucianism, nationalism and collectivist society often prevent people who are different from mainstream society from being perceived as equal citizens in Korea.

2.2.5 Generational Disparity

From my literature search on citizenship in Korea since the 1990s, it seems that the concept of citizenship has been discussed and challenged by minority groups most of the time or deliberated about in terms of widening the concept of citizenship or viewing the concept based on moving from national to transnational. However, there was a study on Korean citizenship by Seok et al. (2005), which illustrated generational disparity in understanding citizens' rights.

Surprisingly, and perhaps worryingly, social rights were considered less important by the young than the old in Korea. Seok et al. (2005) showed that citizens' awareness of social rights and political rights amongst those in their 20s and 30s was lower than among those aged 40 and over. However, awareness of civil rights amongst those in their 20s and 30s was higher than among older age groups. People in their 20s and early 30s who were too young to have been involved in the June Struggle of 1987 might be less conscious of political rights than the older age groups who were involved. Limited awareness of social rights among the young people who will lead society in the future could lead to a deepening marginalisation of minorities in Korea where social rights are currently less developed than civil rights and political rights. Seok et al. (2005) also highlighted a similar situation with regards to citizens' egalitarianism. Specifically, they found a weak sense of egalitarianism amongst those in their 20s and 30s compared to those in their 40s. Another finding from this study was that those in their 20s and 30s had a weaker sense of nationalism than other age groups, although nationalism was still generally strong across Korean society as a whole. Nationalism has hindered Korea in its development towards a modern civil society (Chang, 2012b). Encouragingly, Seok et al. (2005) also revealed that acceptance of the freedom of others and openness to others was higher among those in their 20s and 30s than those aged 40 and over. Interviews in the current study also found that people in their 20s and 30s generally did not observe disabled people from a standpoint of egalitarianism, but were still more open minded regarding disabled people than older people when it came to building relationships with them (this is discussed in the 'Citizenship' chapter).

2.2.6 The Current Concept of Citizenship in Korea

Armstrong (2002, p.1) argued that 'few places in the world can match South Korea for the speed and depth of political and social changes in recent decades'. Despite these dramatic changes, Confucianism and nationalism, which have hindered the acceptance of differences, still prevail within Korean society. As a consequence, people who are different from the majority, such as different ethnic groups and disabled people, are routinely marginalised and discriminated against in the discourse of citizenship (Yoo, 2004; Jang, 2005; Kim, 2006; Kim, 2011; Kim, 2013). The nation's economic development is still considered paramount by some citizens (Chang, 2012a), whilst Koreans have a tendency to believe that money is a means to helping them gain power, freedom and respect in society (Chang, 2002). Woo (2006) found that Koreans understood money as having four different kinds of value: 'Ability — power', 'investment technique — success of children', 'spending power — self-display' and 'life plan'. Ahn et al. (2012) maintained that studies about the effect of money or individual financial status on people's thoughts and behaviours are surprisingly very rare in Korea, despite social interest in money being paramount. Nevertheless, from the above studies and critique on social issues, it is not difficult to imagine how members of society who are less likely to contribute to the industrial sector are often neglected and excluded from Korean society (Yoo, 2004; Jang, 2005; Kim, 2013). Policies and laws in the pursuit of social rights which could secure and support the lives of minorities are not enacted to a sufficient level in Korea (Jang, 2005). Younger generations are less aware of social rights than older generations and also care less about egalitarianism, which does not bode well for those who are already marginalised (Seok et al., 2005). The social environment and circumstances described above often result in minority groups, including disabled people, being deprived of the opportunity to enjoy full citizenship.

However, Jang (2005) argued that the concept of citizenship in Korea has been challenged by various minority groups. As discussed above, *Danil Minjock* (sole ethnicity) was removed from social textbooks after February 2007. One of the reasons for the elimination of *Danil Minjock* from social studies textbooks was the increasing number of different ethnic groups in Korean society as a result of marriages to foreigners and immigrant workers. *Danil Minjock* was no longer a reality in Korea. The crayons which were of a similar colour to a Korean's skin were known as 'colour of skin' until 2001 when this was changed to colour of apricot (Colour of Skin, 2018). This amendment was made upon the recommendation of the National Human Rights Commission of Republic of Korea in response to an appeal by foreigners. It seems that Korea began to expand the concept of citizenship to include minority groups in Korea.

2.3 Disabled People within Korean Society

Jung (2002) pointed out the significance of the influence of Confucianism, the nation's prioritisation of the economy and the importance of military power on Korean culture in understanding disabled people and their lives in Korea. This section discusses how disabled people are perceived within Korean society and how the environment for disabled people has changed and improved in Korea. The changes and improvements are mostly delineated by reviewing the disability movement which has led to some accomplishments including enacting the Anti-Discrimination Act for disabled people in establishing their identities and acquiring their rights (Jang, 2005). The interviewees for this study are disability activists who have been involved within the disability movement in various ways. Understanding the history and background of these movements can help to understand the participants' narratives and explanations more comprehensively. This section also outlines the participation of Korean representatives in the process of the UNCRPD and the Korean government's follow up on the UNCRPD after its enforcement and concludes with a discussion on the need to conceptualise citizenship for disabled people.

2.3.1 Perception of Disabled People in Korea

At the end of 2018, the number of registered disabled people in Korea was 2,585,876, which was 5% of the total population (Ministry of Health and Welfare, 2019a). Of these, 57.9% and 42.1% were men and women respectively. Additionally, 46% of disabled people were over 65 years old. The number of registered disabled people in 2018 was 5% of the population, which was the highest ratio since the recording of such figures began. It was also much higher than 3% in 2003 (Wellbeing Today, 2019). This could be as a result of an improvement in the perception of disabled people within Korean society, along with the improvement in welfare benefit (ibid.). Nevertheless, a survey carried out in 2014 reported that 47.1% of disabled people in Korea had experienced discrimination during their school years and 35.8% of disabled people reported experiences of discrimination in the process of finding a job (Kim et al., 2014).

The wording within disability laws in Korea such as the 'Welfare of Persons with Disabilities Act' (hereafter referred to as the Welfare Act), the 'Special Education for Disabled Persons Act' (hereafter referred to as the Special Education Act) and the 'Employment Promotion and Vocational Rehabilitation for Disabled Persons Act' (hereafter referred to as the Employment Act) still view disabled people as individuals who need to be cared for instead of people who have autonomy and rights. For instance, the Special Education Act does not guarantee that disabled people can choose their own method for receiving special education (Yoo, 2011). Instead, the methods for their education are decided by the government (ibid.). In addition, the Employment Act recognises or positions disabled people as people who need care and need to be rehabilitated (Park, 2014). These basic laws for disabled people fail to recognise or identify disabled people as citizens with equal rights and as being entitled to citizenship. This explains why a survey found that policies and laws are a second major cause of discrimination against disabled people in Korea (RIDRIK, 2003). The reason for this misunderstanding about disabled people in these policies must also result from the prevailing prejudicial attitude towards disabled people, which was the primary cause or reason for discrimination against disabled people in the same survey (ibid.).

Jung (2002) asserted that prejudice and misunderstanding embedded in the Korean traditional way of understanding disabled people must have compounded the strong sense of discrimination towards disabled people in Korea. In Korean culture the existence of disabled people among family members is often related to the idea of dishonour of the family (Choi, 1997). Therefore, having a disabled family member is often considered as bringing shame on the family. This could be related to the idea of karma, which is a result of bad behaviour in a previous life according to Buddhists (Kim, 1994; Choi, 1997; Yun, 1998). Buddhism, which was the main religion in Korea’s penultimate dynasty, believed in reincarnation. Reincarnation suggests that the current life is a result of how you lived in the previous life. Indeed, disability is a result of bad behaviour in the previous life, which is karma (ibid.). Traditionally, karma from Buddhism was a way of understanding people with a congenital impairment in Korea, while sympathy was a typical aspect in understanding people who acquired disabilities as a result of disease (Jung, 2002). On the other hand, in Confucianism, which is one of the main ideologies in Korean culture, disability is a fate which the person should accept as it is. Disability is an imprecation from heaven, but it is not a result of a person’s bad behaviour (Kum, 1996). However, Confucianism understands that a person’s body is ‘herself/himself’, which cannot be separated from the mind, so the person’s inside virtue can be found in the expression of the person’s body and face (Lee, 1999). In addition, Confucianism espouses unity (Moon, 2010). Consequently, the differences in disabled people's bodies and faces caused by their impairments are rarely accepted in a positive manner.

A healthy body, which is the basis of national prosperity and military power, has been emphasised in contemporary Korean society. Military service has become compulsory for men in Korea. Men who do not meet certain conditions are excluded from fulfilling the duty; of course, disabled men are excluded. Disabled people who are exempted from fulfilling the duties of military service are often viewed as unnecessary people (Hong, 1997) and, eventually, become less valued as citizens (Jung, 2002). Economic development is still prioritised by many citizens in Korea (Chang, 2012a). Some groups of people are often excluded from Korean society due to neoliberalism (Kim, 2013). The employment rate of disabled people in Korea was only 36.6% for the second quarter of 2014 (Kim et al., 2014), although it has been argued that economic activity plays an important role in social inclusion for disabled people (Kim, 1998; Kim, 2005; Paik, 2005). Choi and Son (2010, p.88) contended that disabled people can acquire the necessary resources, contribute to society as independent people, experience self-worth and be valued as human beings through economic activities such as having a job. This explains the high level of social inclusion amongst disabled people who have a job and contribute to economic activity (Won, 1994; Choi, 2003; Hong, 2004; Yoo et al., 2008).

Not only the low employment rate but also poverty causes difficulties for disabled people living within Korean society. The average salary of disabled people was only 46% of the average salary in Korea for the second quarter of 2014 (Kim et al., 2014). The poverty rate amongst disabled people's households[3] was 38.9% in 2012, reported by Statistics Korea in 2013 (Kim, 2015). This was more than double the poverty rate for all households in Korea. Park (2010) maintained that the number of working poor, who work but still remain in poverty, increased in the 2000s among a range of groups typically recognised as being

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[3] Households which had at least one registered disabled person.

vulnerable within Korean society, such as elderly people, disabled people and women within Korean society. The rate of people in relative poverty, which represents people who live with less than half of the median income, is increasing, while the rate of absolute poverty is decreasing within Korean society (Choi, 2016). This indicates that the rate of people who are out of absolute poverty but remain in the lower classes of society is increasing and that they are vulnerable to relative deprivation and social alienation as a result (ibid.). Jang (2005, p.102) claimed that the poverty agenda, which used to be considered within the economic aspect, is becoming a social problem which needs to be considered from various social aspects, such as social exclusion and cultural and psychological alienation of people in poverty. All of these factors make it easy to see how disabled people can be marginalised within and excluded from Korean society.

2.3.2 Disability Movement

Until 1988, there was very little systematic movement or development in the field of disability (Yoo, 2005a). A number of protests and individual lawsuits and legal battles took place, but most of these protests involved individual actions or individuals cooperating as a consequence of social barriers and were not systematic and sufficient enough to move the government to take any action for disabled people. As a consequence, the period before 1988 is referred to as the 'Period of Absence of Disability Movement' (ibid.). If the core value of the movement before 1988 was care, the value in the period subsequent to 1988 until the mid-1990s was rights (Kim, 2005). The main leaders during the period between 1988 and the mid-1990s were people with less severe disabilities, whilst the main proponents of the movement prior to 1988 were parents of disabled people and disability professionals (Yoo, 2005a). The disability movement which emerged in 1988 was influenced by the national June Struggle in 1987 and shared the keynote with a social movement which was held nationwide in Korea in the 1980s (Yoo, 2005a; Park, 2008).

In 1988, the Paralympics were held in Seoul, the capital of Korea. However, at that time, the budget for the Paralympics was estimated to be up to six times higher than the annual welfare budget for disabled people in Korea. This issue became a catalyst which moved disabled people to ensure their voices were heard regarding the lack of welfare policies and the lack of a system for disabled people within the nation (Kim, 2005). Disabled groups and individuals began to publicise the seriousness of their circumstances and poverty and held a rally in Seoul (Yoo, 2005a). Disabled people also protested about the absence of reason and logic in holding the Paralympics when government spending on disability amounted to such a small proportion of the Paralympic budget. In 1988, the ‘Korea Differently Abled Union’ was founded and became systemised (ibid.). Disabled people started to demand real changes, such as revising existing laws and enacting the Employment Act (Kim, 2005). This led the government to revise the Welfare Act and enact the Employment Act in late 1989. The revised Welfare Act and the Employment Act began to be enforced, resulting in a number of common practical problems for less severely disabled people being solved. People with less severe disabilities who were the main leaders in this period saw some improvement in their lives. The disability movement led disabled people to enter public space in education and labour to a certain extent. During the period the disability movement also became more organised and systematic, being represented by a number of different organisations (Yoo, 2005a). Disability organisations became more settled and established and public figures came to be more involved in the area of disability during the period. However, there was no real change in understanding disabled people as objects or recipients of a social welfare system (Park, 2008). Disabled people were still positioned as marginalised citizens who needed to be fixed to enter non-disabled society. In addition, these changes were relatively meaningless to people with severe disabilities who could not handle their personal affairs by themselves (Kim, 2005). They became even more marginalised (ibid.).

After the mid-1990s, people with severe disabilities became the main activists and participants in the disability movement. Since the late 1990s, human rights, autonomy and self-determination have become the core values of the disability movement (Yoo, 2005a). The struggle of people with severe disabilities for ‘rights to mobility’, which started in 2001, adopted a decidedly different position from the movement within the 1980s and the mid-1990s (Park, 2008). They not only insisted on their rights, but also attempted to criticise the overall infrastructure and systems which had been built expressly for ‘normal’ people. They started to envisage the disability movement as a project which condemned the pre-existing ‘normalised’ society instead of taking action to challenge the discrimination towards, and exclusion of, disabled people (Yoo, 2005a). They questioned ‘normal’ people and identified disabled people as people who were able to enter society. The social status of disabled people before this struggle had been that of incompetent members of society who, for instance, could not be taken into police custody. However, during their struggle for ‘rights to mobility’, a number of disabled people were taken into police custody (Kim et al., 2004). Disabled people, who had previously been outside the boundaries of the law, pushed themselves within these boundaries. Paradoxically, this disability movement proved that disabled people were citizens who had general rights and entitlements, such as being allowed to be taken into custody within a jurisdiction, and not merely special rights such as income security. After their struggle for ‘rights to mobility’, lifts were installed at most underground stations and a number of these stations were also rebuilt in a way that allowed greater access for disabled people and low-floor buses began to run.

2.3.3 Anti-Discrimination Act for Disabled People

The ‘Prohibition of Discrimination against Persons with Disabilities, Remedy against Infringement of their Rights Act’ (hereafter referred to as the Anti-Discrimination Act), which was enacted in 2007, was one result of the movement after the mid-1990s (Yoo, 2011). Disabled groups became engaged in thinking about the discrimination towards disabled people that was embedded within Korean society after a disabled candidate had been excluded from promotion to the position of director of a public health clinic in 2000 in Jecheon in Korea, although the disabled person was the only person who satisfactorily met all the requirements for the position (Donga-A, 2002; PSPD, 2002). Disabled groups and individuals began to speak up regarding their rights as citizens (Cho & Park, 2007). A member (with cerebral palsy) of a disability group called 'Open Network' voiced their view on citizenship and articulated the need for an Anti-Discrimination Act for disabled people (ibid.). The significance of this Anti-Discrimination Act was that disabled individuals and groups initiated the Act for their own needs and took the lead role in the legal development process from its initial inception until the Act was finally passed in the Korean Parliament (Lee, 2007b; Nam, 2007; Kim & Fox, 2011; Yoo, 2011). This was in stark contrast to all previous disability policies and Acts, which had been developed by the government. The Anti-Discrimination Act was intended to reflect the voices of disabled people more than any other previous laws and policies for disabled people (Yoo, 2011). This was possible as disabled people took the lead role throughout the entire policymaking process of developing the Act. The Act articulates what it is that disabled people want from society and how they want to be perceived within society (Nam, 2007) and the purpose of the Act articulates the need for the inclusion of disabled people in mainstream society as citizens (Yoo, 2011).

In the process of developing the Anti-Discrimination Act in Korea, disabled people battled with the government on several different issues. One of the conflicts with the government saw a fundamental issue in disability in terms of the perception and inclusion of disabled people (Nam, 2007). In Korea, disabled people have often been perceived and understood as individuals with medical problems. Indeed, most disability issues have traditionally been dealt with under the umbrella of the Ministry of Health and Welfare (Yoo, 2011). However, disability organisations agreed that the Anti-Discrimination Act should be a human rights policy instead of a welfare policy (ibid.). Therefore, disability organisations wanted the Anti-Discrimination Act to be proposed by members of congress of the Law Commission, not members of the Ministry of Health and Welfare. Disabled people also warned the government that the Ministry of Health and Welfare should not be an agency for modification for the Anti-Discrimination Act; they thought the National Human Rights

Commission would be more appropriate. Disability groups asserted that there was a high possibility that a perception or view of disability as a medical problem would become embedded in the Act if the Ministry worked as an agency for modification for the Anti-Discrimination Act (ibid.). From the draft of the Anti-Discrimination Act which was developed by the Ministry but never enacted, it was very clear how the Ministry viewed disabled individuals (ibid.). In the draft, the Ministry defined disabled people as those who have some form of deficit or deficiency. Furthermore, the purpose of the Act was to protect disabled people from discrimination. This is another pervasive view of disability which does not view disabled people as citizens with full citizenship and autonomy. Nevertheless, the entire process of developing the Anti-Discrimination Act and the purpose of the Act was to include disabled people within society and make them citizens with voices to speak up for their rights (Nam, 2007; Yoo, 2011). Yoo (2011) claimed that the Act also shifted the disability paradigm in Korea from the 'medical/individual model', which perceives disabled people as individuals with impairment who need medical treatment, to the 'social model', which understands and views social barriers as the main cause of disability.

2.3.4 The UNCRPD in Korea

2.3.4.1 Korean Delegation and Enactment in Korea

When disabled individuals and disability organisations were struggling to make progress in forming the Anti-Discrimination Act within Korea, internationally, disability organisations were also preparing to form the UNCRPD. The Ministry of Health and Welfare, which was in charge of issues and affairs related to disabled people in Korea, however, was not aware that the discussion on the formation of the UNCRPD was underway internationally (Seo, 2013). Rather, Korean disabled people and disability NGOs who participated in the sixth DPI (Disabled People's International) conference held in October 2002 learned that discussion regarding the UNCRPD was in progress and the first Ad Hoc Committee had already been held in August 2002. Some Korean disability NGOs realised the importance of the global movement. In conjunction with government representatives, they participated in the conference and seminars for the International Treaty for Disabled People’s Rights and Dignity organised by UNESCAP (The United Nations Economic and Social Commission for Asia and the Pacific) held in July 2003 and the second Ad Hoc Committee for the UNCRPD in New York in July 2003. However, those who participated in the meetings realised it was difficult to even catch up on the issues raised in the conferences and meetings (ibid.). They decided to appoint a delegate with knowledge of the issues as one of the government representatives (SegyeIlbo, 2004). Lee Iksop, who was a disabled professor with visual impairment and who also worked for a disabled people’s NGO at that time, joined the team preparing the UNCRPD as a government representative.

After they set up a team for the UNCRPD, the team saw some progression in understanding the international movements and planning strategies (National Human Rights Commission of Korea, 2005). Korean disability NGOs began to actively look to include Korean disabled people’s views and needs in the UNCPRD. In some UN meetings, Korea was the country with the greatest number of NGO members participating in the meetings (Seo, 2013). However, nationally, the number of NGOs and organisations which participated in the solidarity for the UNCRPD was relatively much smaller than the number of groups which worked for the Anti-Discrimination Act, which was in progress within Korea at the same time (ibid.). Many disabled people and NGOs doubted the effect of an international law within Korea and decided to focus more on making the national Anti-Discrimination Act, which would have a direct effect on their lives.

The UNCRPD and its Optional Protocol were adopted on 13th December 2006 at the UN headquarters in New York. In Korea, the UNCRPD was approved by the National Assembly on 2nd December 2008 and was ratified on 11th December in the same year (Jung, 2010; Seo, 2013; Jung, 2016). The UNCRPD came into effect as treaty No. 1928 on 10th January 2009 in Korea, but the Optional Protocol to the UNCRPD was not ratified. ‘The Support Department for Disabled People’s Rights’ under the Ministry of Health and Welfare was assigned as the focal point for the UNCRPD in Korea. The Korean government submitted the first report to the UNCRPD committee in June 2011, as the countries which ratified the UNCRPD needed to submit the first report within two years of the ratification (Ablenews, 2012). The UN committee approved the concluding observation for the first Korean report on 30th September 2014 at the 165th meeting. The concluding observation included 66 clauses (UN Human Rights, 2014). The next report should have been submitted four years after the first submission, which was 2015. However, the UNCRPD committee decided that its combined second and third periodic reports would be appropriate instead of individual second and third reports due to the delay in judging the first report (Jung, 2019). On 8th March 2019, its combined second and third periodic reports were submitted to the UNCRPD committee. The report is expected to be discussed by the UNCRPD committee in 2020.

2.3.4.2 Concluding Observation and Follow Up

The concluding observation on the first report pointed out that the medical model was embedded in the Welfare Act and expressed concerns about the disability rating system and the determination of new disability defined under the Act (UN Human Rights, 2014). The committee described how the disability rating system in Korea relied only on medical assessment in providing services, without full consideration of the various needs of disabled people. They were also concerned that the rating system failed to encompass all disabled people, including those with psychosocial disabilities. They also commented that welfare services and personal assistance were limited based on the ratings, as a result.

A phase out of the disability rating system began in July 2019 in Korea (Ablenews, 2019a; Joonbu Mail, 2019). The disability rating system was originally introduced in 1988 and disabilities were rated from grade one to grade six based on medical assessments. Disabled people with the most severe disabilities were in grade one and less severe disabilities were in grade six. From July 2019, the six grades were reorganised into two levels which refer to disabled people with severe disabilities and disabled people with less severe disabilities. Based on a total assessment, instead of a medical test, each disabled individual would receive services dependent on that individual's needs. The Ministry of Health and Welfare announced that it would configure a system which would provide adequate services for service users, not for the convenience of service providers (Ministry of Health and Welfare, 2019b). The phase out of the disability rating system was reported in the combined report submitted in March 2019 as an achievement among the three main achievements, including an overall revision of policies and laws for the promotion of mental health and social welfare for people with mental disabilities, which came into effect in May 2017, and the enactment of the mandatory policy on Barrier Free (BF) certification for newly built public buildings, which came into effect in January 2015 (Jung, 2019).

However, it is difficult to argue that the phase out of the disability rating system is a result of the UNCRPD recommendation. Abolishing the rating system was one of the primary issues which the field of disability had claimed for a long time. Organisations of disabled people had been protesting about the issue for a long time and had begun to object more actively since 2010 (Ablenews, 2019b). The issue became an election pledge by the previous president elected in 2012 and was appointed as part of the national political agenda in 2013. Work on the phase out of the disability rating system continued under the new president's regime elected in 2017. Finally, the new policy came into effect in July 2019.

2.3.4.3 Current Status

In a conference held after the submission of the combined report to the UN in 2019, a lawyer, Ms Lee, contended that none of the cases related to the administration works and lawsuits for disabled people in Korea mentioned or used the UNCRPD as a basis for their strategies or decisions, although the UNCRPD possesses the same effect as that of domestic legislation and acts, and claimed that people in Korea do not even recognise the existence of the UNCRPD (Ablenews, 2019c). This is in contrast to the Anti-Discrimination Act, which was often used in lawsuits as a basis for decisions. In the first observation conclusion, the UN committee encouraged the Korean state to ratify the Optional Protocol to the Convention (UN Human Rights, 2014). In the combined report the Ministry of Health and Welfare responded that it would do its best to ratify the Optional Protocol (The Ministry of Health and Welfare, 2019c). A representative of the Ministry of Health and Welfare in the conference said that discussions between the Ministry of Justice and the Ministry of Health and Welfare were in progress to prepare to ratify the Optional Protocol (Ablenews, 2019c). Ratifying the Optional Protocol seems to be a practical and effective way for the UNCRPD to be more broadly utilised and applied in Korea.

2.3.5 Need for the Concept of Citizenship for Disabled People in Korea

As described above, it is not difficult to assume that disabled people are rarely perceived as equal citizens and hardly have any opportunities to enjoy a sense of full citizenship within Korean society. However, there have been some positive changes in the field of disability. Disabled people in Korea now enjoy more rights than they did decades ago. Disabled people began to take a position which enabled them to criticise the social infrastructure and systems built without consideration for disabled people (Park, 2008). The Anti-Discrimination Act raised awareness of discrimination against disabled people in Korea and indicated discrimination as the main obstacle to disabled people being included within society (Kim, 2014). The Ministry of Health and Welfare, which is in charge of affairs and issues related to disabled people, has recently shown some attitude changes in understanding disabled people and disability. They proclaimed that they would set up a system which would provide adequate services for service users, not for the convenience of service providers, when they began the phase out of the disability rating system (Ministry of Health and Welfare, 2019b). The announcement could be a confession that they used to manage a system which was convenient for the service provider. They have increased their interest in matters regarding disability and are now trying to catch up with the international disability movement, as they try to ratify the Optional Protocol of the UNCRPD (Ablenews, 2019c). They have created a department named ‘The Support Department for Disabled People’s Rights’ in the Ministry, which is also a focal point for the UNCRPD. This department works for disabled people’s rights. Forming the department shows a change in the Ministry’s perception of disabled people. The Ministry often understood disabled people as people with medical problems and as objects of welfare. Now the Ministry at least tries to perceive disabled people as people who have rights to claim.

Recently, Korean scholars have begun to claim that disabled people's assertion of their rights needs to be considered as claims of citizens' entitlement and disabled people need to be included within society as citizens (Kim, 2008; Yoo, 2011; Cheong, 2014; Kim, 2014; Shin et al., 2013; Shin et al., 2016; Shin et al., 2018). Shin et al. (2013) stated that growing interest in the social inclusion of disabled people suggests the need for a new concept for disabled people who acquire equal rights and resources. They affirmed that the new concept would be the concept of citizenship and this perspective understanding disabled people as citizens would be a useful tool to encourage disability policies which would enhance the QOL of disabled people (ibid.). Furthermore, as discussed in the section on 'The Concept of Citizenship in Korea', the concept of citizenship has been challenged by minority groups (Jang, 2005) and it seems that this concept is expanding to include different minority groups in Korea. In order for the concept of citizenship for disabled people to be reflected and included in the concept of citizenship in Korea, conceptualising citizenship for disabled people seems to be the very first and indispensable next-step which has to be accomplished.

In addition, disabled people have struggled to establish citizenship by claiming their rights and proving their position as equal citizens in society for the betterment of their lives. This implies that exclusion from citizenship for disabled people has an impact on their lives and QOL. Understanding how the opportunities for or barriers to citizenship are related to their QOL can also provide opportunities to elucidate on how the concept of citizenship can be applied in disabled people's everyday lives. Ultimately, finding these relationships could result in the concept of citizenship being a useful tool in enhancing the QOL of disabled people.

2.4 Korean Literature on Disabled People's QOL and Citizenship

This study was embarked upon from an assumption: disabled people are not routinely perceived as equal citizens and do not always live as equal citizens and a 'limited citizenship' may have an adverse effect upon their QOL. It would be ideal to review Korean literature on disabled people's QOL and citizenship to examine how previous research has been conducted and what the findings were to compare with the discoveries from this study. However, it is difficult to find empirical studies in Korean literature which cover disabled people's citizenship and, furthermore, studies which investigate disabled people's QOL in relation to their citizenship, because—as has been discussed—the concept of citizenship for disabled people has not been firmly established, or even discussed, in many cases.

Consequently, this section reviews Korean literature on disabled people's QOL and social inclusion, which is often the closest concept to the concept of citizenship for disabled people. Utilising the concept of social inclusion instead of the concept of citizenship may also impart that disabled people are often considered as objects that need to be included within society, rather than subjects that live as equal citizens. This section first looks at how Korean scholars and researchers in the disability field understand and define social inclusion and Korean empirical studies on disabled people's QOL and social inclusion follow. The terms 'social participation' and 'social integration' are also used interchangeably with 'social inclusion' and are commonly used in Korean literature.

2.4.1 Definitions of Social Inclusion

Social participation is often defined as existing in a community and participating in social activities (Woo, 2006; Shin & Kwak, 2008; Shin & Kim, 2011; Lee & Park, 2012). Shin and Lee (2013) argued that the meaning of social participation is sometimes limited within personal and social relationships in casual meetings and social activities in organisations. Meanwhile, health, level of impairment and disability are often considered important domains which are deeply interrelated with social participation for disabled people (Kim et al., 2010). However, some scholars understand social participation from a broader perspective and claim that this term needs to include active participation in policy decision making to assert their rights through involvement in activities in various areas within their communities, such as living socially and culturally as the equals of non-disabled people (Yoo, 2005b; Lee & Park, 2012; Kong & Kang, 2013). Meanwhile, some scholars also extend the meaning of social participation to include the following: official and unofficial activities increasing their sense of belonging and self-development; employment; voluntary service activity; religious activity; and partaking in hobbies (Choi, 2013). In addition, social participation is also understood as a real-life necessity for disabled people to live as members of a society and this is related to the concept of social integration (Park, 2012).

2.4.2 Limitation of the Meaning of Social Inclusion

As described above, some Korean scholars in the disability field understand and interpret the concept of social participation/social inclusion from a wide perspective, which embraces different aspects of social context, but the concept is still routinely defined as entailing existence in a community and participation in social activities. The meaning of social inclusion is often limited in many Korean empirical studies on disabled people’s QOL too. Some dispute has arisen here as to why social participation (social inclusion) does not often seem to be interpreted as a broad and comprehensive concept in Korean empirical studies. I think there are at least two identifiable reasons for this being the case.

First, disabled people are not often perceived as members of a society who have a full sense of citizenship and/or as autonomous subjects who can live independently, even though the studies concern the social inclusion and social participation of disabled people. In many studies on disabled people’s QOL, ‘social support’ is presented as a factor which can have an influence on disabled people’s QOL. Factors which are assumed to be important for QOL are predetermined by the researchers in most of the Korean studies on disabled people’s QOL, as most of them are conducted using quantitative methods such as questionnaires. It is important here to understand what ‘social support’ means in the studies. Ten statements, or similar sets of statements, have repeatedly been used in these studies on the QOL of disabled people in Korea to ascertain how much ‘social support’ disabled people receive and how social support influences their QOL (Lee, 2007a).

The statements are as follows: 1. My family genuinely try to help me; 2. I receive the emotional support and help that I need from my family; 3. I can talk to my family about my problems; 4. My family help me in the decision-making process; 5. I have special people, such as friends and/or acquaintances, around me who can help me in emergencies; 6. I have special people, such as friends and/or acquaintances, who make me feel comfortable; 7. My friends or acquaintances genuinely try to help me; 8. I can rely on friends or acquaintances when I am having a difficult time; 9. I have friends or acquaintances with whom I can share my happiness and sadness; and 10. I can talk about my problems with friends and acquaintances. Including these questions in the studies on disabled people’s QOL rather implies that disabled people are excluded from social networks and can have difficulties in forming relationships with other members of society, including family members, in Korea. Shin and Kim (2011) argued that, in Korea, non-disabled people who have disabled family members discriminate against disabled people more than those who do not have disabled family members. This might result in emphasising and affirming the importance of social support in terms of disabled people’s QOL.

It seems that the set of statements for ‘social support’ could equally be bracketed under other terms such as ‘social relationships’ or ‘social network’ or ‘sense of belonging’. This might indicate that the researchers often perceive disabled people as people who need social support instead of people who can have social relationships and a social network. This leads us to the second reason for social inclusion in Korean literature often being kept within certain bounds, as disabled people do not receive the opportunity to talk explicitly about their thoughts in the research, what social inclusion means to them and how social inclusion is important in relation to their QOL.

2.4.3 Studies on Disabled People's QOL and Citizenship (Social Inclusion)

As discussed above, studies on disabled people's QOL which have included the concept of social inclusion instead of citizenship are reviewed in the following section and social participation and social integration are used interchangeably when reviewing social inclusion in Korean literature. The amount of research on the social participation or social inclusion of disabled people conducted in Korea has also been limited so far (Kim, 2007a). Moreover, research on the relationship between either the social participation or social inclusion of disabled people and their QOL has been particularly rare (ibid.).

Amongst the studies on disabled people's social participation/social inclusion and QOL, social participation is sometimes described as a range of activities, such as shopping, productive activities, economic activity, religious activity, educational activity and community activity (Paik, 2003; Ryu, 2004). Some studies have tried to broaden the meaning of social participation, such as 'interpersonal relationships', 'socio-economic activity', 'family life', 'communication', 'mobility', 'civil life' and 'overall health condition' (Kim et al., 2016). However, some studies have not illustrated what social participation/social inclusion means in their studies (please refer to Roh & Hwang, 2010).

Many studies which investigated the effect of social participation/social inclusion on disabled people's QOL found a positive relationship between disabled people's social participation/social inclusion and their QOL (Paik, 2003; Ryu, 2004; Roh & Hwang, 2010; Lee, 2014b; Kim et al., 2016). However, Lee's (2014b) study, which analysed a longitudinal study in Korea, including 3,206 disabled people who responded annually to questions about their lives between 2009 and 2012, found no relationship between social participation and changing QOL over the years, whilst the QOL of disabled people who maintained good relationships with people decreased slowly over the years.

Roh and Hwang (2010) conducted a study on the QOL of adults with intellectual disabilities, focusing on choices and community involvement, as they claimed that studies on the QOL of people with intellectual disabilities in terms of social inclusion were very rare. The analysis of this study was based on 247 returned questionnaire surveys. However, most of the questionnaires distributed to disabled people in their 20s and 30s were completed by their parents, whilst people with intellectual disabilities in their 40s or older completed the questionnaires themselves. This suggests that it is still difficult to hear the opinions of people with intellectual disabilities directly from them in Korea. This study also proved that their participation and choices had positive relationships with their QOL in the study. However, this study did not clearly define the meaning of social participation.

Additionally, social support was often included and found to be a strong factor affecting disabled people's QOL in some of the studies (Paik, 2003; Kim et al., 2016), while factors related to finances, such as 'having a job', the 'kind of job' and 'salary' had the most significant impact on the QOL of disabled women in Ryu's study (2004). The study of Kim et al. (2016) found that there was a weak relationship between 'physical and psychological condition' and 'interpersonal relationships'. This could imply that disabled people's satisfaction with their 'physical and psychological condition', which could relate to their disabilities, might not have much of an effect on their relationships with people.

The abovementioned studies might not be exhaustive. However, they do provide an indication of how studies are generally conducted and how disabled people's social participation or social inclusion are often interpreted and defined in Korean literature. Studies on the QOL of disabled people and social participation have often found a positive relationship between disabled people's social participation (and/or social inclusion) and their QOL. Researchers have tried to understand social participation and social inclusion from diverse perspectives in various areas. However, it seems that studies which perceive disabled people as citizens who possess all rights and freedoms within society are rare. As a result, the definition and meaning of social inclusion (or social participation and social integration) seems to be restricted in Korean empirical literature.

2.5 Korean Literature on the QOL of Disabled People

This study is about not only citizenship, but also disabled people’s QOL. It is important to look at Korean literature on the overall QOL of disabled people in Korea to investigate the areas which have been found to be important in relation to disabled people’s QOL. The next sections review some of the studies on the overall QOL of disabled people in Korea. However, the number of studies on the QOL of disabled people in Korea is relatively small and the QOL of disabled people still does not receive much attention as a research subject (Park, 2000; Park, 2009b; Lee, 2014b). Lee (2014b) argued that the lack of studies on disabled people’s QOL could itself be a cause of disabled people’s low QOL in Korea. This could also explain why the studies on disabled people’s QOL, including social inclusion, are even more limited, not only when it comes to the meaning of social inclusion but also in the quantity of research. Even amongst the rare studies on the QOL of disabled people in Korea, the subjects and methods of study have been limited. Such studies have been mostly delivered through quantitative methods using questionnaires/surveys. Subjects related to the QOL of disabled people are, therefore, often constrained within written questionnaires.

2.5.1 Important Domains for Disabled People’s QOL

Domains/factors used or raised in the studies can be a means to understanding how disabled people are positioned and perceived in the studies and, furthermore, Korean society. This section presents domains/factors which are frequently raised as important for disabled people’s QOL in Korea.

‘Social support’ is one of the most frequently used factors in studies to have investigated relationships between various factors and QOL in Korea. Many of the studies found ‘social support’ to be important for disabled people’s QOL (Paik, 2003; Kim & Kim, 2005a; Kim, 2007a; Jung & Kim, 2009; Nam et al., 2011; Kim et al., 2016), whilst the study of Park et al. (2013), which analysed the data of 1,927 disabled people with severe disabilities from the fourth ‘panel data of disabled people’s employment’, illustrated no relationship between social support and life satisfaction for severely disabled people.

It was also found that social support had a positive effect on disabled people’s self-efficacy and QOL, and also high self-efficacy increased QOL (Nam et al., 2011). This may imply that strong social support could increase disabled people’s self-efficacy; this, ultimately, would improve disabled people’s QOL. Self-efficacy, along with self-evaluation, self-esteem and sense of self, which concern ‘self-respect’, are factors raised and found to be important in studies on disabled people’s QOL (Paik, 2003; Kim & Kim, 2005a; Lee, 2006; Lee, 2007a; Jung & Kim, 2009; Nam et al., 2011). A study on QOL consisting of 244 disabled women and 253 disabled men over 18 years old discovered that ‘recognition as an important person’ and ‘social support’ were more important variables for men, while ‘level of education’, ‘family income and having a job’ and ‘self-esteem’ were more important variables for women (Lee, 2007a).

Although not substantial enough to confirm gender differences, economic and financial problems have been included more often in studies on disabled women’s QOL (Ryu, 2004; Lee, 2006; Lee, 2007a), although factors related to economic and financial issues have still been found to be important in relation to disabled people’s QOL in general (Kim & Kim, 2005a; Jung & Kim, 2009; Kim et al., 2016). This should not lead to an interpretation that women are more concerned than men about their finances. Instead, this finding could help to explain how disabled women are in greater financial need than disabled men. Including economic matters in studies on disabled people’s QOL could show that these issues are actual problems in disabled people’s lives and may show researchers that they need to consider them as important issues for disabled people.

Disabled people have also often been asked whether their health status or physical condition has an influence on their QOL in Korean studies (Lee, 2007a; Jung & Kim, 2009; Kim et al., 2016). Jung and Kim (2009) found that health status was an important factor for their QOL. However, some studies have shown there is not a strong positive relationship between disabled people’s health status or disability issues and their QOL. Lee (2007a) found that disability rating did not have any influence on the QOL of disabled people and Kim et al. (2016) also found that physical condition had a very weak relationship with disabled people’s QOL.

Albrecht and Devlieger (1999) found a relationship between disabled people’s health and their QOL in a study conducted in the USA, but the participants in the study received an opportunity to explain how physical difficulties should not be considered the only thing determining their QOL. However, in Korean literature, the detail about the relationship between health status and physical condition with regards to QOL has not been articulated by disabled people.

‘Social support’ is raised as an important domain for disabled people’s QOL in many studies, while self-esteem and self-efficacy are also often found to be important. These findings may reflect that disabled people do not receive support, even from their families, and tend to have low self-esteem. All of these issues could be a result of the strong stigma, discrimination and social exclusion encountered by disabled people in Korea (Jung & Kim, 2009; Kim & Fox, 2011; Lee, 2014a). Many social and environmental problems faced by disabled people relate to discrimination and stigma and are also often found to negatively affect their QOL (Seo & Kim, 2004; Kim, 2007a; Park et al., 2013). It has been found that disabled people who accept their disability have better life satisfaction, but only when they have faced a relatively limited amount of discrimination (Park et al., 2013). This may imply that disabled people who have experienced a significant amount of discrimination are less likely to accept their disability identity positively, which can influence their life satisfaction.

As discussed, most of the studies have been conducted through questionnaires. As a result, the definition of the concepts utilised in the studies and factors affecting disabled people's QOL must have been selected by the researchers. This might have resulted in some limitations in the abovementioned studies in terms of discovering what disabled people really want in order to have a good QOL.

2.5.2 Different Views among Different Participation Groups

A Korean scholar, Park (2000), conducted a study which examined which components of disabled people's lives were important with regards to their QOL. In the study, three different groups were invited to be participants. The results of the study clearly described how different participant groups have different views on disabled people's QOL.

Park (2000) agreed that the concept of QOL is very complicated to measure mechanically with certain criteria and/or formulations. She, therefore, aimed to determine the most important components affecting disabled people's QOL and included different components from various areas of their lives in the study. Ultimately, she suggested 67 components as being important for disabled people's QOL. These components were divided into one of the following eight categories/areas: 'emotional stability and satisfaction', 'social life', 'economic well-being', 'personal performance and development', 'physical well-being', 'self-determination and choice', 'social inclusion' and 'guarantee of rights'. She claimed that the 67 components were categorised based on a conceptual framework using four 'complicated' steps instead of using the findings in previous empirical studies or following the patterns of previous relevant literature.

The participants were from three different groups: disabled people (141); parents of disabled people (206); and professionals, including special secondary school teachers, representatives of government agencies related to disabled people, professors in special education and rehabilitation, vocational rehabilitation staff for disabled people at welfare centres, special class teachers and social workers (344). The study was conducted nationwide. In the group of disabled people, only five had an intellectual disability. Park claimed that the study included parents of disabled people and professional groups in order to hear the voices of people with intellectual disabilities and developmental disabilities.

The participants answered how important each component was for the QOL of disabled people using a five-point Likert scale (1—not important; 5—very important). The results of the study identified that at least one component from each category out of the eight categories ('emotional stability and satisfaction', 'social life', 'economic well-being', 'personal performance and development', 'physical well-being', 'self-determination and choice', 'social inclusion' and 'guarantee of rights') was ranked in the top 25 by disabled people, while none of the components from the 'economic well-being', 'physical well-being' and 'self-determination and choice' categories were selected by the professional group and none of the components from the 'self-determination and choice' category were ranked by parents of disabled people in the top 25 (Park, 2000, p.97). The results gave an indication of how disabled people understand their QOL differently compared to parents and professionals. The results of the study also showed that ten components from 'personal performance and development' and seven components from 'guarantee of rights' were ranked in the top 25 components by the disabled people group. Disabled people's selection of 17 components out of the top 25 components from 'personal performance and development' and 'guarantee of rights' revealed how disabled people want to have the ability to live independently and exercise their rights in society.

In this particular study, five components deemed important for social inclusion or connecting to society, or skills needed for social inclusion, were ranked in the top ten components by disabled people. These components were as follows (the different rankings of the different groups are parenthesised): access to information and communication (Disabled People: 1; Professionals: 26; Parents: 41); communication skills (Disabled People: 4; Professionals: 19; Parents: 20); vocational skills for employment (Disabled People: 5; Professionals: 18; Parents: 39); socialisation with colleagues at work (Disabled People: 8; Professionals: 24; Parents: 31); and self-determination and problem-solving skills (Disabled People: 10; Professionals: 48; Parents: 51). Clearly, views on the importance of each component differed significantly from group to group. This implies that studies on disabled people's lives need to include disabled people's voices directly to avoid the misleading preconceptions of other people, including researchers themselves. The components cited as important by disabled people illustrate that disabled people are keen to be connected and involved within society as members of society, while professionals and parents seem unaware of the importance of social participation and social inclusion with regards to disabled people's QOL. The results emphasise how important it is for disabled people to live as independent people with abilities and to belong alongside others within society. The top ten components stated by disabled people are in the following table.

Table 1: Top 10 components stated by disabled people in the study (Park, 2000)

Component	**Ranking**		
	Disabled People	**Professionals**	**Parents**
Access to Information and Communication*	**1**	**26**	**41**
Mainstream Education & Transition	2	7	4
Secured Education Rights	3	5	1
Communication Skills	**4**	**19**	**20**
Vocational Skills for Employment	**5**	**18**	**39**
Physical and Mental Stability	6	6	7
Risk Management Skills**	7	21	35
Socialisation with Colleagues	**8**	**24**	**31**
Basic Education Skills	9	59	24
Self-determination and Problem-solving Skills	**10**	**48**	**51**

*Includes various print, Braille, TV, sign language on screen, video, radio, phone, Internet, computer

** Skill to make emergency calls, use public telephones, etc.

2.6 Studies on Disabled People's QOL in Various Countries

In this section, some studies on disabled people's QOL in countries other than Korea are investigated to identify what the studies have revealed and how the studies were approached by the researchers. This part demonstrates that various findings can be explored and that different and copious stories can be heard from participants when the meanings of terms are not restricted and when diverse research methods are utilised. For this section, English literature on disabled people's QOL or QOL and citizenship was researched. Literature on the QOL of disabled people from various approaches, but especially social approaches, was also considered. There was no restriction in terms of countries as long as the literature was written in English. The search focused on literature from the late 1990s until the time of the research.

2.6.1 Social Inclusion, Rights and Personal Relationships

Studies on the QOL of disabled people in other countries have also identified relationships between social domains and QOL. A study conducted in Ireland included people with intellectual disabilities as researchers, along with other non-disabled researchers and conducted 23 focus group interviews (16 in the Republic of Ireland and seven in Northern Ireland), comprising 168 people with intellectual disabilities. The aim of the study was to answer the questions of 'What was life like for adults with an intellectual disability in Ireland?' and 'How could life be better?' (Iriarte et al., 2014, p.566). As a result of the focus group interviews and a review and discussion of the results by co-researchers with intellectual disabilities, eight themes were identified as important for the betterment of their lives. The eight themes included: 'living options, employment, relationships, citizenship, leisure time, money management, self-advocacy and communication' (p.565). Four of these eight themes (relationships, citizenship, self-advocacy and communication) seem to be directly connected to the idea of living or co-existing with others as members of society. The research found that relationships were more related to private life, while citizenship, self-advocacy and communication were more related to public life; for example, in terms of inclusion and exclusion from society and speaking out for gain or to claim rights. The study also identified how communication was found to be related to advocacy for inclusion. Therefore, it could be implied that disabled people in the study took autonomy and rights in society very seriously for their QOL. Within the study, some disabled people identified employment as an important way of meeting people and friends. Accordingly, they considered employment as an opportunity to maintain social connections with others. From the study, it was also found that relationships with other members of society, having a voice and rights, and being included in society were important domains for a better QOL. Interestingly, a study by Haigh et al. (2013), which involved interviewing 20 people with intellectual disabilities from Sheffield in the UK, revealed similar results. The participants in this study named ‘relationships, choice and independence, valuable roles, somewhere to go and someone to go with’ as sources of improving their life happiness (Haigh et al., 2013, p.31). These results also revealed that disabled people can find fulfilment in their lives through engagement with others as members of society. This study also confirmed that autonomy, social relationships and rights were all very important areas for disabled people. Similarly, a study conducted in Porto Alegre in Brazil found that integration into society and social inclusion, along with work, education and leisure, were important themes relating to the QOL of disabled people (Mattevi et al., 2012). The study entailed five focus group interviews with 23 participants including four disabled people with mixed physical disabilities, five disabled people with intellectual disabilities, six disabled people with visual disabilities, four professionals and four disabled people’s relatives and caregivers. Moreover, this study found that friendship was claimed to be one of the most important aspects. It can be assumed that this stems from the idea that friendship helps to establish ‘social and moral standing’ for disabled people (Hughes et al., 2011, p.198).

2.6.2 Health Condition and Having Control

It is not only social relationships which dictate the QOL of disabled people, as their health conditions, fatigue and depression are all critical issues which directly affect their QOL. This is especially true for those who suffer from physical disabilities, such as multiple sclerosis (Labuz-Roszak et al., 2013). In a study by Labuz-Roszak et al. (2013), a group of 61 participants with multiple sclerosis in Zabrze in Poland reported a significantly lower QOL than a group of 30 healthy volunteers who also took part in the study. This infers that impairment itself can have an effect on disabled people's QOL. Albrecht and Devlieger (1999) conducted a study by interviewing 153 disabled people living in Chicago in the USA. The participants were living in a community, rather than institutions or clinics and health centres. The study reported a poor QOL of disabled people when they experienced both pain and fatigue. The study also provided evidence that disability and health conditions are also important domains in maintaining a high QOL. However, disabled people who reported a poor QOL also described how their poor QOL was as a result of their pain as well as losing control in their social lives and within their environment because of the pain and fatigue. This further illustrates that disabled people are concerned about their social involvement and inclusion within society and how such social involvement and engagement can improve their QOL. The interviews also demonstrated the 'disability paradox', where disabled people who have physical difficulties claim to have a high QOL, although their lives may look undesirable to others (ibid.). In the study, the respondents identified finding a balance of body, mind and spirit as a source of making their lives highly satisfactory. People who reported an excellent QOL also expressed how they had control over 'their bodies, minds and lives', although they may have disabilities and experience some physical and mental limitations.

2.6.3 A Circular Concept of Inclusion and High QOL

In spite of these similar findings, Mattevi et al. (2012) concluded in their study that disability itself and additional themes related to disability, such as the unique perception of disability, attitudes towards disability and cultural traits, were all concerns which need to be highlighted in any study on the QOL of disabled people. A study on the QOL of disabled people living in two villages, Parala and Bahirgharia, of Manirampur upazila (sub-district) in the Jessore district of Bangladesh collected data via various methods such as questionnaires including closed and open questions, formal focus group discussions and personal interviews with both disabled people and non-disabled people (Hosain et al., 2002). The study revealed how disabled women who lived in these areas experienced a lower QOL than disabled males in the same regions. Hosain et al. (2002) stated that this was partly because of the higher prevalence of negative attitudes towards disabled women than men. These negative attitudes towards disabled people led to them being excluded from society. As a consequence, more disabled women had dropped out of school than disabled men. The results suggested how social aspects, such as attitudes towards disabled people and cultural traits, can have an impact on QOL. This also explains why social inclusion is one of the most important and most frequently emerging themes for disabled people in terms of improving disabled people's QOL. As a result of these negative attitudes, disabled people are at risk of being excluded from society. Such exclusion has a negative effect on disabled people's QOL. A study with 818 participants with severe or multiple disabilities in Finland investigated 'which individual and social issues were associated with their participation' in political life (Puumalainen, 2011, p.274). The participants answered a questionnaire survey. In the study, it was found that 'self-rated QOL' was one of the strongest factors for their social participation, along with 'self-rated income, the ability to communicate, duration of their disablement, age and assistive devices for the person's participation in the community and political life'. This study found a connection between how disabled people with a higher QOL more effectively participated in community and political life as citizens. This suggests that inclusion in society and a high QOL might be something of a circular concept for disabled people in that, while disabled people want inclusion and relationships in society to obtain a higher QOL, it is those disabled people with a higher QOL who tend to participate in political life more as citizens within society.

2.6.4 Section Conclusion

The abovementioned studies in various countries provide evidence of how various findings can be revealed when different research methods are utilised and when disabled people are included as participants and are allowed to talk about their lives themselves. The studies have also been conducted with disabled people with different disabilities. In most of the studies, relationships have been identified or emphasised as an important area determining disabled people's QOL. This contrasts with the findings of many studies in Korea that 'social support' is a significant factor determining disabled people's QOL. This can be explained by looking at who articulates the issues and concerns affecting disabled people's QOL: researchers or disabled people themselves. As discussed above, a Korean study conducted by Park (2000) revealed clear differences in the selection of important components determining disabled people's QOL by different groups (disabled people, parents and professionals). It would seem natural and fair to ask disabled people directly to describe their QOL. This argument is supported by the study of Albrecht and Devlieger (1999), in which the participants in the study reported that a poor health condition led to them having a low QOL, but they explained that this was not solely because of their poor health condition, but also because of a subsequent loss of control over their social lives and environment caused by their poor health condition. Such findings have not emanated from Korean studies, since the relationships have not been heard from disabled people directly. Most Korean studies have found only whether there are relationships between health conditions and QOL, and whether the relationships are positive or negative. This lack of consideration for disabled people's voices represents a shortcoming of Korean studies on disabled people's QOL.

2.7 Research Questions

As the concept of citizenship for disabled people has not been well established in Korea and the meaning of being a citizen has not been informed by the perspectives of disabled people directly, this study seeks to find out how disabled people perceive the meaning of being citizens/concept of citizenship:

1. How do disabled activists in Korea speak about, experience and conceptualise what it means to be a citizen/citizenship?

It is evident that disabled people have not had opportunities to define QOL and talk about important areas for their QOL in previous studies on the QOL of disabled people. How disabled people themselves define QOL is the next question of this study. The definition of QOL would then reveal the important areas/domains for disabled people's QOL:

2. How do disabled activists in Korea speak about, experience and conceptualise quality of life?

The two questions above are expected to relate to the following question:

3. Do the two concepts of citizenship and quality of life speak to each other in everyday life and in theory?

Furthermore, as I interviewed disabled activists, I added one more question to investigate how the activists' experiences in the disability movement and their work in the disability field helped to develop their ideas on citizenship and QOL. So, answers to the following question are also sought:

4. What is the impact on both citizenship and quality of life of being an activist and part of the disability movement?

This chapter focused on reviewing Korean literature to illustrate the background of the study and locate it within the Korean context. The next chapter outlines how the concept of citizenship and the idea of QOL are understood in this study.

Chapter 3: Conceptual Framework

This chapter outlines the two main concepts of the study—citizenship and QOL. The section for each concept starts by depicting how the concept is generally understood and expands to a framework for the concept applied to this study. This chapter concludes by indicating how the two frameworks might work to probe the third research question: Do the two concepts of citizenship and quality of life relate to each other in everyday life and in theory?

3.1 Citizenship

In this study, it is understood that citizenship is socially constructed and contested and often produces excluded people and groups through the process of 'normalisation of citizenship'. Disabled people are one of the groups that are easily marginalised and excluded from the discourse of citizenship. Morris's (2005) work on citizenship for disabled people is a key framework which I have applied in this study to understand how disabled people are included/excluded within society and the implications for citizenship.

3.1.1 What is Citizenship?

Marshall set out the concept of citizenship in 1950 in his essay, *Citizenship and Social Class*, and established the rights-based definition of citizenship (Marshall, 1950). He contended that the concept of citizenship is based on three rights— civil, political and social rights—and the responsibilities rest on the 'equality of social status'. Citizenship is still widely and generally understood as a concept which involves rights and also reciprocally requires responsibilities and obligations, which proves the significance of Marshall's influence on the concept (Oldfield, 1990; Turner, 1993; Faulks, 2000; Lister, 2003; Dwyer, 2004).

Since Marshall's concept of citizenship, the concept has been discussed, developed and claimed based on various discourses. Dwyer (2004, p.3) argued that 'the language of citizenship is used in a multitude of contexts (for example, political, legal, philosophical, academic)'. Furthermore, Faulks (1998, pp.2-4) observed that citizenship is generally discussed based on three main definitions: 'a legal definition', 'a philosophical definition' or 'a socio-political definition'. The legal definition is about how to define citizens' rights and duties. The philosophical definition concerns answering some 'normative questions', such as which model of citizenship can adequately 'deliver a just society' (ibid.). The socio-political definition emphasises citizens' membership of a society, which is related to citizens' social practice. In addition, Lewis (1998, p.104) noted and summarised three salient points for citizenship as:

1. the citizen is one way of imagining a link between the state and the individual;
2. the concept of citizenship implies membership of some form of community; and
3. citizenship is a social status that allows people to make claims in relation to state-organised welfare services.

In recent decades, the concept has been more dynamic in responding to conflicts arising from the reconfiguration of the nation-state from government to governance and transnationalism due to globalisation (Kymlicka, 1995; Kooiman, 2003; Turner, 2016). Scholars discussed that the concept of citizenship is universal, but there is no common idea for what citizenship means and how this is experienced (Lister, 1998; Faulks 2000; Dwyer, 2004).

3.1.2 Exclusion from Citizenship and Inclusive Citizenship

However, one thing is prominent: there are always debates about who is included and excluded and how the excluded challenge the social structure (Kabeer, 2002; Urrieta & Reidel, 2008; Glenn, 2011). Diverse groups based on class, race, gender, culture and disability assert their exclusion and demand equality for their citizenship (Somerville, 1998; Lister, 2007; Holston, 2009).

For example, Marshall’s argument produces second-class citizens; people who are not able to carry out their responsibilities become second-class citizens (Lewis, 1998). Not only Marshall’s citizenship, but both capitalist and neo-liberalist citizenship intentionally and unintentionally exclude some citizens who are more likely to be in a situation where they cannot be in the labour market and cannot act as ‘active citizens’, and disabled people are a group that is more likely to be in this situation. Hall and Held (1989) argued that, historically speaking, it is easily identifiable that citizenship has frequently been limited for certain groups. This process of limitation has normalised citizenship through certain standards of society. ‘Normalization of citizenship’ defines how full citizens ‘should’ be and the process of ‘normalization of citizenship’ is produced according to different criteria, which range ‘from physical appearance to cultural, social and economic ways of being, along with sensibilities and dispositions’ (Urrieta & Reidel, 2008, p.91).

As a consequence of this, some citizens within a certain gender, race, culture or disability are limited in their ability to access or enjoy full citizenship and are also marginalised. In other words, not everyone with legal citizenship actually enjoys the status of ‘full citizenship’, since the idea of citizens implies certain specific expectations about what citizens ‘should’ contribute. Some people with legal citizenship are often categorised as ‘others’ by dominant groups (Urrieta, 2004), whilst the policy rhetoric still equates legal and full citizenship and also identifies these terms with ‘inclusion’ in society (Jenson, 2007). This ‘othering’ process results in people defined as ‘others’ being marginalised to ‘second, third or non-class citizenship’ (Urrieta & Reidel, 2008). Furthermore, these marginalised groups or individuals are perceived as being worth less than the dominant, mainstream groups (Cary, 2001; Houser & Kuzmic, 2001) and ‘exclusion from citizenship rights interacts with and magnifies other social inequalities’ (Glenn, 2011, p.2).

The language of inclusion and exclusion is, indeed, embedded within the concept of citizenship (Stychin, 2001). Somerville (1998) argued that social exclusion is socially constructed: 'What lies at the heart of all processes of social exclusion is a sense of social isolation and segregation from the formal structures and institutions of the economy, society and the state' (p.762). Thus, social exclusion results in society being unable to keep all groups or individuals within reach by pushing away 'vulnerable and difficult' individuals into undesirable places (Power & Wilson, 2000). As a consequence of such action, those excluded are often detached from social relations and are routinely limited from full participation in social activities which are normatively prescribed in the society in which they live (Oxman-Martinez et al., 2012).

In recent decades 'inclusive citizenship'—which is mostly about 'recognition' by other members of society and access to formal rights—became a prominent theme in the discourse on citizenship in both practice and theory (Kabeer, 2005; Yuval-Davis, 2006; Isin & Turner, 2007; Lister, 2007). For citizenship, recognition and relationships have been emphasised in relation to various terms such as belonging and interaction with other members. Glenn (2011, p.3, emphasis in original) defined citizenship as 'a matter of *belonging* which requires *recognition* by other members of the community'. Lister (2005, p.18) asserted that 'citizenship is at heart about membership and belonging'. Yuval-Davis (1999) claimed that citizenship is better understood from the perspective of 'relationships' rather than any political science definition. People who have citizenship need to be recognised as full citizens by other members (Jenson, 2007) and need to be recognised as members of the community without any question (Fox, 2005).

3.1.3 Disability and the Concept of Citizenship

Disabled people are, nevertheless, often isolated, denied of and excluded from communities which involve interdependence, communication and mutual help, because people who consider themselves to convey a 'normal' appearance and behave in a 'normal' way are often not willing to associate with people perceived as being ‘different’ (Morris, 1989). On top of this, disabled people have long been routinely considered as a distinct group who are not rational, autonomous or even fully human by non-disabled people (Goodley & Runswick-Cole, 2014). This attitude and view demonstrates how the idea of normalisation is prevalent within society (ibid.).

The idea of normalisation results in disabled people often not being accepted in mainstream society, which has normative expectations of physical appearance and social and cultural behaviours (UPIAS, 1976; Oliver, 1990; Finkelstein, 2001; Oliver & Barnes, 2012). However, it is also argued that normalisation for disabled people refers to the idea that they should, as closely as possible, enjoy the same norms which non-disabled people enjoy (Nirje, 1969). The concept of normalisation ensures that disabled people can also have the opportunity to enjoy the freedoms, choices and rights which non-disabled individuals take for granted. Normalisation also helps to ensure that disabled people remain away from institutionalisation, isolation and special treatment (Bank-Mikkelsen, 1980). However, this is only when there are positive, socially-valued images and concepts, such as having a ‘normal’ education, job and house; not having a ‘normal’ life in society becomes devaluing (Wolfensberger, 2011). Society intends to set a level of acceptance and, through this, it transforms devalued people into valued people (Brown & Walmsley, 1997). In this model, society tends to make everyone similar, rather than to accept the differences that exist; to highlight norms rather than appreciate differences. Normalisation is seen as a force to integrate disabled people into a ‘normal’ life. However, disabled people who have less of an opportunity to live in this way could become devalued in society because of these very norms. As a consequence, normalisation gives disabled people a more negative social image. Yates et al. (2008, p.250) argued that, ‘in normalization the emphasis is on social influences that act on the individual, limit “personal competencies”, impart roles and shape behaviour and on the ways that these competencies and behaviours subsequently affect the social perception of devalued groups’. In reality, disabled people are often not able to be like everyone else in a normalised world. There has been some misinterpretation in enjoying citizenship and rights ‘like anyone else’. In normalisation, the real problem lies beyond differences and disabilities. The real problem is that a disabled person is implicitly understood as a problem within society instead of as a citizen.

The perception of disabled people ultimately results in them being excluded from society. Barton (1993) asserted that exclusion can be described as ‘institutional discrimination’, which limits membership within the community, whilst discrimination could be defined as acts expressed either intentionally or unintentionally which are favourable to some groups/individuals and unfavourable to others (Jackson et al., 1998). Additionally, the concept of inclusion itself is sometimes even interpreted from different perspectives for disabled people. Social inclusion for disabled people is often understood as someone living their life in a community and having a social role within that community (Paik, 2003). Living in a community and having a social role within the community entails disabled people becoming deinstitutionalised and living within a community (Willer et al., 1993). Sainsbury (1993) even argued that some disabled people and the elderly tend to feel more comfortable and freer when they are disconnected from mainstream community (referred to in Lee, 2000). According to Sainsbury, the culture of disabled people is different from that of non-disabled people and disabled people tend to deem their own culture more valuable. On the contrary, some scholars argued that excluded people and groups need to be included within social structures, social networks and social conventions as members of society (Bowring, 2000; Schalock, 2004). I think that living within a community of disabled people is a choice that disabled people can make as citizens in their own right. They should not be excluded from a community because they are disabled or because they have their own sense of belonging.

Simply living in a society and having a social role can be presented as being ‘in’ the community, while being included in social structures and social conventions can be presented as being ‘of’ the community (Rapley, 2000; Reinders, 2002). These terms, being ‘in’ and being ‘of’ the community, also equate with the terms articulated for disabled people by Gilbert et al. (2005, p.292)—'the identification of a physical environment'—which represents being 'in' the community and 'membership of a community of identity', which stands for being 'of' the community. Jenson (2007) argued that contemporary citizens' rights are not limited to the idea of supporting political and social goods for citizens, but include offering opportunities for citizens to actively participate when they wish to do so.

Many scholars and writers claim that disabled people are often 'in' the community but not 'of' the community (Rapley, 2000; Reinders, 2002; Bray & Gates, 2003; O'Brien, 2003). It is, indeed, apparent that disabled people are not often recognised as members of a community by other members; as a consequence, they are not able to feel a sense of belonging in society and access or enjoy full citizenship.

3.1.4 Morris's Concept of Citizenship for Disabled People

Morris (2005) developed a concept of citizenship for disabled people. Morris's concept of citizenship emphasises belonging and social rights, which are important elements for inclusive citizenship. She argued that, 'most theoretical and empirical discussions about citizenship fail to consider disabled people' and 'human and civil rights have yet to be fully extended to this group' (p.5). She pointed out the significance of 'recognising and valuing disabled people's differences and humanity' for establishing disabled people's belonging in society and claiming social rights for them, as their differences have been the most profound reason preventing them from being included in society. She proposed three concepts—'self-determination', 'participation' and 'contribution'—as a way for disabled people to become included and to belong in society as citizens as well as a way to explain how social rights for disabled people are lacking and where social rights are needed.

This thesis follows and draws upon Morris's notion of citizenship for disabled people. Morris's concept of citizenship tackles the very fundamental problem—recognising and valuing disabled people's differences and humanity—as a premise for establishing the concept of citizenship for disabled people. Furthermore, the concept of citizenship suggests the ways in which disabled people could belong in society, as 'belonging' is an important notion for citizenship and a concrete way to live as members of society. The definition of citizenship for this study summarises the argument put forward by Morris:

> Disabled people's differences and humanity should be recognised and valued, so they can exercise their self-determination, participate in and contribute to society; furthermore, belong in society (Morris, 2005, p.40).

In the following sections, and to contextualise how I intend to discuss and frame my data, I discuss how the three concepts of self-determination, participation and contribution are important and how social rights are needed for disabled people to belong in society as citizens.

3.1.4.1 Self-Determination

Self-determination is defined as the 'rights of individuals to make choices and decisions and, in essence, to live autonomous lives' by Wehmeyer and Bolding (2001, p.372) or the ability to exercise their power and control over their lives (Kabeer, 2002). Morris (2005, p.6) claimed self-determination refers to 'an assumption that individuals have capacity for free choice and full citizenship involves the exercise of autonomy'. Self-determination is necessary for individuals to live autonomous lives. Furthermore, the concept of self-determination is closely related to the concept of agency and identity. Lister (2003, p.39) identified that a sense of agency with regards to citizenship is not only about how one can act and choose, but also about having a 'conscious capacity' for action. Conscious capacity allows an individual to understand herself/himself and this is relevant to the individual's self-identity (ibid.). Having a stable self-identity supports an individual to have the necessary self-esteem to participate in society (James, 1992). On top of this, individuals with a sense of agency can come together to claim their particular identities and rights—they perform 'acts of citizenship' (Isin, 2008).

However, in discussing disability, a number of topics are naturally embedded within the subject. These include the mental and physical limitations of the individuals in question, as well as their sense of being distinct or isolated from others. No matter how disability is defined, the question of being able-bodied like others is profoundly underpinned within the idea of disability (Kittay & Carlson, 2010). Most social policies and social sciences are predicated on this idea of humanity. However, disability threatens this idea of humanity in terms of 'who' should be normative and autonomous (ibid.). In other words, being human is profoundly related to the idea of normalisation in that individuals are supposed to be able to live in certain ways in which society expects them to live. The central argument in social attitudes and state policies, which often reject, deny and ignore disabled people, is how society insists on the 'sameness' and 'unity' of their citizens (Mégret, 2008; Meekosha & Solidatic, 2011). In order to strengthen this uniformity, citizens are prepared and trained 'to be' and 'act' as citizens through education (Urrieta & Reidel, 2008). Disabled people, who are not often able to be prepared and trained in this way, are treated as a different species that violates the equality and universality of society (Mégret, 2008). However, these social attitudes and policies systematically and persistently violate disabled people's rights. The idea of 'normalisation' endangers disabled people's human rights, because the 'normal' and the able are rooted in the 'language of citizenship, law and humanity' (Goodley & Runswick-Cole, 2014, p.5). Therefore, disabled people are more likely to be in a position in which they cannot exercise their self-determination (Mégret, 2008). This results in disabled people being less autonomous or not being autonomous (ibid.). Unless disabled people exercise their self-determination, it is difficult for them to be autonomous agents. Furthermore, disabled people's lack of agency causes them to be deprived of opportunities to realise their identity or even damages their self-identity. Albert et al. (2005) claimed that the lack of self-determination in disabled people, along with a lack of self-empowerment and equality, makes disability a human rights issue.

Within the human rights approach, each person's differences and humanity need to be recognised and valued as they are. The human rights argument for citizenship is about focusing on an individual’s potential instead of maximizing citizens’ capacity (Stein, 2007). Thus, disabled people can develop their talents and their talents can flourish, although every individual’s talent is unequal (ibid.). Based on this argument, disabled people can become self-determined agents who can act and choose and even have ‘conscious capacity’, allowing disabled people to find their identity. Then, they can find their stable self-identity, which supports individuals to have the necessary self-esteem to participate in society as active citizens.

The purpose of the UN’s human rights convention for disabled people, UNCRPD, is ‘to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity’ (UN, 2018). The UNCRPD invoked a moral imperative in regards to disabled people, which is that every human being has worth and needs to be respected (Stein, 2007; Quinn, 2009; Degener, 2016). This human rights approach is based on valuing each person’s inherent dignity and prohibits a view of measuring each person’s functional ability in society, which is a concept based on the idea of normalisation. Mégret (2008, p.496) argued that human rights which promote equal rights for everyone may be about working to inquire deeply into the issues of ‘identity, survival and dignity of particular groups’. When disabled people’s differences and humanity are respected and valued, as Morris (2005) claimed, they would be more likely to exercise self-determination and become autonomous agents, and, furthermore, realise and develop their self-identity.

Morris (2005), however, argued that the problems in exercising self-determination faced by disabled people are not only about removing barriers, but also the lack of provision of sufficient services and assistance. Mithaung (1998, p.42) also asserted that the concept of self-determination draws our attention to ‘the interaction between a person’s capacity to choose and act and the social environment that mediates opportunities for those choices and actions’. Morris (2005) illustrated some examples, one of which is: when ‘direct payment’ is offered to disabled people, the level of such assistance is often not sufficient to give them full control and choice and essentially exercise their self-determination. Indeed, providing a sufficient level of social rights is an indispensable condition to disabled people exercising their self-determination. The UNCRPD affirmed that every human has the 'right to have rights'. Wickenden (2013) argued that one of the advances made by the UNCRPD is recognising the differences of disabled people as citizens: 'It underlines their entitlement to the same privileges, services and opportunities as others, but also points out that sometimes in order to achieve equality, extra resources (e.g. adaptation, equipment, legal protection, time) must be provided' (p.15). Recognising and valuing disabled people's differences and humanity is vital for disabled people's self-determination. Then, when disabled people can exercise self-determination, they will be closer to a position where they can participate in society as active and autonomous citizens.

3.1.4.2 Participation

Van Steenbergen (1994) argued that the primary concern of citizenship is about social participation: the way in which citizens can be integrated. Morris (2005) asserted that, 'participation includes political participation, but also encompasses the broader concept of community participation' (Morris, 2005, p.6). She claimed that the concept of participation is often mentioned by disabled people 'in the debate on social exclusion'. The struggle of excluded groups for social inclusion into mainstream society is also the main discourse of analysing and evaluating citizenship (Kabeer, 2002; Isin, 2008; Holston, 2009).

According to Morris (2005), there are two common attitude barriers hindering disabled people from participating fully in the community. First, disabled people are often viewed as people in need of care and not perceived as people having autonomy over their own lives. Community participation is a form of participation related to the concept of belonging. Gilbert et al. (2005), however, observed that an equivocal situation for disabled people is often produced, when disabled people attempt to participate in the community. The situation 'brings together elements of citizenship, charity, belonging and dependence' (p.292). The situation often stems from the normative notion of 'human', which views disabled people as a group who are not autonomous, rational or human (Kittay, 2008; Goodley & Runswick-Cole, 2014).

The second barrier refers to discrimination against disabled people, whereby they are often considered as 'not belonging to the communities in which they live' (p.25). As a result of the second barrier, community participation often involves only printed materials and spoken words at meetings, and jargon is often used. Fraser (2003) emphasised that the ability to interact with other members of society is important for citizenship to be realised. However, the ability is often misunderstood based on the idea of normalisation. Garland-Thomson (2011) asserted that one of the embedded ideas in disability policies is the notion of social justice, which looks to influence the world to fit or be inclusive of disabled people. This does not mean changing disabled people, but instead changing the world so that disabled people can join the world as citizens. This is a contrasting idea to normalisation, which, conversely, proposes the transformation of disabled people to 'fit' into the world to enjoy their freedom, rights and autonomy as citizens. Garland-Thomson argued that disabled people should have the same opportunities to communicate with others. Sometimes, this communication could involve different forms of non-verbal communication techniques and skills including sign language, if necessary, instead of simply artificially assisting the deaf with high-tech hearing aids to communicate. Emphasising the need for high-tech hearing aids for the disabled is a way of imposing normalisation on them in order to force them to fit into the normalised world. Of course, Gerald-Thomas does not suggest that disabled people do not need to try to develop themselves or even reshape their bodies. The emphasis of this argument is not on ability, but instead on their identities (ibid.). It seems that when disabled people's identity is recognised by non-disabled people in society, they could have more opportunities to enjoy equal relationships with non-disabled people and belong in society.

Taylor (1996) noticed that there are two kinds of participation: 'active participation' and 'passive participation'. Self-advocacy and consumerism can be examples of 'active' participation and 'passive' participation respectively (ibid.). In 'active' participation, the relationship between participation and people's self-esteem was found, as participation can promote disabled people's self-esteem (Gilbert et al., 2005). In 'passive' participation, poverty can be a barrier preventing disabled people from participating in society. In order to participate in 'the normal activities of society', 'a reasonable standard of living' should be afforded (Burchardt et al., 1999, p.231). However, the high rate of poverty amongst disabled people obstructs many from participating in society and enjoying their full citizenship. A lack of accessibility to voting places for some disabled people during elections and inadequate support being provided for them to partake in jury service are additional examples of disabled people being hindered from participating in society (Morris, 2005). Morris argued that funding or other support provided to disabled people to participate in society is not sufficient. It seems that disabled people will remain excluded from full participation, unless sufficient social rights are secured for them.

Disabled participants in Milner and Kelly's (2009) study emphasised 'how' they participated in the community, not 'where' they participated. They said that they also wanted to be viewed with expectation by other community members and they also felt a sense of belonging when their opinions were valued. This substantiates the argument of Gilbert et al. (2005) that disabled people want to be 'of' the community as 'membership of a community of identity', not just to be 'in' the community as 'the identification of a physical environment'.

3.1.4.3 Contribution

As well as enjoying rights, fulfilment of responsibilities is also required to feel a sense of belonging within society as citizens (Sachs, 1997; Marks, 2001) and a 'felt responsibility' is understood as a critical implication for social integration, which is essential for citizenship (Sachs, 1997). Kabeer (2002) observed that fulfilling contribution can increase people's self-esteem and, furthermore, motivate them to participate in society more actively. However, disabled people who challenge 'normalcy' are often put in the argument of binaries of rights/duties and active/passive citizenship (Meekosha & Dowse, 1997). Active citizens are expected to take their duties seriously in order to claim their rights, but disabled people often need additional or different support to fulfil their duties and make a contribution to society (ibid.). Morris (2005) claimed that the concept of the contribution of disabled people is relevant to the debate ‘on the limits to social rights’ (p.6). She explained that the value attached to disabled people’s contribution to the economy and society needs to be emphasised by making the necessary resources more readily available for disabled people. She argued that the current debate on citizenship places more emphasis on people’s ‘responsibility to make a contribution’ than on people having the ‘right to make a contribution’. Furthermore, the perception of disabled people as recipients and the assumption that disabled people have nothing to contribute often ‘undermines disabled people’s *rights* to make a contribution’ (p.28, emphasis in original). The discussion on the lack of social rights to contribute is in line with the discussions above regarding self-determination and participation. Disabled people’s differences and humanity should be recognised and valued and adequate social rights—sometimes additional support—are necessary for disabled people to contribute to society.

Morris’s definition of citizenship recognises and values disabled people’s differences and humanity. This point of view is imperative for the disabled, since their differences have often been a major barrier in being accepted as citizens. Furthermore, the definition articulates in detail how disabled people can be included in society by deploying ideas of self-determination, participation and contribution. As disabled people can exercise self-determination, participate in and contribute to society, they, eventually, can belong in society. For this, it is claimed that an adequate level of social rights is also essential to support disabled people in exercising self-determination, participation and contribution to society.

It is evident that disabled people in Korea are discriminated against, marginalised and excluded from both discourse of citizenship and practising citizenship in everyday life. Furthermore, they are often perceived as objects of care and help. This could imply that disabled people's differences are misunderstood and are not valued. Additionally, disabled people in Korea are not perceived as the same human beings as non-disabled people, whose inherent dignity should be respected as they are. Morris's concept of citizenship tackles the misperception of disabled people in Korea. When disabled people's differences and humanity are not recognised and valued and current normalisation continues to be imposed on the view of disabled people in Korea, disabled people will not be able to even get close to a position where they can belong in society and access and enjoy their full citizenship as equal citizens. Furthermore, Morris's citizenship deployed the three components of self-determination, participation and contribution as tools to explain in more practical ways how disabled people's citizenship is denied, but also how citizenship can be experienced, so they can belong in society. Indeed, I use Morris's concept of citizenship as a framework to find out how disabled people in Korea have been excluded and how the exclusion from citizenship has an adverse impact on their QOL.

3.1.5 Is the Concept Developed for Disabled People in the UK Suitable for Disabled People in Korea?

Research funded by the National Research Foundation of South Korea and conducted by Shin et al. (2013) conceptualised the social inclusion of disabled people. Their study conceptualised the social inclusion of disabled people from two perspectives: the social structure perspective and the psychological perspective. The social structure perspective is about securing basic rights for disabled people, according to the authors. They, thus, argued that disabled people should be considered as equal citizens who have equal social rights that allow them to gain equal access to the entire social structure and all of its systems. They also claimed that 'differentiated' social rights, which entail extra resources and the necessary settings to allow disabled people to access the social structure and systems, need to be established. Meanwhile, the psychological perspective focused on relationships, acceptance, sense of belonging, feelings of solidarity and self-worth in the study. They explained that the psychological aspect mainly influences the process of forming identities and that emphasis is placed on whether disabled people feel a sense of belonging and consider themselves to be citizens within society.

Shin et al. (2013) discussed social rights and relationships and a sense of belonging in terms of the inclusion of disabled people. They also claimed that in order to access ‘differentiated’ social rights, which entails extra resources and support, disabled people’s differences have to be recognised and valued. Their argument is related to the idea of Morris’s citizenship for disabled people, recognising their differences and emphasising belonging. The argument of Morris’s citizenship is not a completely new idea in Korea. However, in the research of Shin et al. (2013), how disabled people can be included in practice is not explicitly described, as Morris explained in her writing with the three concepts of self-determination, participation and contribution. Indeed, this thesis could also examine how Korean disabled people are excluded from society and want to be included within society as citizens by utilising the three components. In addition, the findings could be compared with Morris’s citizenship; illustrating how Korean disabled people’s opinions about their citizenship are different or similar to the citizenship of disabled people in the UK.

3.1.6 How Citizenship was Translated into Korean in This Study

In this study, the concept of citizenship is examined according to each interviewee’s understanding of citizenship. All interviews were completed in Korean. It was, therefore, important to find a consensus on what citizenship entailed for interviewees in Korean during the interviews, since the direct Korean translation of the word ‘citizenship’ does not embrace the variety of meanings that the term connotes in English.

The word *siminkwon* (citizens’ rights or civil rights) is generally used as a direct translation for the word ‘citizenship’ in Korean by many social scientists (Choe, 2006). The Korean word, however, does not convey the full meaning of ‘citizenship’. Even in law, legal citizenship is bounded not only by rights, but also duties, and *siminkwon* does not capture the meaning of nationality either. Furthermore, *kookmin* (nation—people constituting a nation) in Korean is generally used instead of *simin* (citizen—people constituting a city). Meanwhile, modern citizenship is deemed to mean being part of a national community (Roche, 1987) and members of a society (Glaeser et al., 2007). Arguments relating to citizenship often emphasise the membership of a society (community, country, etc.). Thus, citizenship can also be interpreted as living as a member of a society. The meaning of citizenship embraces not only a legal term referring to rights and duties, but also includes citizens' social activities within the country as allowed according to their position and status. Therefore, in this thesis, citizenship was explained to the interviewees as 'living as a citizen (*simin*) or a nation (*kookmin*) or a member of society'. This fairly broad definition was used to prevent the restriction of interviewees' ideas of citizenship and to enable their ideas on citizenship to be heard.

3.2 Quality of Life

As this study sets out from an assumption that disabled people's marginalised citizenship in Korea must have influenced their QOL in an undesirable way, QOL is another key concept along with the concept of citizenship. Indeed, it is imperative to examine how the concept of QOL is understood in this study. I chose Felce and Perry's (1995, p.51) model of QOL which 'takes account of concerns that externally derived norms should not be applied without reference to individual differences' as a way to understand QOL for this study. However, Felce and Perry's model of QOL is not rigidly followed in this study; rather, their view on the concept of QOL that individuals' 'values' and 'aspirations' can be different for people who are in different situations—thus individual weight needs to be considered and strengthened in the model of QOL—is applied in this study.

This section first describes how the concept of QOL is generally understood in the sections of 'Importance of Social Domains' and 'Influence of Subjective Views in Determining QOL'.

Then, the rationale for choosing the concept of QOL over similar concepts, such as well-being and life satisfaction, is illustrated. The last section discusses Felce and Perry's (1995) model of QOL and elucidates how the model is applied in this study.

3.2.1 Importance of Social Domains

QOL is a multi-scale and multi-dimensional concept, which involves different ways to determine its meaning and there are various domains to consider. Some researchers, such as Delhey et al. (2002) and Veenhoven (2005), added even more dimensions such as individual level and societal level and different terms such as external/internal or chances/outcomes to the composition being used in determining QOL. These ideas, levels and different kinds of QOL make a definition even more difficult. This is why scholars generally agree on and recognise the issues regarding QOL, such as an unfixed definition of the concept, the complexity of the concept, various areas related to QOL and the absence of universally accepted domains and a way to define it (Cummins, 1996; Haas, 1999a; Veenhoven, 2005). Pukeliene and Starkauskiene (2011) even argued that this complexity in defining QOL appeals to the idea that the essence of QOL is not to define it, but rather to identify more detailed issues and domains in determining it.

Fortunately, there has been more general consensus in terms of agreeing on the domains and areas which would constitute QOL (Costanza et al., 2007). Based on 15 previous studies, Felce and Perry (1995, p.60) claimed that QOL can be ascertained through the following five domains: 'physical well-being', 'material well-being', 'social well-being', 'development and activity well-being' and 'emotional well-being'. Pukeliene and Starkauskiene (2011) identified several social areas, such as personal relationships, family, friends and public life, as important areas for QOL. They then asserted that people not only 'want to communicate, but also to be recognised and respected in society (social life is important)' (p.153). Areas related to the social activity of people have become more important in recent years (Felce & Perry, 1995; The WHOQOL group, 1995; Pukeliene & Starkauskiene, 2011). These social areas generally include family, leisure, communication, interpersonal relationships with family, friends and acquaintances and a level of community involvement. This tendency supports the claim of Salvador-Carulla et al. (2014) that in the beginning of the twentieth century, QOL has evolved into ‘social studies of happiness’. The importance of social well-being in QOL has become more apparent (Diener & Suh, 1997). The importance of a social life for QOL was also found in a study on QOL by Raphael et al. (2001). They found that people’s social life, such as how they engage with others, is correlated with people’s QOL. In the study, it was discussed how receiving care from other members of the community and knowing that people around us are concerned are important for QOL. All these social domains are also related to the idea which understands people as a species who live with other members of a society (Kittay, 2002). As long as people are social animals, the effect of social areas on their QOL should not be overlooked.

3.2.2 Influence of Subjective Views in Determining QOL

Thorndike was one of the first social scientists to attempt to determine QOL by combining social statistics data on literacy rate, infant mortality and standard of living to determine life quality in the 1930s (Zautra, 1983). Since then, the concept of QOL has been developed and discussed mostly in the fields of social science and medical science (ibid.). In the 1960s, social scientists began to insist that economic value alone was not sufficient to assess a nation’s living conditions and added social indicators to economic values to evaluate living conditions (Stensman, 1985). Researchers and scholars have tried to determine the concept of QOL in their fields and the meaning of QOL has been expanded into various areas and has evolved from various perspectives. It became accepted that QOL is a more subjective than objective concept (Emerson, 1985), although there is also a strong argument that self-evaluation of ‘behaviours, states and capacities and satisfaction’ is not sufficient to inform us accurately about QOL (The WHOQOL group, 1995, p.1405). However, the WHOQOL group (1995) also agreed that in every model of QOL, the following three domains are considered in determining QOL: ‘physical (individuals’ perceptions of their physical state), psychological (individuals’ perceptions of their cognitive and affective state) and social (individuals’ perceptions of the interpersonal relationships and social roles in their life)' (ibid., p.1405). This implies that a person's QOL is influenced by individual perceptions.

People who tend to understand the concept of QOL as an objective concept place emphasis on statistics and objective data related to people's lives, such as income level, demographic data, education level, cultural life and equality within society (Johnston, 1988) and use survival rate, disease rate and life expectancy at birth as objective data in the medical and rehabilitation field (Dasgupta & Weale, 1992). However, even some objective data, such as personal characteristics, objective living conditions and various environmental conditions, are still influenced by an individual's self-awareness (Lehman et al., 1986). In addition, people often claim to have a lower QOL than that which their objective environmental data might indicate (Campbell, 1976) and disabled people who have physical difficulties may claim to have a high QOL even though their lives may look undesirable to others (Albrecht & Devlieger, 1999). Good or bad objective data, therefore, does not always accurately reflect a person's QOL. This does not mean that no objective data is used in determining QOL. Rather, people's QOL cannot be judged only based on demographic data and statistics. Scholars and researchers, therefore, have focused on people's subjective views in determining the concept of QOL and argued that how people see their lives themselves is important for their QOL (Engel, 1981).

Korean scholars have also tended to interpret QOL from a subjective perspective. Oh and Jung (2010) argued that life satisfaction is subjective and that a person's QOL depends on how they experience their social environment. Im (1996) also argued that QOL represents a person's self-awareness of objective living conditions, while Park (2009b) stated that a person's QOL is defined according to how positively (or negatively) they assess their life compared to their expectations. How people think about their life is important, since everyone has different living standards and goals. From a similar point of view, Emerson (1985, p.282) also defined QOL as 'the satisfaction of an individual's goals and needs through the actualisation of their abilities or lifestyle'. Taking a subjective view on QOL seems to be generally accepted in the process of defining the concept of QOL. This explains why different terms, such as well-being, subjective well-being and a good life, are often used interchangeably with regards to QOL (Diener & Suh, 1997). The current study also investigates how disabled people define their QOL based on their subjective views.

3.2.3 Why QOL rather than Other Terms?

Salvator-Carulla et al. (2014) observed that the concept of well-being and the concept of QOL are closely intertwined. They claimed that 'QOL was defined as the subjective aspects of well-being, while well-being was assessed as a generic component of QOL' (p.53). Haas (1999b) also claimed that QOL is a broad concept, which comprises objective indicators and subjective indicators, such as life satisfaction or well-being. Although there is some contention regarding which is a component of the other, it is generally accepted that the two concepts are not binary, rather they are overlapped—the boundary of the two concepts is blurred (Gasper, 2010; Salvator-Carulla et al., 2014).

According to Gasper (2010, p.351), the concept of QOL is 'more to refer to context and environment', so it comes more from disciplines such as 'sociology and social policy'. On the other hand, the concept of well-being is used 'somewhat more to refer to actual experience', so it stems from 'psychology' (ibid.). Dodge et al. (2012, p.230) defined well-being as 'the balance point between an individual's resource pool and the challenges faced'. Cummins et al. (2004, p.415) defined subjective well-being (SWB) as 'a stable sense of feeling positive about one's self and one's life'. Meanwhile, objective well-being (OWB) can be imputed to individual's fulfilment of resources and choices (Gasper, 2010, p.354). Some scholars claimed that the emphasis of well-being is constructed in terms of satisfaction with life, happiness and positive/negative effects (Kahneman, Diener & Schwarz, 1999; Lyubomirsky & Lepper, 1999). In addition, Waterman (1993) claimed that the concept of well-being highlights human development and positive psychological functioning. Well-being often refers to a stable and balanced psychological status and relates to the feeling of satisfaction with life and happiness. Salvator-Carulla et al. (2014) claimed that there are differences in the definition of well-being from QOL and the differences stem from the different backgrounds to the terminologies from which the concepts originated and developed. The tendency to understand the concept of well-being from a psychological context can be traced from the origin of the study of well-being. Agner (2011) claimed that at the beginning of the twentieth century, the concept of well-being originated from a discipline which studied the ‘well-being of the normal’. This evolved into psychology, personal studies, education and the social studies of marital success and happiness in the late 1920s and 1930s (ibid.). Later on, the concept of well-being came to be used as the definition of happiness related to satisfaction (Hart, 1940). Kahneman (1999) observed that the concept of well-being is often used and evolves around the idea of personal psychology, such as happiness, satisfaction, pleasure, fulfilment, misery and distress.

The concept of well-being in Korea came from the USA in the late 1990s or early 2000s (Park, 2003) and is understood as a lifestyle for people who regard organic food and the environment as being of vital importance in Korea (Kim, 2004). Park et al. (2005) conducted a study to probe the meaning of well-being in Korean society through four personal interviews and predominantly via an online search to investigate how the concept of well-being is used online. They found that it is often understood as a type of lifestyle or a new culture code. The study illustrated that well-being is understood as a lifestyle for people who are interested in well-being. The characteristics of these people are: being eco-friendly; keeping their composure; eating healthy food such as organic food, which is possible due to their economic power; and doing exercise to keep healthy. It was found that the important elements of the lifestyle are economic power and subjective standards: living in my own way or living like myself (Kim, 2016). Thus, the term well-being is often used in connection with products related to health, beauty, food, food-related products and stress and life trends (Kim, 2004; Kim & Kim, 2005b; Kim, 2007b; Jung, 2012). Fields of study examining well-being in Korea are also often related to those areas, unless QOL is deployed as a main concept and well-being is described as a similar concept in the study. Furthermore, the Korean word for well-being does not exist. The English word well-being is used with Korean characters; thus, when the Korean characters of well-being are read, it sounds like well-being in English. In a study conducted by the Korean scholar, Lee (2007a), the author discussed the subjective QOL of disabled people in Korean literature without using or explaining the term ‘well-being’ at all, but suddenly used ‘subjective well-being’ instead of subjective QOL for the English title and the English abstract (Korean authors often attach an English title and abstract to their Korean articles). This is not generally the case and she did not explain a reason for doing so.

The World Health Organization (WHO) defines QOL as:

> an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHO, 1997).

The WHO definition of QOL is in line with Gasper’s (2010, p.351) argument that the concept of QOL is ‘more to refer to context and environment’. Indeed, QOL comes more from disciplines such as sociology and social policy (ibid.). The definition of the WHO’s and Gasper’s argument can explain why social areas which describe individuals within the context of society and social life, such as social roles, interpersonal relationships, communication and community involvement, are important in determining QOL.

This current study interrogates how disabled people live as citizens and how this is related to their QOL. In order to examine how they live as citizens, it is essential to understand how disabled people are positioned and perceived within the social context. Thus, it seems that the concept of QOL is more appropriate in discussing its relationship with disabled people’s citizenship, since the concept of QOL embraces more social meaning than the concept of well-being or a good life or satisfaction with life or happiness. Furthermore, using well-being during interviews might mislead the interviewees in Korea, since the concept of well-being is generally understood as a specific lifestyle in Korea, which does not meet the purpose of this study. In addition, the term QOL can be translated exactly into the Korean term *Salm-ui-Jil* (quality of life). The concept of QOL is not understood in a different way, especially in Korea, from the one generally understood in other countries (Park, 2003). Some words, such as a good life, life satisfaction and *an-yung* (similar to the meaning of (public) peace or stability or wellness) are often described as similar concepts in Korean literature (Park, 2003; Kim, 2016).

3.2.4 Felce and Perry's Model of Quality of Life

The definition of QOL for this study follows the definition of QOL which Felce and Perry (1995) defined. However, the definition of QOL for this study is intended not to determine but rather to describe how the concept of QOL is understood and approached in this study. Felce and Perry (1995, p.51) maintained that model of QOL which 'takes account of concerns that externally derived norms should not be applied without reference to individual differences'. Therefore, they claimed that different individuals' QOL can vary, depending on an individual's set of values, even in the same situation. They provided an example—income—which, although usually considered as being important, might not be important for certain people's QOL: 'for example, size of income (the objective measure) may contribute little to quality of life for a person whose values are non-materialist' (p.59). In addition to that, they contended that, 'an individual's personal autonomy to maintain and change their quality of life is a paramount consideration' (p.56).

The definition is set out below:

> Quality of life is defined as an overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social and emotional well-being together with the extent of personal development and purposeful activity, **all weighted by a personal set of values** (Felce & Perry, 1995, p.60, my emphasis).

In the definition above, the three elements—'objective life conditions', 'subjective feeling of well-being' and 'personal values and aspirations'—all interact with each other (please refer to Figure 1). In addition, all three elements are open to 'external influence' and can also change independently as a consequence of 'external influences'. 'Such external influences might include genetic, social and material inheritance, age and maturation, developmental history, employment, peer influences and reference points, and other social, economic and political variables' (p.63).

All three elements—'objective life conditions', 'subjective feeling of well-being' and 'personal values and aspirations'—are necessary to obtain a good QOL and changes in one element can affect the levels of other elements. For example, changes in 'objective life conditions' can change either satisfaction levels regarding the 'subjective feeling of well-being' or 'personal values and aspirations', or both. Similarly, changes in 'personal values and aspirations' can change satisfaction levels regarding the 'subjective feeling of well-being' and may also precipitate changes in some 'objective life conditions'. Changes to satisfaction levels regarding the 'subjective feeling of well-being' may also lead to a reappraisal of 'personal values and aspirations' and 'objective life conditions'. The relationships between the three elements differ for different individuals and QOL is, eventually, influenced by 'a personal set of values' at the last stage.

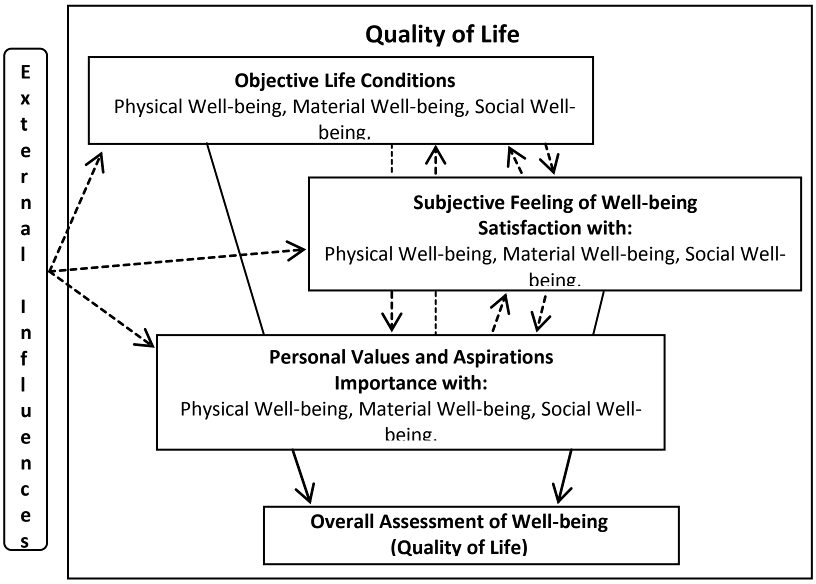

Figure 1: A model of Quality of Life (Felce & Perry, 1995, p.62)

As mentioned before, I do not rigidly follow Felce and Perry's (1995) model of QOL; rather, I respect their view on the model of QOL (how the concept of QOL is understood and approached): individuals have different 'values' and 'aspirations' in their lives for their different situations and their differences could differ from the 'norm'; thus, personal 'values' and 'aspirations' should be accounted for in the definition of QOL.

3.2.5 The Value of Money and QOL

Considering the importance of personal finances for disabled people's QOL found in previous Korean empirical studies on disabled people's QOL and Felce and Perry's (1995) example about the value of income for QOL, examining how the interviewees valued money for their QOL seemed appropriate. A study conducted by Lee and Song (2014, p.114) found a lower level of sense of happiness and life satisfaction amongst people in Korea who chose money as one of the two most important values in their lives in a study which examined 'if and how household income and attitude towards money (materialism) affect happiness and life satisfaction in Korea'. In the study, 29% of Koreans chose money from leisure, power, health, academic background, family, friends, neighbours, money, religion and career as one of the two most important areas for their lives. The findings of the study were in line with the outcomes of previous studies, which showed that materialism has a negative effect on people's QOL (Ryan & Dziurawiec, 2001; Kasser & Ahuvia, 2002; Deckop et al., 2010; Karabati & Cemalcilar, 2010). Lee and Song (2014, p.114) argued that studies examining the effect of money and the value of money on QOL are very rare in Korea; thus, the findings of the study suggest that 'reflective discussion and social debate on Korean society, in which economic achievements and development have been the most valued, are required'. This study will contribute disability activists' voices and opinions on this issue.

3.3 How the Two Concepts Might Relate to Each Other

Morris (2005) elaborated on the concept of citizenship for disabled people with the three components of self-determination, participation and contribution, to explain how disabled people’s differences and humanity are not routinely recognised and valued; thus, disabled people cannot belong in society as equal citizens as a result, but the concept also advises the way to find how disabled people can be included as equal citizens. Morris’s concept of citizenship suggests that disabled people currently lack access to full citizenship and want to exercise self-determination, participate in and contribute to society and belong in society as equal citizens. As a consequence, there is a possibility that a sense of belonging and enjoying full citizenship might be more valuable to disabled people, and disabled people’s aspirations to access citizenship might be stronger than people who take full citizenship for granted.

Felce and Perry’s (1995) model of QOL points out individuals’ differences in defining their QOL and emphasises the importance of taking account of individuals’ personal ‘values’ and ‘aspirations’ in the model of QOL. As Felce and Perry (1995) offered an example that the size of income would not contribute to QOL much if the person was not materialist, an individual’s personal value in life would play an important role in defining the individual’s QOL. Lee (2000), a Korean scholar, also argued that although the same domains are considered in studies into QOL for both disabled people and non-disabled people, the results would be likely to differ. He provided the example of culture and leisure, which he attested can be an important domain determining non-disabled people’s QOL, whilst rights to mobility can be a crucial area in determining disabled people’s QOL. This implies that the areas lacking in individuals’ lives influence their QOL in some ways to some degree. Therefore, disabled people’s lack of citizenship must influence their QOL. The interviewees in this study are disability activists and leaders who worked for their citizenship as a goal of the movement. It seems that Morris’s (2005) concept of citizenship for disabled people and Felce and Perry’s (1995) model of QOL are the appropriate frameworks to examine how disabled people’s lack of citizenship in Korea may relate to their QOL.

This chapter identified and described key frameworks relating to the two main concepts of citizenship and QOL. The next chapter outlines my choice of methodologies and rationale behind this and describes each step of the process of the study.

Chapter 4: Methodology

This chapter comprises two parts. This chapter comprises two parts. The philosophical background of the study, the semi-structured interviews and the thematic analysis, which form the methodologies utilised in this study, and trustworthiness are explored in the first part. This part also describes the rationale for the selection of the methodologies for the study. The second part illustrates each step of the process in executing the research, including the process of recruiting the participants, the interview process and the data analysis process. Ethical issues and the researcher's reflexivity are also discussed at the end of the section.

4.1 Methodologies

4.1.1 Philosophical Background of the Study

I believe that reality is constructed by people’s experience and interpretation of the world created through their social interactions with other people and continuously recreated by people’s sense of their worlds, such as their perceptions, thoughts and the purpose of their worlds. Therefore, reality is subjective and there is more than a single reality, and it embraces value and meaning. I, indeed, believe issues can be understood by how people perceive and interpret things within social context.

Therefore, this study takes an ontological stance of social constructionism, which believes that social objects and entities are socially constructed and built up by the perceptions and actions of social actors (Crotty, 1998; Snape & Spencer, 2003; Bryman, 2004; Lazar, 2004; Flick, 2009). This study seeks to investigate the social world as perceived and constructed by the research participants. Their worlds are expressed or conveyed through an interpretation of their behaviours, as well as their knowledge and understanding of the social world (Crotty, 1998; Bryman, 2004; Flick, 2009). This study revealed how society is constructed in the participants' minds, such as non-disabled people's society versus disabled people's society, and how they are positioned within society through their interpretation of the world. Therefore, I regard people's perceptions as amounting to acceptable knowledge within the social world (Bryman, 2004) and take the standpoint of interpretivist epistemology.

Much of the participants' narratives in this study involve the participants' life stories and personal experiences. Caine et al. (2013, p.576) claimed that their 'story is how people make sense of their existence' and people's experience is knowledge. Therefore, I believe that it is imperative to respect the participant and their stories and value relationships with the participants, since I worked with them to explore how we live together.

4.1.2 Qualitative Research

Jootun et al. (2009) claimed that the aim of a qualitative study is to explore how participants use their experiences to construct reality and to examine how meanings are constructed. In this study, the aim is to probe into how the participants utilise their experiences to construct the reality of how they live as citizens and how their QOL is fulfilled or restricted. Additionally, the meaning of their behaviour, their knowledge and their understanding of the social world needs to be examined. In order to do this, the participants' opinions, views and experiences of these issues need to be explored in depth and it is necessary to gain an understanding of how disabled people live in Korean society and what their desires are for their lives in detail. Houser (2009) argued that qualitative study gives researchers the advantage of gaining in-depth and comprehensive responses and stories as well as more detailed, 'thick' descriptions of social phenomena through participants' understanding of the social world by interacting closely with them. The participants' experiences and stories about their activities in the disability movement also need to be explored. Therefore, qualitative research was chosen as the best method for this study.

Palaganas et al. (2017, p.430) asserted that in qualitative research 'researchers probe into the experiences of their participants and try to abstract and theorize inductively to reveal valuable insights that can be interpreted and applied to other cases'. This is in contrast to a quantitative study, which usually deduces a generalisation/hypothesis and confirms or rejects this according to new findings. A quantitative study often takes the view of positivism as an epistemological stance defined as 'a collection of rules and evaluative criteria referring to human knowledge' (Kolakowski, 1972, p.2) and objectivism as an ontological stance, which refers to 'a conceptual attempt to get beyond our individual views' (Babbie, 2012, p.67).

4.1.3 Data Collection: Semi-Structured Interviews

As discussed in the 'Literature Review' chapter, opportunities to listen to disabled people's views directly regarding their QOL, and especially their citizenship, have been very rare in Korea. Consequently, it was deemed important to listen to their voices directly, so I decided to interview disabled people in order to understand their stories and opinions and views regarding their citizenship and QOL.

However, the rarity in hearing disabled people's direct voices in research is in contrast to cases which use inclusive research in the disability field, including emancipatory research, in which disabled people participate in research as more than research respondents, such as co-researchers, advisors, interviewers and autobiographers (Walmsley, 2001; Oliver, 2002). Especially in emancipatory research, research is controlled by disabled people as experts in disability. Barns argued that:

> Emancipatory research is about the systematic demystification of the structures and processes which create disability and the establishment of a workable 'dialogue' between the research community and disabled people in order to facilitate the latter's empowerment (Barnes, 1992, p.122.)

Involving disabled people in research is not only a way to understand their worlds and their thoughts, but also a means to empower disabled people.

However, as discussed in the 'Literature Review' chapter, in studies on intellectual disabled people's QOL in Korea, some questionnaires were answered by their parents instead of disabled people themselves. This manifests how disabled people in Korea are marginalised even in research about themselves and their lives. In contrast, in this study it is understood that reality is constructed by disabled participants' experiences and their interpretation of the world. Indeed, it is important to listen to their voices and understand the social world perceived by the participants. Therefore, the participants are not objects of the study, who answer questionnaires created by the researchers. Rather, the study understands the participants as people who work together with researchers to explore how disabled people live within Korean society. This view provided the disabled participants in the study with opportunities to talk about their stories, opinions and experiences in a more emancipatory environment and empowered disabled people in the research paradigm, although the study does not present a complete form of emancipatory research.

Scholars have long argued that interview is an appropriate and valuable method to elicit people's views, opinions, beliefs, information, attitudes and experiences to produce knowledge and find meaning therein as told through the interviewees' own voices (Arksey, 2004; Bryman, 2004; Kvale, 2007; Brinkmann, 2018). In order to listen to a range of opinions and stories, a semi-structured interview, rather than a structured interview, was utilised, since one of the strengths of the semi-structured interview is its flexibility compared to a more structured interview (Ritchie & Lewis, 2003; Bryman, 2004; Brinkmann, 2018). Brinkmann (2018, p.579) asserted that 'semi-structured interviews can make better use of the knowledge-producing of dialogues by allowing much more leeway for following up on whatever angles are deemed important by the interviewee', whilst structured interviews 'do not take advantage of the dialogical potentials for knowledge production that are inherent in human conversations'. The interviewers are also able to reword and reorder the interview questions and supplementary questions can be asked to elucidate on topics and clarify any uncertainty in the interviewees' answers in semi-structured interviews (Ritchie & Lewis, 2003; Bryman, 2004). Every interviewee is asked the same main questions in the semi-structured interview, but there is some flexibility in terms of what and how additional questions can be asked (Kvale, 2007). All of these aspects make the semi-structured interview technique flexible and fluid, while the prepared interview protocol serves as a guideline for each interview. A semi-structured interview can also help to mitigate issues arising from 'rambling' when performing unstructured interviews and lead the interview to focus on the issues that the interviewer deems as important for the goal of the research project with the interview protocol (Measor, 1985, p.67).

While the interviewees in the study told their experiences and views, they also delved into other topics and/or experiences that arose in their minds naturally and/or expanded on the scope of the context of their interviews and provided additional information which was not directly related to the questions asked. Therefore, I was able to explore their stories about their own lives, their views on social phenomena and their feelings in depth. The unexpected parts of the conversations made the interviews richer.

The details of the interview questions and information about the interviewees of the current study are discussed later, in addition to the interview and analysis process, when the process of the study is illustrated in full.

4.1.4 Data Analysis: Thematic Analysis

Thematic analysis has been known and used as 'data analysis techniques in the social sciences' and a 'method for identifying themes in qualitative data' since at least the early twentieth century (Terry et al., 2017, p.17). Braun and Clarke (2012, p.57) defined thematic analysis as 'a method for systematically identifying, organizing, and offering insight into patterns of meaning (themes) across a data set'. Willing (2013), however, argued that it is still contentious whether thematic analysis is a fully-fledged method or it is just a technique that supports various other qualitative approaches. Braun and Clarke (2006, p.77), therefore, observed that thematic analysis is hardly acknowledged as a method and poorly defined, although it is widely used as a qualitative analytic method. However, it is generally and widely accepted by qualitative researchers that coding of data begins ‘with a very basic descriptive level of coding and work[s] upwards in a systematic manner towards a more interpretative level’ in the thematic approach (Langridge, 2004, p.267). As a consequence of the process, researchers can identify overall shared meanings through looking at the meanings in the data set (Braun & Clark, 2012).

Furthermore, Braun and Clarke (2017, p.297) asserted that thematic analysis ‘can be used to identify patterns within and across data in relation to participants’ lived experience, views and perspectives, and behavior and practices; “experiential” research which seeks to understand what participants think, feel, and do’. The participants in this study recounted their life stories and experiences, as well as their feelings, thoughts and opinions. Through recounting their life stories, they shared their own experiences of how they were excluded from and discriminated against in society, and the stories contained complex social phenomena, attitudes and culture relevant to disability and disabled people and conveyed meaning. Therefore, I decided to use thematic analysis for my study, because thematic analysis allowed me to find patterns and meaning related to how the participants understand society and their position within society, how they feel about this and what they do to resolve problems. My approach to thematic analysis is the same as the one set by Braun and Clarke (2012).

I conducted an inductive study, which is a form of data-driven analysis which derives codes and themes from the data (Terry et al., 2017). Inductive study is in contrast to the deductive approach, which is a theory-driven analysis. In a deductive study, researchers bring a series of topics, concepts and ideas to code the data. As discussed in the ‘Literature Review’ chapter, not much literature exists regarding the QOL and citizenship of Korean disabled people. Therefore, it was hardly possible to determine the theoretical construct, pre-determined topics, concepts and ideas for coding prior to the study. Terry et al. (2017), however, claimed that it is not possible that a study is purely either inductive or deductive. Even when an inductive study is conducted, it is impossible for the researcher not to bring anything to the data. The semantic meaning of data would not be ignored completely when the researcher carries out a deductive study, which brings a theoretical framework to the data. Therefore, both approaches are often mixed in coding and analysing the data of a study (ibid.). Terry et al. also asserted that 'coding and theme development are assumed to be a subjective and interpretative process' and 'analysis is seen as something created by the researcher' (p.20). Therefore, how researchers apply their knowledge, conceptual standpoints, experiences and analytical skills in the process of analysis could result in various analyses for the same data (ibid.). From this point of view, my perceptions and concerns regarding disabled people and disability must have influenced my work in coding and analysis, since I set out on this study from my assumption of the existence of discrimination and exclusion of disabled people in Korean society and the influence of this on their QOL. Furthermore, Braun and Clarke (2012) maintained that analysis allows identification of meaning relevant to the research questions. Indeed, only through analysis did the answers to the research questions become apparent (ibid.). For example, some of the participants shared their stories about going to university, but only through analysis did the meaning of failing to enter a university which they wished to attend and their struggle to attain their rights on campus become apparent as part of an answer to the research questions. My analysis process will be discussed in the data analysis section in this chapter.

Before I carried out the interviews, I had thought about utilising critical discourse analysis (CDA) as an analysis method for this study. I expected the interviewees would directly criticise society and the content of the data would embrace 'relations between discourse, power, dominance, social inequality and the position of the discourse analyst in such social relationships', which is the presupposition in utilising CDA, according to Van Dijk (1993, p.249). The interviewees' discourses were socially constructed; thus, it seems CDA also would have been an appropriate analysis method to interrogate how society is constructed and to probe what material and structure were utilised in the construction (Fairclough & Wodak, 1997).

However, this study is the very first study in Korea which has listened directly to disabled people regarding their lives and their thoughts and opinions concerning their citizenship and QOL. They described their experiences and life stories in various settings. This was not what I had expected before the interviews. It seemed that keeping their narratives and stories as a whole would be more appropriate to deliver the nuance and meaning embedded in the narratives as the first study of this kind in Korea. Thematic analysis, which is interested in finding 'thematic meanings' and 'point of narrative', also seemed more appropriate in interrogating what living as citizens means to the interviewees and what the definition of QOL is in the interviewees' 'cognitive world'.

4.1.5 Trustworthiness

In qualitative research, trustworthiness, which has four components ('credibility, transferability, dependability and confirmability'), has been suggested as an equivalent to the ideas of reliability and validity in quantitative research (Guba & Lincoln, 1994, p.114), while generalisability is not commonly a goal of qualitative research, unlike its quantitative alternative. Guba and Lincoln argued that these four aspects of 'credibility, transferability, dependability and confirmability' could also be translated as 'internal validity, external validity, reliability and objectivity respectively' (ibid.).

Credibility can be understood as where 'investigators attempt to demonstrate that a true picture of the phenomenon under scrutiny is being presented' (Shenton, 2004, p.63). This study accomplished credibility, since all the procedures of the study, including the interviews, were carefully scrutinised and the procedures were described in detail to the participants and also in this thesis. In addition, all the procedures were reviewed and checked by the relevant supervisors and the Ethics Committee to accomplish credibility. Details of the process are described in the study to address transferability (or external validity), which concerns whether the data collected could be duplicated in different settings (Bryman, 2004). In terms of dependability (or consistency or reliability), Thomas and Magilvy (2011) argued that this is about the stability of the data. Bryman (2004) explained that reliability in qualitative research can be understood from two dimensions; namely, internal reliability and external reliability. Internal reliability is about 'whether members of the research team agree about what they see and hear' (ibid., p.273) when there is more than one researcher and/or observer. External reliability is about whether the study is replicable. However, for qualitative research, it is not possible to 'freeze' the exact setting of a study and make it replicable (Lewis & Ritchie, 2003). Shenton (2004) argued that dependability for qualitative research can be achieved by reporting the process of the study in detail. Therefore, a future researcher may duplicate a particular study, but the result may be different. The details of the research process have been reported in this chapter. Confirmability refers to the objectivity of the researcher. Shenton (2004, p.72) claimed that 'the concept of confirmability is the qualitative investigator's concern to objectivity'. The findings of the research should reflect participants' ideas and experiences rather than 'the characteristics and preferences of the researcher' (ibid.). I, as a researcher without any previous knowledge of or dealings with the interviewees, carried out the study and all the findings were supported directly by the narratives of the interviewees.

4.2 The Research Process

4.2.1 Sample Size

Suri (2001) argued that the sample size for the qualitative method can be small, because a qualitative study is not about generalising or representing a total population, but instead to gather rich information and allow for in-depth interpretation. Kohli (1981) suggested that a sample size of 15 is an acceptable minimum sample for qualitative studies, while Guest et al. (2006) asserted that 12 is sufficient, since 97% of key codes are discovered after that many interviews. Green and Thorogood (2009) argued that new themes begin to become saturated after 20 interviews are conducted, while Ritchie et al. (2003) recommended a sample size of under 50 for qualitative studies. Some studies have used particularly small samples, such as one (Sands, 1988) or three (Marks, 1989). The sample size can vary depending on the qualitative research method applied. It seems that there isn't a clear consensus on sample size for qualitative research.

In a research methods review paper, Alder and Alder suggested a sample size of between 12 and 60 as being suitable for graduate students, while experts emphasised the importance of saturation, rather than providing an appropriate sample number (Bake & Edwards, 2012). The participants in this thesis were assumed to have profound thoughts and ideas and to be capable of recounting in-depth stories, since they had all worked as activists and had spoken up for disabled people and themselves as leaders and representatives in the field of disability. A sample of 15+ participants was sought for this study, because this number was considered to be feasible and enough to create a valuable amount of rich qualitative data. A sample of 16 participants in the current study produced rich, detailed, deep and lengthy data, allowing for in-depth interpretation, which is important for qualitative research.

4.2.2 Research Participants and Sampling Process

The recruitment criteria for participants in this study were that they were involved in the disability movement as disability activists and worked as disability leaders in the field of disability. The reason behind recruiting people meeting such criteria was that it was assumed that they meet disabled people in various situations and from different backgrounds to listen to them and discuss and examine issues, so they were deemed to know about the different circumstances which disabled people face in society. Furthermore, they had more opportunities to think about the relevant issues, such as disabled people's citizenship and QOL, to address and articulate their ideas in public as disability representatives and act to obtain disabled people's citizenship and equal rights. Therefore, the interviewees were expected to have more comprehensive and detailed ideas concerning disabled people's citizenship and QOL. This does not mean that disabled people who do not meet such criteria do not have ideas about their citizenship and QOL and their opinions are not as valuable as the opinions of people in this study. I set the criteria because I wanted this study to provide a more comprehensive picture of disabled people's citizenship and QOL in Korea, since this study is the very first to examine disabled people's citizenship and QOL in Korea.

Two sampling strategies were combined to select participants. First, eight participants were recruited through a gatekeeper, a professor in the disability field who had worked with disability leaders and activists in Korea. The leaders included the President of the Seoul Centre for Independent Living, the President of the Korea Federation of Organisations of the Disabled, the President of the Korea Disabled Artist Association and a manager of a local independent living centre in Seoul, who was a former member of parliament. The selected leaders had all worked with professors in the disability field for various reasons, such as to share their ideas for research on Korean disabled people and to work together to improve disability policies. The leaders had worked in the disability field for a long time and were in high positions in Korean disability organisations, so they possessed abundant knowledge and information about Korean disabled people's lives and were expected to have profound thoughts and opinions on disabled people and disability. However, it was not easy to contact them directly, perhaps due to me not having any personal connection with disability or disabled people. Therefore, the activists were first informed by the professor (gatekeeper) about this study and agreed to give me their contact information. Eight relevant people meeting the criteria to participate were first introduced by the gatekeeper and were then interviewed.

For this study, purposive sampling was expected to be more effective than random sampling, since this study sought people who met the criteria. Purposive sampling 'is essentially strategic and entails an attempt to establish a good correspondence between research questions and sampling' (Bryman, 2004, p.333). After the initial eight interviews, the snowball sampling method was utilised, since it was difficult to find potential participants from the general population to expand the sample (Berg, 2007). I asked the initial eight participants to introduce others who also met the criteria for interview.

Overall, 16 participants were selected through the combined sampling strategies. Of them, 14 were physically disabled and two of them were blind. Four of them were in their 30s, six of them were in their 40s and six of them were in their 50s. Eleven of the participants were men and five of them were women. In terms of academic background, two of them had graduated from secondary school, two of them had graduated from university and 12 of them had completed post-graduate education. Four had only become disabled after their 20s due to an accident or disease. Some people had begun to get involved in the disability movement to challenge national policies and/or social infrastructure and/or social culture, while some had started their activities as students campaigning for disabled students' rights. Some of the participants were disability writers and/or publishers fighting for the rights of disabled people through culture; one participant was a businessman who supplied equipment needed for disabled people and spoke out about disabled people's living conditions; whilst some of them worked as leaders at disability organisations at the time of interview.

It seems that the education level of the interviewees was higher than disabled people in general in Korea and the range of impairment amongst the interviewees was also limited. First of all, the high education level and limited range of disability presents the tendency of the current demography of disability leaders in the field of disability in Korea. This might have resulted in a limitation in applying the data analysis to a whole range of disabled people in Korea, but also allows room for further research on the same issues with disabled people from a range of backgrounds.

4.2.3 Interview Protocol

Rabionet (2011, p.564) contended that there are two important ingredients in interview protocol: '(a) how do you (meaning the interviewer) introduce yourself to the person being interviewed and (b) what are the questions to be asked'.

4.2.3.1 Opening Interviews

I embarked on the interviews by introducing myself. Since I had not previously had any relationship with the disability field, I tried to introduce my background and myself in detail to establish a rapport with each interviewee. I explained that I had studied business management at undergraduate level and statistics at post-graduate level 20 years ago and had worked in advertising companies for most of my career, while I also talked about studying disability in the UK. After introducing myself, I began to explain the process and purpose of the study, as well as the rationale behind it.

Before I asked the questions directly related to this study, I began the interviews by asking each of them about their lives in general and asked them to recall their memories since childhood if the interviewee had been disabled from an early age. I also asked about any differences in their lives before and after they became disabled, if the person had acquired a disability in their 20s or later. I also asked questions about how they had become involved in the disability movement after I listened to their life stories.

4.2.3.2 Protocol Questions

This study set out from my assumption that disabled people's limited citizenship must deprive them of a satisfactory QOL. However, as discussed in the previous chapters, disabled people's citizenship and QOL have not received much attention as subjects of research so far in Korea. This has resulted in a lack of literature to assist in forming protocol questions. Instead, it was deemed better to ask the interviewees to define the meaning of citizenship and QOL in their own terms. As a result, the definition defined in this study could help in conceptualising citizenship and QOL for disabled people in Korea. I developed the protocol questions for the purpose of interrogating how they define the terms citizenship and QOL, exploring how disabled people are positioned and perceived in Korean society and understanding what they really want for their lives. Questions about the relationship between their involvement in the disability movement and their citizenship and QOL were also added. Based on feedback from my supervisor, the last question, asking about their hopes and goals for their activities, was added. Additionally, I asked the Korean professor who worked as gatekeeper for my initial eight interviewees for her recommendation. She responded that the questions looked appropriate.

Ultimately, the protocol questions were as follows:

1. How do you define a good QOL? What does a good QOL mean to you?
2. What do you consider to be important things for QOL and/or a happy life? (If this question had already been answered in the previous question, I briefly asked or even skipped this question.)
3. What do you think about your QOL?
4. What do you think about the QOL of Korean disabled people in general?
5. What does living as a citizen (*simin*) or a nation (*kookmin*) or a member of society mean to you? How do you define a citizen or a nation or a member of society?
6. How would you explain or what do you think about your life as a citizen or a nation or a member of society?
7. What do you think about the lives of disabled people in Korea as citizens or nations or members of society?

8. Do you think there is any relationship between your disability movement involvement and being a citizen or a nation or a member of society? If so, how are they related?

9. Furthermore, has your disability movement involvement affected your QOL? If so, how are they related?

10. How do you want your activities to affect the field of disability? Or do you have a goal for your activities?

4.2.4 Interviews

4.2.4.1 Participants

The 16 interviews were conducted between 10th June 2015 and 19th August 2015. The participants were asked to commit to one hour for interview on the information sheet. Most of the interviews lasted for between one hour and one-and-a-half hours. However, three interviews lasted for two-and-a-half hours, as the interviewees in these cases wanted to prolong their interviews. A private room at the relevant interviewee's workplace was utilised for 13 of the interviews. Two interviews were conducted in cafés and one was held in the tea room of an interviewee's dormitory on campus (no one else entered the tea room during the interview). The interviews were all conducted in Seoul, where all the interviewees worked. All interviews were conducted in Korean and were digitally recorded. All the transcriptions were stored as digitally recorded interview files in the same password-protected file on my personal computer and in a password-protected solid-state drive (SSD). Pseudonyms for all of the interviewees were used in the interview texts.

4.2.4.2 Rapport

Most of the interviewees welcomed me, despite having jobs and living busy lives. Age hierarchy is strict in Korean culture and 12 of them were older than me. I think that the age hierarchy might have helped in them being nice to me, as I was younger than 12 of them and new in the field of disability, and the hierarchy often requires generosity and kindness of older people to younger people. Many of the interviewees kindly explained things in detail which might have been unfamiliar to me. It was not difficult to see they were trying to help me.

Some of interviewees who were of a similar age were glad to talk to me. One of the interviewees in his 40s said he felt comfortable because I was of a similar age and I could understand what Korean society had been like in his 20s and 30s. He said he was somewhat worried that a young person would be conducting the interview. I also had a short conversation with another interviewee about social problems during his interview, since the interviewee asked for my opinion. The interviewee was also of a similar age and I felt this helped him in terms of sharing his stories. As discussed in the 'Literature Review' chapter, Korean society experienced big social changes, such as the June Struggle (*Yuwol Hangjaeng*) in 1987. It seemed that sharing a similar understanding of our social background helped to establish a stronger rapport with these interviewees.

As they were leaders in the Korean disability field, they were very interested in disabled people and disability policies in other countries, including the UK. An interviewee asked me for literature references from the UK to help with her writing after her interview, whilst another interviewee asked for some information about disability policies in the UK. One interviewee encouraged me to write about disability policies in the UK, so he could have a reference for his own writing. Meanwhile, another interviewee said, 'I helped you this time, so you need to help me next time'. It seemed that many of the interviewees did not think of me as an interviewer. Instead, it seemed that they thought of me as a person with whom they might work again in the future and such views helped them to talk about their personal stories more openly and to discuss issues in depth during the interviews.

4.2.4.3 Order of Protocol Questions

The main concern in asking the protocol questions was preventing the interviewees from developing and elaborating on the idea of citizenship before the idea of QOL. Although I informed the interviewees that the study was about disabled people's QOL and citizenship in the information sheet which had been sent before the interview, I did not want the idea of citizenship to permeate the interviewees' minds before they discussed their QOL. I was worried that the interviewees would be focused on and limited by the idea of citizenship when they discussed QOL. Therefore, I asked questions about QOL before the concept of citizenship.

4.2.4.4 Interview Process

Most of the interviewees were well aware of the purpose of the study and its topics at the interview, since they had read the information sheet beforehand. The questions regarding their life stories and their participation in the disability movement at the beginning of the interviews encouraged participants to reflect on their lives and on what it was like to live as a disabled person and as a disability activist. Their life stories naturally led me to ask about the main topics of this study: QOL, citizenship and the disability movement. When discussing their QOL and citizenship, they sometimes linked their thoughts and feelings to their life stories that had been told at the beginning of the interviews. The protocol questions were also reordered from time to time.

Anderson and Jack (1991) suggested using reflective listening, which involves rephrasing, paraphrasing and affirmations to bring out more of the interviewees' understandings, feelings and thoughts and to allow the interview to pass on to subsequent topics and further dialogue. They also argued that this reflective responding makes respondents' experiences more vivid and gives meaning to them, rather than leaving the stories just as a part of the text. During the interviews, I used reflective listening to express that I understood what the participant had said and I stated simple words as an expression of curiosity, which often led the interviewee to continue telling his/her stories. One interviewee, whose interview lasted for two-and-a-half hours, said that she knew whether a person was really listening to her or not by looking at his/her eyes, and she could see that I was listening, which encouraged her to talk for longer. Therefore, I was told many of her life stories and heard her profound thoughts and opinions on disabled people and disability.

4.2.4.5 Additional Questions

The prepared protocol questions were used as a guide to make the interviews flow and additional questions, such as 'Would you explain this with your life experiences?', were asked to clarify their thoughts and ideas and to enrich their responses. For example, when I asked one of the interviewees about his QOL, he explained why he was currently satisfied with his life. After this, I asked him to further explain his views by referring to his life experiences/stories when he had had a good QOL and/or when his QOL was not good and I also asked him to explain why this had been the case. He then illustrated his view using his life stories from childhood and explained why his childhood had been happy even though he was not able to go to school. He also identified how his childhood affected his current life as an adult. Such additional questions resulted in interview data being rich with stories.

Bryman (2004) claimed that researchers themselves act as the main tool in the process of collecting data in qualitative research. According to Peredaryenko and Krauss (2013), in such cases the researcher is an 'informant-centred' instrument who gathers information and knowledge from the interviewees. Researchers facilitate interaction and allow room for participants to tell their stories. In this study I, as such a tool, approached the interviewees to probe their knowledge and allowed them to share their stories and provide their opinions and information on the topics being studied. I was able to explore their stories of their own lives, their views on social phenomena and their feelings by asking the interview questions. Meanwhile, questions related to their stories were also asked, if necessary. The additional answers given by the participants could help to explain their thoughts and experiences more explicitly.

4.2.5 Data Analysis

4.2.5.1 Translation

All 16 interviews were transcribed in Korean after the interviews. Two of the whole interview texts were translated into English to provide explanations to supervisors of how the interviews had proceeded. Except for the two interviews, I only translated the parts used in the process of analysis into English. Sometimes, the interviewees talked unnaturally, even in Korean, and such parts were also translated into unnatural English. Pseudonyms were used in the interview texts.

The most difficult task in translation was finding adequate English expressions or words which conveyed meaning and nuance as closely as possible to the Korean expressions and words. When I faced difficulties in finding an expression or word, I asked people who were fluent in both Korean and English or provided an explanation about the word or expression in English to a Briton to suggest an English word or expression.

4.2.5.2 Data Analysis with Thematic Analysis

I followed the six phases outlined by Braun and Clark (2012, pp.60-69) in my approach to thematic analysis: 'Phase 1: Familiarizing Yourself with the Data; Phase 2: Generating Initial Codes; Phase 3: Searching for Themes; Phase 4: Reviewing Potential Themes; Phase 5: Defining and Naming Themes; and Phase 6: Producing the Report'. All transcribed interviews in Microsoft Word were imported into NVivo 10® before coding. The data analysis for the separate topics (citizenship, QOL and disability movement) formed the three different analysis chapters.

Before generating codes, I read and listened to the interviews several times to familiarise myself with the data. I simultaneously made some notes, such as 'a view of normalisation?' next to Youngji's story about her failure to secure a place at a university which she wished to attend and 'lack of opportunities?' next to Joonho's definition of QOL, or I highlighted words which I thought captured important insights or could explain the story. I did not intend to, but I began 'open coding'. Flick (2009, p.310) maintained that 'the result of open coding should be a list characterizing codes and categories attached to the text and supported by code notes that were produced to explain the content of codes'. Although the open coding process phase was not completed here, some of my notes from the initial reading became a code, some of them were discarded and some of them were collapsed with other notes and were renamed with a new code.

The protocol questions of the current study are clearly divided to probe different topics: QOL, citizenship and the disability movement. The questions were used as criteria to select data for different topics. Therefore, interviewees' answers to the questions relevant to QOL, citizenship and the disability movement were selected as datasets for QOL, citizenship and the disability movement respectively. The interviewees' life stories, which were asked about in the beginning of the interview were selected based on how the interviewees referenced the stories. For example, Minsoo described his life as a minority and he referred to this when he answered the questions related to QOL. The story became data for analysis on the topic of QOL. Data which were not referenced during the interviews were coded under different topics according to their relevance.

For each topic, coding was generated separately. Not all of the data were coded and one story was often coded under different codes. For example, I coded Sanghoon's story about citizenship under different codes, such as 'respect', 'a sense of belonging', 'impact of disability movement' and 'emancipated lives'. Some of the codes were driven from the participants' accounts, some of them were a kind of summary of the data and some of them were an interpretation of the data. The names of the codes were sometimes a word, a sentence or even a question. I constantly modified the existing codes, incorporated and collapsed them with other codes and renamed them. I also made sub-codes under some of the codes up to two levels. Some of the sub-codes became a new main code.

After I finished the 'open coding' process for citizenship, I noticed codes clustering around views on/prejudice towards disabled people and the importance of having a job and fulfilling responsibilities. A range of different views on disabled people were described in different codes. The coding process transferred to 'axial coding', which 'identifies relationships between open codes, for the purpose of developing core codes' (Strauss, 1998, p.109). The codes around views on/prejudice towards disabled people became a theme: ‘non-disabled people’s views on disabled people’. However, before finalising the themes, I combined the codes in different ways and drew different thematic maps to find a framework which answered the research questions better and told a coherent story of the overall data. In this process, the selective coding process was combined. ‘Selective coding continues the axial coding at a higher level of abstraction [through] actions that lead to an elaboration or formulation of the story of the case’ (Flick, 2009, p.310). Kangin’s opinion about institutional discrimination was coded under both ‘discrimination’ and the ‘meaning of a citizen’. The code ‘discrimination’ was added to the theme ‘non-disabled people’s views on disabled people’ and the code ‘meaning of a citizen’ was included in the theme ‘ways to be recognised as citizens’. In the analysis I quoted Kangin’s opinion under the theme ‘ways to be recognised as citizens’ instead of ‘non-disabled people’s views on disabled people’, because the opinion was better placed there to describe what the environment disabled people in Korea face in everyday life is like and to explain the meaning of citizenship for disabled people in Korea.

Searching for themes in the data relevant to QOL was not easy, but it was easier than in the data related to citizenship and the disability movement because the participants’ answers to the questions related to QOL were more direct and clear. I observed that codes clustered around different issues related to their QOL *relatively* equally. I drew different thematic maps, but decided to list the themes articulated as being important for the QOL of participants and disabled people. I found that some of the data described and demonstrated the participants’ life stories and the issues and social phenomena related to their QOL in more detail than other narratives for the same theme. This was the result of some of the interviewees explaining their thoughts and stories in more detail during the interviews. Therefore, some interviewees who discussed issues in depth and in detail appeared in the analysis more often.

It took longer to find themes and settle on a final thematic map for the disability movement than for citizenship and QOL. The research question was about the impact on both citizenship and QOL of involvement in the disability movement. It was found that codes were clustered around themes such as ‘identity’, ‘solidarity’ and ‘fellowship’ the first time. However, the themes did not succinctly answer the research question and capture what the data really told. After looking further at the data and drawing a range of thematic maps, themes related to stages of activity in the disability movement, such as ‘beginning’, ‘growth’ and ‘accomplishment and future’ were developed. Citizenship and QOL were found to be changed and improved through the stages of involvement in the disability movement. I thought it was more appropriate to explain how their citizenship and QOL were developed through their stage of involvement in the disability movement. This allowed me to explain how their involvement in the disability movement actually affected their citizenship and QOL.

I analysed the data based on whole data. I did not categorise the data based on other different characteristics, such as gender or age or duration of their disablement. However, I noticed that some differences existed in the opinions and views of people who acquired their disability at early ages or people with congenital disabilities, and people who acquired their disability after their 20s. However, the differences have not been specifically analysed in this study. Gender difference, which is often raised as a topic of study, was not specifically identified during my analysis.

4.2.6 Ethics

Hammersley and Traianou (2012, p.16) claimed that ethics can refer to:

> A field of study, concerned with investigating what is good or right and how we should determine this. In this interpretation, ‘social research ethics’ means the study of what researchers ought and ought not to do, and how this should be decided.

Lincoln and Guba (1989) argued that ethics in qualitative research pertains to a position held by the researcher, whilst Shaw (2003, p.11) asserted that ethics in social work resonates with ‘a contextual or situational ethical position, with the emphasis on researchers’ moral values and ethical skills in reflexively negotiating ethical dilemmas’.

In addition, Peled and Leichtentritt (2002, p.148) claimed that ‘ethical standards and procedures should be developed and understood in the context of a relationship that takes place between the researcher(s) and the researched’. It is important to notice that research is a kind of dialogue between researchers and the researched which produces valid knowledge (Reason & Rowan, 1981) and the researcher needs to be concerned with the moral aspects of the relationship with the researched in the study (Reamer, 1982).

This section describes the ethical challenges which I faced and explains how my values and my concerns regarding relationships with the participants acted to influence the decisions made when challenges arose.

4.2.6.1 Asymmetrical Power in Interview

Shaw (2003, p.12) argued that ‘the relationship between researcher and respondent is one between equal partners with equal voices. The respondent therefore keeps control of the process’. Nevertheless, Brinkmann (2018) claimed that interviewers define the interview situation and approach interviewees with scientific competence and lead the interview in each step of the process, such as initiating the interview, establishing the topic, asking the questions, following up on the answers and even ending the interview. Thinking of the interview as a dominance-free process can be an illusion, since the interviewer controls the conversation for his/her research aim and agenda and has specific knowledge interest (Rapley, 2004; Kvale, 2007). Furthermore, an interview is generally conducted in a one-directional questioning and answering process: interviewers ask questions and interviewees answer the questions (Rapley, 2004). When the role of the principle is broken and interviewees begin to ask questions, it is often considered ‘bad taste’, as Brinkmann (2018) claimed. This can happen because the interview is sometimes understood as a means of conveying the researcher’s goal of obtaining narratives, texts and descriptions which the interviewer can interpret according to his/her research interests (ibid.).

However, I understand participants as people who work together with researchers, whilst I believe that it is important to respect participants and value relationships with them. In addition, the interviewees in the study knew they were experts in the field, not only as leaders and activists, but also as scholars, since many of them had a degree or degrees in the field of disability. As a result, it seemed that I did not own much dominant power as an interviewer, although I led the interviews. Most interviewees seemed to feel comfortable in telling their stories during the interviews, since the majority of the participants were accustomed to talking about their stories as disability leaders and activists and/or as authors who had published their life stories. They looked to me to be quite comfortable and confident.

4.2.6.2 Interviewees’ Vulnerability

Dalton and McVilly (2004) claimed that vulnerability and coercion must be taken into consideration when interviewing vulnerable people, whilst Lai et al. (2006) pointed out that a protective attitude for the purpose of ethics might rather exclude vulnerable people from research. Although the participants of this study were disabled people who may sometimes be considered as a vulnerable group, I think that understanding the participants of this current study as vulnerable people as object of research does not seem right.

All interviews took place where there were people around whom I could ask for help, if it was needed, since 13 interviews were held in their offices, with other colleagues working next door, two of the interviews were held in cafés and one interview was held in a tea room in a dormitory. During the interviews, two interviewees stated that they were becoming emotional while they recounted their memories of their mother and family. Even when they said they were becoming emotional, they smiled. When this happened, we took a short break to allow them to regain their composure or we had an informal chat. When they were ready to restart the interview, they answered the questions again or continued talking from where they had stopped.

However, I should have paid closer attention to the participants' post-interview emotional vulnerability. The participants recounted their life stories, which included unpleasant memories, but I did not sufficiently consider the emotional difficulties of recounting the memories which they *might* have had after the interview. Kostovicova and Knott (2020) maintained that scholars have not paid sufficient attention to the emotional discomfort driven by the participants' process of creating knowledge, while the issue of participants' emotional distress during interview has been much focused on in research ethics. They, therefore, argued that participants' post-interview emotional harm, which could have occurred after the process of creating knowledge, also needs to be taken into consideration by researchers. In particular, I was committed to the study being a collaboration between the interviewees and me. On reflection, checking the participants' post-interview emotional vulnerability would have been appropriate and important.

4.2.6.3 Rapport with the Participants

Duncombe and Jessop (2002) maintained that the researcher sometimes has a hidden agenda or goal for the interview. In order to gain what the interviewer wants, the interviewer could sometimes manipulate the dialogue and the relationships with interviewees. Duncombe and Jessop claimed that interviewers would sometimes engage in 'faking friendship' and 'doing rapport' in an unethical way to obtain knowledge. However, as the participants and I proceeded to explore how disabled people live within Korean society through the interview process, we developed our relationships. The relationships were like ones that comrades would have. We found reasons to fight for disabled people's rights against current society. Furthermore, some of the interviewees were also disability writers. Some of them asked me to recommend articles from the UK after the interview and I also provided some information as a colleague in the disability field. Some of the participants in the study expressed their appreciation for the opportunity presented to them by the interview. They explained that the interview gave them a chance to reorganise their thoughts and plans. Hutchinson et al. (1994) claimed that qualitative interviews can also present an opportunity for participants to demonstrate self-awareness, self-acknowledgement and to feel a sense of purpose and empowerment, as well as a chance to experience a sort of healing process. I keep in touch with some of the interviewees via email. The emails consist of greetings and keeping in touch. I do not perceive any expectations from them. I did not have any difficulties in exiting from the research relationships with the participants. This might be because the participants had experience of being interviewed and they are all busy.

4.2.6.4 Process of Analysis

I did my best not to misinterpret and/or to undermine and/or overestimate the data to seek to convey the real meaning of the data, as Rapley (2004) warned interviewers to focus on what the interviewees really tried to explain. I promised that a one-page summary (in Korean) of the study would be sent to the interviewees after the thesis was finished. The interviewees all agreed to this and did not express any concerns about the study or interview when asked. However, it would have been preferable to the study to have sent interview transcripts and, furthermore, my analysis to the participants to confirm if there was any miscommunication. I did not want to waste their time, since the interviewees were all busy. However, it would have been better to have at least asked their preference regarding reviewing their interview and my analysis. Reid et al. (2018) asserted that ethical dilemmas exist in the phase of exiting the study. It would have been more ethical for me, using their stories and experiences as my data, to ask for their thoughts and opinions, since an interview is a collaboration between participants and the researcher, not an interaction that shares knowledge (Tanggaard, 2009; Fujii, 2017).

4.2.6.5 Consent Form

An informed consent form is important for studies involving human beings as subjects (Berg, 2007; Bryman, 2004). The consent form and information sheet for this study were approved by the University of Bristol's School for Policy Studies Research Ethics Committee. The consent form and information sheet were sent to each interviewee before the interviews via email. Two of them were blind, but they had a machine capable of reading PDF format documents at their offices. Signed consent forms were received at each interview after I had asked the respondents whether they had any questions or concerns regarding the interview. All respondents' names were kept confidential in this study.

4.2.7 Researcher's Reflexivity

Gouldner (1971, p.16) asserted that reflexivity is about 'analytic attention to the researcher's role in qualitative research' (cited in Dowling, 2006). Ackerly and True (2010) claimed that reflexivity pertains to a recognition that researchers are also a part of the social world which they examine. Reflexivity is a continuous process for researchers to understand, examine and recognise how their 'social background, location and assumptions affect their research practice' (Hesse-Biber, 2007, p.17).

It is worth reviewing my background to understand my positionality, which may have influenced this study.

I studied business management and statistics at undergraduate level and post-graduate level respectively. After I finished studying, I worked in advertising companies as a media specialist and in a fashion magazine company as a marketing manager. Having meetings with clients and colleagues and communicating with people was one of the most important parts of my work. It is through these circumstances and experiences that I was shaped as a communication specialist. In contrast to this, I did not have an academic background in social science and did not have any prior personal experience of disabled people before conducting this research. It is also important to note that I began my disability study in the UK and not in Korea.

Doubtless, my previous personal background must have affected the study. This study involved my journey away from objectivism and positivism stances towards social constructionism and interpretivism as ontological and epistemological stances respectively in every process of the study from setting the research questions to analysing data and writing the thesis. My career experiences may have influenced the interviewing of the participants and the development of relationships with them. I respected the participants in the interviews as partners who were working with me, instead of understanding them as research objects which I needed for my research. My career experiences also helped me not to immerse into the relationships with the participants and to know how to respond to the participants' requests and emails without being embarrassed. Setting out on disability studies in the UK may have caused me to approach the study from understanding disability and disabled people within the context of disability studies from the UK and the West and, furthermore, to choose a qualitative study to listen to disabled people in person. At the same time, this allowed me to consider and problematise disabled people's position in research and some words and issues which were naturally accepted in the Korean disability field, such as the usage of the words 'social support' for disabled people, which I argue can be interchangeably used with social network or social relationships. Furthermore, my age helped me to build a rapport with some of the participants, as discussed above. However, I did not notice any gender differences or benefit/harm during the interviews or in analysing the data, although there were more male interviewees.

This chapter outlined methodologies, demonstrated the rationale behind the methodologies and elucidated the research process. The findings from the analysis of data for each topic follow in the next three chapters in the following sequence: 'Citizenship', 'Quality Of Life' and 'Disability Movement'.

Chapter 5: Citizenship

5.1 Introduction

This chapter is based on my analysis of the answers given by participants to the interview questions related to the concept of citizenship, such as what citizenship means to them or how they would define this, and what they think about their life or the lives of disabled people in general as citizens. The answers also included their relevant life experiences and opinions. This chapter informs us how disabled people live in Korea and how they think they are perceived and positioned by non-disabled people within Korean society. This will also steer readers towards a position where they can understand the participants' stories, opinions and feelings more comprehensively in the next two analysis chapters; namely, 'Quality of Life' and 'Disability Movement'.

The 16 participants conceptualised citizenship from different points of view. Regardless of how they conceptualised citizenship, they described how their lives differ from non-disabled people's lives and how they are treated differently in society. In many of their accounts, the participants discussed how society is constructed in the form of a dichotomy of a society for disabled people and a society for non-disabled people. Therefore, I open this chapter with Minsoo's story, which depicts his perception of the dichotomous society (section 5.2), before proceeding to explore the interviewees' accounts by themes. The following section is 'Non-Disabled People's Views on Disabled People' (section 5.3). This section focuses on examining how disabled people are perceived by non-disabled people. It is crucial to investigate non-disabled people's views on disabled people, since disabled people live together with non-disabled people within Korean society. However, non-disabled people's views on disabled people are examined through the participants' understanding of non-disabled people's perceptions of disabled people, since this study aims to investigate how disabled people understand the concept of citizenship and QOL and interviews were conducted only with disabled people. Although this will limit the understanding of non-disabled people's views on disabled people, it is still worth interrogating non-disabled people's perceptions of disabled people even through the participants' understanding. The next section is 'Disabled People's Views on Disabled People' (section 5.4). Some participants described the difficulties which disabled people often face in society and criticised society for causing such difficulties for disabled people. Thereafter, this chapter continues to explore how disabled people live within Korean society (section 5.5) and the various ways suggested by participants in which disabled people can be recognised as citizens (section 5.6) and finishes with summarising this chapter (section 5.7).

Each participant conceptualised citizenship. Five of them—namely, Kangin, Heesun, Sanghyun, Heechan and Joongsoo—articulated the concept of citizenship as referring to 'rights' and 'responsibilities', whilst three of them—namely, Minjae, Younggil and Una—emphasised the recognition of the differences of disabled people and identified the importance of 'social rights' for citizenship. Three of them—namely, Jongun, Minsoo and Hojin—talked about citizenship in terms of a 'sense of belonging', whilst Jiah also emphasised the recognition of the differences of disabled people and discussed 'membership' as part of the concept of citizenship. Meanwhile, Youngji, Joonho, Sanghoon and Chulsoo each discussed the topics of 'mutual help', 'social participation', 'safeguarding of the nation' and 'recognition and autonomy' respectively in the process of conceptualising citizenship.

The details of the participants' opinions and views on their citizenship are discussed in the following sections, which reveal in-depth insights into how they are positioned within Korean society and how they want to be perceived and live as equal citizens.

Table 2: Themes and Sub-Themes for Citizenship

Themes	Sub-Theme
Non-Disabled People’s Views on Disabled People	Being Different Beneficiary The Unblessed The Vulnerable Not Existing in Society
Disabled People’s Views on Disabled People	Education Personalities
Disabled People’s Lives in Mainstream Society	Not Being Valued Sense of Belonging
Ways to Be Recognised as Citizens	Having a Job and Paying Tax Re-Imaging Disabled People

5.2 Minsoo’s Narrative: Dichotomous Society

Minsoo elucidated on his experiences to clarify how society is divided for him and disabled people by extension. In the special school which Minsoo attended, junior high school students (year 7 to year 9) and high school students (year 10 to year 12) studied in the same building. Classes for high school students in Korea are five minutes longer than for junior high school students. However, the bell in the special school which signalled the end of class rang only for the junior high school, so the bell automatically applied for high school students too. Therefore, Minsoo, who was a high school student in the special school, received 30 minutes less education per day than students from mainstream high schools. Minsoo recalled a story of when he ran into a group of students coming out from a mainstream high school on his way back to school with a snack bag in his hands.

> Minsoo: After school … I was on the way back to school after I had bought some snacks. The time coincided with the time that friends from other junior high schools and high schools go home from school. There was an alleyway and the width of the alleyway was about the same size as this office. Hundreds of people were coming from the opposite end, like this, but I was in a situation about to go from the one end to the other end alone. It was like a hugely shocking moment. The flow of people was, then, very general, universal. There was nothing like, any different serious special message. I didn't see anything like that while these friends passed me by chatting and romping. However, the flow of how people moved and walked seemed like a very general flow. When I saw this, it didn't seem like a flow of people to me; rather, I got the impression that a certain value was moving. However, I was put in a situation where I had to move against this. Honestly, the reason that I was able to finish 30 minutes earlier and came out of school earlier than the friends was a 'discount', discounted 30 minutes ... and it was a time I felt very ashamed about holding the snack bag in my hand.

As Minsoo said, there was nothing immediately remarkable about this situation. However, it probably made Minsoo think more about his circumstances. Minsoo was in a situation where he had to move against the students from other, non-special schools. He considered the students to be representative of a general value. This implies that he did not think he was part of this general value stream. Rather, he thought he was separate from this general value and seemed to be going against the stream.

At that time, Minsoo left school 30 minutes earlier than students in other high schools. Having 30 minutes discounted from each of their school days, which must have diminished his learning opportunities, was something that he had not chosen himself. This was decided for him, without his permission. He articulated this as a 'discount'. However, this was not the only such 'discount' that he experienced at school. When he was asked how he lives as a citizen, he gave several examples to clarify how he does not think he lives as an equal citizen. One of the examples he gave was the lower cost of school lunches for those at special schools (compared to that at general schools). He recounted that when he found out the low cost of school meals, he asked himself whether this lower cost menu was made specifically for disabled people. His education was diminished by 30 minutes each day and his nutrition must also have been discounted in comparison to what he could have enjoyed if he attended a mainstream school rather than a special school. He had probably experienced this 'discount' repeatedly throughout his life, probably even before attending the high school. These experiences may have caused him to consider his life or aspects of his life as being different from other general values within society. He instantly matched the general values of society to those non-disabled people who attended general schools. Minsoo expressed or referred to this marginalisation in terms of a 'discount' in the sense that his rights to education and nutrition had been reduced or diluted.

From his point of view, there is clearly a dichotomy in society. If disabled people such as Minsoo understand this society as one espousing general values versus 'something else', then how people positioned within this general value think about these 'others' (here, the general value would be non-disabled people and 'others' would be disabled people) and how they understand this society are very important because their thoughts would affect society and the lives of disabled people as equal citizens. The next section identifies non-disabled people's views on disabled people.

5.3 Non-Disabled People's Views on Disabled People

This section explores non-disabled people's thoughts and views about disabled people according to the participants' understandings. According to many of the participants, disabled people are often perceived as people who are different from non-disabled people, are routinely stigmatised and their existence is often not even recognised by non-disabled people within Korean society. This section provides insights into how disabled people are positioned in non-disabled people's minds within society from disabled people's points of view.

5.3.1 Being Different

One of the interviewees, Jiah's, disabled friends moved into an apartment. Community members living in the same building complained about the inconvenience of living and sharing utilities, such as lifts in the building, with disabled people. Jiah, as their friend, approached the community members to discuss the issues they had raised.

> Jiah: They said disabled people have never lived in this apartment building, but what they said was that they don't dislike living with disabled people in the building and don't mean that disabled people should leave … but what they said was that it is just inconvenient. They said, 'It is so hard for us'. Eventually, what they meant was that this inconvenience is hard and it is awkward and unfamiliar. Eventually, this unfamiliarity results in difference and it becomes the case that disabled people are different, so shouldn't they live in another place? Not here. It is like this. While I was talking with the community members, I realised it was so hard to become accepted as a citizen and as a community member.

First of all, the community members did not have the right to ask whether disabled people should leave the apartment or not, since everyone living in the apartment paid their rent. Therefore, everyone living in the apartments had their own rights. It seems that the non-disabled community members here were trying to prove or demonstrate that they were not narrow-minded by saying that, 'They [we] don't dislike living with disabled people in the building and don't mean that disabled people should leave'. They might have even been trying to prove that they were generous. However, telling a person that you don't dislike living with ‘someone’ in front of that person might reflect their understanding of their position in the relationship. Above all, they seemed to understand or position themselves as people who could give permission to Jiah’s disabled friends. This means that they thought they were dominant in this relationship between disabled people and non-disabled people and, furthermore, they perceived disabled people as objects to whom they could give or deny permission.

‘It is so hard for us’ is a statement reflecting a very dichotomous discourse. In this sentence, although ‘you’ is not stated expressly, there is still a clear boundary or distinction between ‘us’ and ‘you’. Looking at the statement ‘It is so hard for us’, it can be identified that ‘you’ (the disabled) made trouble for ‘us’ (the non-disabled) because ‘you’ crossed the line between ‘you’ and ‘us’. This perspective can be understood from the community members’ argument that disabled people had never lived in the apartment building. Here ‘us’ must mean people who live in society, where ‘you’ (disabled people) do not exist and where every system is settled by ‘us’ without ‘you’. So, this insinuates how ‘you’ do not have any ownership within this arena, but ‘you’ are here and this creates difficulties for ‘us’. The boundary line must have previously been very high and difficult to cross, meaning that disabled people had never been able to live in the apartment building mentioned in the narrative. It is likely that disabled people had never dared to try to live in this apartment building. From Jiah’s account, the division between disabled people and non-disabled people is clear. The dominant position of non-disabled people within the discourse is evident, while they even tried to use their dominant position to influence disabled people.

Jiah also spoke about another instance.

> Jiah: We do an event where we take a bus once a month. I was stuffed onto a bus at Heahwa-Dong, just a bus. I was brought onto the bus by university students and I stayed in a narrow space. Then a young man said, ‘This bus is not for disabled people’. I asked him, ‘Are there different buses for disabled people?

> Do I need to take that bus? Just let me know'. Then the person turned his face the other way. In this way, people think things are separate for us and that disabled people should do things differently to them.

There are low-floor buses in Korea which do not have stairs and have wider doors and wider aisles, so wheelchair users can easily get on. These buses started to run after a long struggle by disabled people concerning their rights to mobility. However, the proportion of low-floor buses among the total number of buses is still very small. It is likely that the young man was referring to these low-floor buses and might have been trying to show some kindness by letting her know this. However, he perhaps did not know how rarely these buses run because it did not matter to him, since he could take either. Having access to all of these buses meant the young man was likely to be unaware of the difficulties of travelling and so he had not paid attention to this issue. Not paying attention to matters which do not affect our lives is very common. However, unless disabled people's lives are considered by non-disabled people, the former cannot live as equal citizens with non-disabled people, since non-disabled people are major citizens in terms of population and actually dominant citizens within current society.

In Jiah's first narrative, the community members at the apartment building said that they didn't dislike living with disabled people. This could be interpreted to mean that they do not discriminate against disabled people per se. However, it does seem that they were trying to exclude disabled people from staying there because they found living with disabled people 'inconvenient'. Although the community members on this occasion claimed that they did not dislike living with disabled people, the very fact that they were complaining about living with them represents a form of discrimination. If these complaints were accepted, this would have amounted to exclusion. The man on the bus who turned away after Jiah asked questions could be interpreted as signalling that he no longer wanted to be involved. If he knew more about the low-floor buses, he could have explained this better. However, he did not have any wish to be involved in a conversation with Jiah. He showed a clear unwillingness to do so by turning away and avoiding a conversation. He drew a line between himself and Jiah.

Jiah described how she, her friends and disabled people in general can be excluded from society. Jiah said, ‘I realised it was so hard to become accepted as a citizen and as a community member’ in her first narrative. However, exclusion is sometimes expressed in an even more direct and negative manner by non-disabled people and disabled people are often stigmatised and marginalised in Korean society. In the following section, non-disabled people’s perceptions, which often obstruct disabled people from attaining the position of equal citizens, are illustrated.

5.3.2 Beneficiaries/The Unblessed/The Vulnerable

Jiah’s second narrative poses the question of whether disabled people would be free from discrimination and exclusion if they caught a low-floor bus. Chulsoo talked about a specific instance of taking a low-floor bus as an example to describe how he lives as a member of society.

> Chulsoo: … the low-floor bus is a right, but if a wheelchair user gets on the bus, some people would start to glower at that disabled person, right? Then, I should appreciate people who don’t glower at me. Why? Why should I appreciate this? Why do I need to? Then, er … should I ask this of people who glower at me? Why do you …? So, I mean, for example, they would talk down to me and ask why you are getting on the bus at this busy time.

Chulsoo’s narrative suggests that disabled people who get on the low-floor bus at busy times can be treated as ‘intruders’ who delay non-disabled people and take space and time from them. For Chulsoo, the low-floor bus is a right. This exposes a huge gap in the mindsets of disabled and non-disabled people regarding this one issue. In addition, glowering at someone and talking down to a stranger for no reason are clear expressions of discrimination. Indeed, non-disabled people seem to try to exclude disabled people from the low-floor buses as well. Low-floor buses do not seem to really be built for disabled people either. It seems that there are no limitations preventing non-disabled people from taking the bus, but this is not the case for disabled people. The low-floor bus is another place where disabled people seem to require permission from non-disabled people, much like the example of the apartment building in Jiah's first narrative.

The non-disabled people's attitudes pose some questions such as why non-disabled people would think disabled people should not be busy when they are busy and why non-disabled people think disabled people should be appreciative for being able to take the bus. Heesun's narrative below might partly answer these questions.

> Heesun: Only after I go out of my apartment door, the man living next door and the man living downstairs, whom I meet in the lift, would ask why I go out to work every day. They say, 'Since both of you are disabled people, you probably get a lot of money from the government'. As they say this, they see disabled people like that. However, before this, if they asked what I do, then I would answer their questions. They don't ask. These questions are always omitted. Instead they ask, 'Why do you go out, even though the government provides a lot of money?'

To non-disabled people, disabled people might seem like people who only receive benefits from the government. Disabled people are often perceived as people who are a waste of government finances because of welfare services for them. In other words, from the perspective of many non-disabled people, disabled people might seem to be taking advantage of them. Indeed, the low-floor bus, from the perspective of many non-disabled people, might not be a disabled person's right. Such misunderstanding can create a wide gap between disabled people and non-disabled people and may even produce instances of discrimination, such as people glowering at, talking down to and even turning away from disabled people as gestures of exclusion. As a result, those spaces in which disabled people can stand in society as equal citizens would become narrower and fewer and disabled people could be viewed and thought of as less than equal members of society. However, misunderstanding might not be the only reason why non-disabled people would think like this. Another cause could be stigmatism. Stigma attached to disability has long been embedded within society and has obstructed disabled people in terms of living as equal citizens.

Chulsoo recounted his experience with one particular community member regarding his disability.

> Chulsoo: My ex-wife was a non-disabled person. Ah, I can’t forget this. I was disabled by contracting polio and I can’t walk further than 20 metres. So, when I walk a long distance, I use an electric wheelchair. Once, while we walked together, a community member said to me, ‘You are blessed’ and to my wife, ‘You will be blessed’. Yeah, this is violence. Not only hitting people is violence.

This narrative represents another dichotomous way of thinking within the disability field: ‘You are blessed’ versus ‘You will be blessed’. Having a non-disabled spouse is seen here as a blessing for disabled people according to the opinion of this community member. The concepts of being blessed and being cursed have become somewhat intertwined with the idea of disability. That you are blessed to have a non-disabled wife could be interpreted to mean that you were originally not blessed or that you may even have been cursed. That you will be blessed because you have a disabled husband could mean that you are compassionate enough to get married to a disabled person, so you will or should be blessed. To this community member, disability must clearly have been a stigma which positions people as being different, tainted, discounted and deeply discredited from others. Here, how disability is understood by non-disabled people is clear: disabled people are cursed individuals who need charity to be a part of non-disabled society rather than equal citizens.

As some of the previous narratives illustrate, disabled people are frequently perceived as having lower value than non-disabled people. However, this does not only happen within communities, but also within the workplace and labour market where disabled people enter through the usual channels and processes, as Jongun pointed out below.

> Jongun: When I joined the company, I didn’t feel that people in the company thought of me as an equal colleague. They didn’t seem to think of me as a competitor or, er … a colleague, but a little bit as a person who needs help? It was like that. It was huge. So when people who joined the company with me brought their work, sometimes they were scolded and so on. However, when I brought my work, I was rarely scolded. They only said, ‘Oh, you did good, you did good’, although actually, I am not a person who does work well. I think the expectation of me was very low.

‘A person who needs help’ is a statement whereby disabled people are often seen as symbols of vulnerability or deficiency. Disabled people are often not treated equally in society. Sometimes this manifests itself in the form of discrimination or over-care/over-kindness. Both of these approaches make disabled people feel uncomfortable. Although not expressly said, it is clear that Jongun wanted equal treatment from her boss and colleagues, just like anybody else would. She understood this interaction within the context of being disqualified or valued less as an employee within the company. The over-care described here can stem from ideas or notions that disabled people are not capable of receiving criticism or scolding. Jongun’s boss might have thought that scolding a disabled person would not be appropriate. Alternatively, the boss might have been worried about being seen as an impolite person by scolding a disabled person who is vulnerable according to the common non-disabled perspective. One clear thing is that Jongun understood that she was different from others in the boss's mind. She was over-cared for by colleagues instead of being marginalised. This is nevertheless a way of discriminating and can be a way of expressing stigma. Jongun had graduated from the most prestigious university in Korea and worked at a public corporation. So, the colleagues in her office must have been well educated on how to act towards people who need beneficence. However, categorising disabled people in non-disabled people's minds as people who need beneficence might have been caused by stigma. Furthermore, this is still the same as identifying disabled people as less than equal citizens.

5.3.3 Not Existing in Society

Another interviewee, Heechan, recounted his experiences with the student union at his university. He received support from the student union in the process of appealing to the university for special needs due to his disability. This case describes another instance of misunderstanding towards disabled people.

> Heechan: Honestly, they see disabled people for the first time. So, something like this happens. They see a disabled person for the first time, but I speak pretty well and get along with people, I do like these ... So, they see me as a very amazing person. This is also a form of prejudice. So, I told them disabled people are not a god, you don't have to look up to me and, if you know me well, I am not a very outstanding person. I told them you should break this kind of illusion, but this was not broken easily. Anyway, since this happened, they tried hard to support me, yes, they did.

The students in the student union had not met any disabled people in the approximately 20 years of their lives. This narrative shows how disabled people can be 'invisible' in Korea. Of course, some of them might have seen disabled people on the street. However, they had never been involved with disabled people in terms of a social relationship, such as being friends, fellows, community members or classmates. Heechan stated, 'I speak pretty well and get along with people'. This infers that Heechan thought that non-disabled people often think disabled people usually do not have these kinds of abilities or characteristics. Heechan, nevertheless, started to solve the problems caused by his disability at his university on his own and managed to get the student union involved in the problem-solving process. He might seem to be an amazing person to his non-disabled friends. However, Heechan identified the lack of opportunities for non-disabled people to meet disabled people as a reason for this inaccurate view. A lack of opportunities to meet non-disabled people means disabled people do not have much chance to become part of society, since non-disabled people represent the majority. This creates another barrier for disabled people in terms of living as citizens.

The participants' accounts clearly illustrate how disabled people are often stigmatised, misunderstood, discriminated against and excluded by non-disabled people and they depict how disabled people are routinely invisible in Korean society. Disabled people do not seem to exist as equal citizens in the minds of many non-disabled people. This might result in a failure to recognise disabled people as citizens in social systems, infrastructure, policies and the community in general, essentially erecting a barrier hindering disabled people from living as equal citizens.

As discussed before, all of the accounts were provided by the participants, who are disabled people. There must be some limits in understanding non-disabled people's views about disabled people in terms of disabled people being citizens. However, as this study aims to investigate how disabled people understand the concepts and how society is constructed within their minds as a result, the participants' understanding of non-disabled people's perceptions of disabled people can ultimately help to interrogate how the participants actually understand how this society is constructed in their minds and provide even partial information about how non-disabled people recognise disabled people as citizens.

5.4 Disabled People’s Views on Disabled People

The participants, as leaders in the disability field, had all met disabled people from various backgrounds. Some participants talked about the lack of opportunities and domestic abuse of disabled people causing barriers, which hindered disabled people from belonging in society and criticised the reasons for such problems existing in the first place.

5.4.1 Lack of Opportunities to Be Educated

Minjae and Joonho talked about the lack of opportunities for disabled people to be educated due to exclusion.

> Minjae: … [disabled people in general] have not been able to go to school close to their homes within their community, and they have always been excluded from education due to the fact that they have a disability. And these opportunities, they are not often allowed. So because of this, disabled people’s capabilities are often obviously, whoever sees this, a little lower …
>
> Joonho: so … many disabled people have lived isolated lives and have been excluded from general communication. And they are often not properly educated. Indeed, they are often not able to give any information … or it is hard to get attention from others.

Disabled people have often not been educated properly, so they may lack knowledge and skills. This results in disabled people being broadly considered as people who cannot provide much information, so it is also hard for disabled people to get attention from others. This seemed natural, even to disabled people, according to the participants. It is not difficult to guess how non-disabled people view disabled people.

5.4.2 Domestic Abuse of Disabled People

Kangin, who did not receive a formal education until he went to a university, identified another reason for disabled people undergoing difficulties in belonging in society.

> Kangin: I am … family didn’t send me to school, but they brought me to relatives’ weddings or, anyways, I have been … well … they didn’t hide me and within the family, I was treated well. In this way, I have grown without being hurt. However, as I have met many disabled people within this society, they have been wounded seriously, not by society, but by family members. So, basically they can’t be healthy. Then, as they are daunted and then, the … on top of the disability, as they are psychologically shrunk, they don’t do well in their social life. [Lines omitted.] As, if you want social inclusion, then relationships, affiliation and participation are also important, but you should be able to know about self-protection. So … there is no one who grows up to have this skill of self-protection.

Weddings are very sacred ceremonies in Korea and also occasions to meet up with all relatives and acquaintances. So, if parents think their disabled children are cursed or bring shame on the family, they will not bring their children to a wedding, since they would want to hide their children and their disability. Kangin seemed to identify weddings as an example of how his family members treated him. He outlined that growing up with love and respect—as well as a formal education—can be important to help people live in society.

Una explained that if people grow up without love and respect from their family members, it can affect their social lives in a negative way, while she talked about a particular member of her organisation.

> Una: she has often heard bad words from family members, mother and father, such as ‘crikey’, ‘retarded’, ‘how would you live?’… instead of being understood and embraced for things like her disability and lisp. If she comes to us, she can do a lot of things by being able to move her body among disabled people, but she has always been treated like this at home. She now currently works as an administrative worker at a school. This is not easy for disabled people. Anyway, she gets information fast. As she went out to find this and that, she was able to get a job. However, it seems that she has had trouble with teachers at school because of this. She quarrels with teachers and the head teacher because she has a character that she doesn’t want to lose. So, now the head teacher doesn’t argue with her because the head teacher has realised it is not good to get on her nerves.

Although this member of Una’s organisation has the necessary skills to collect information and solve problems (such as finding a job), she does not know how to work with other staff at her workplace. Una discussed how this particular member had been mistreated by her family members. The member of her organisation had been discriminated against and abused by her own father and mother. Her disability does not seem to be serious, as Una clarified that she is a big help at her organisation because her physical disabilities are limited. However, her emotions and characteristics seem to have been harmed by her family. This organisation member is overly self-protective, an interesting contrast to Kangin’s claim that disabled people lack skills in self-protection. Whether people are too self-protective or lack skills of self-protection, if they have been abused and hurt by their family members, Kangin and Una argued that they would find it difficult to get along with other members of society. Getting along with people is not just about a material relationship, it is an emotional and psychological relationship. So, unless people can interact with others emotionally and psychologically, it can be difficult to integrate well into and belong in society.

Younggil, who thought he had integrated well into society, picked out his personality traits as the reason behind this.

> Younggil: although I am not highly educated, I have the intellectual ability to get a job and to integrate with others. And I have a well-rounded personality, so I didn't have problems in community life or in my career path.

The purpose of Kangin, Una and Younggil's accounts was not to claim that disabled people need to establish or fix their personalities to integrate well and belong in society. Rather, they raised the issue of domestic abuse which is often perpetrated on disabled people by their family members. As a result of abuse, disabled people often cannot develop personalities which enable them to get along with people and to belong in society. Belonging is an important aspect for people who want to live in society, as well as in terms of citizenship, although not all people need to get along with others and belong in the same type of community or do not need to feel the same degree or same kind of a sense of belonging. Una revealed in another narrative that the member of the organisation often had trouble with other members of her organisation, which constituted only disabled people. If disabled people develop personalities that hinder them from belonging in society because of abuse as a result of discrimination against them, the issue of abuse should be paid more attention and taken into consideration in discussion about disabled people's citizenship.

The above participants, Minjae and Joonho, who talked about the lack of opportunities for disabled people to be educated, and Kangin, Una and Younggil, who discussed domestic abuse, do not blame disabled people's lack of education or personalities, which often obstruct disabled people from belonging in society. Rather, they criticised the social systems and social structures which prevent disabled people from belonging in society.

5.5 Disabled People’s Lives in Mainstream Society

This section espouses that simply having a better education and a well-rounded personality would not eradicate the discrimination and exclusion which is so often suffered by disabled people in society.

5.5.1 Not Being Valued

One of the interviewees, Sanghoon, described his life story as follows.

> Sanghoon: Maybe I was well-assessed in school, but not in other places, especially in the labour market, although I finished my master’s degree faster than any others with a great mark, at a well-recognised school. I finished my master’s like this. I did bring a signed letter of recommendation from my supervisor in my research centre, the centre. I applied to a related research centre with my thesis and with the recommendation. However, the research centre didn’t show any interest in my research at all, such as what my results were, how I wrote the thesis, what I contributed and what I would do in the centre. They have never had any interest in me. I did not appeal to them, or they didn’t favour me at all. And after my disability had become more severe, people, including my mother, treated me as a patient. Whenever relatives visited my home, my mother always said, ‘My son is ill’. She always said this. We have an alumni association. We meet one or two times a year. We get along because we are friends. But they look at me with pity ... some kind of pity ... Due to this kind of perspective I am not often involved in business conversations used in normal society. There is this side of my life. But within the field of disability, oh … people have been very nice to me.

It seems that Sanghoon has been educated to a level which is higher than many within society achieve and higher than society expects citizens to attain. He also seems to have a suitable personality to get along with people and knows how to socialise. However, it seems that he has been marginalised and/or discriminated against by 'normal society', as he expressed that, 'I am not often involved in business conversations used in normal society'. There is clearly a dichotomous argument in Sanghoon's narrative above as well. He depicted his life as being within two separate societies: one within so-called 'normal society', versus one within 'the field of disability' (Sanghoon described mainstream society as 'normal' society in the above narrative). It seems that he did not feel that he had been treated fairly within mainstream society.

He had been treated as an ill person among family members and perceived as a pitiful disabled person by his friends within society. He has multiple disabilities (he talked about his disabilities in narratives which are not included in the study). He has been blind in his right eye since birth. He is short and explained that he is about the height of a tall preschool student. This might result in his friends perceiving him as a pitiful person. However, he asserted that he did not consider the blindness in his right eye as much of a disability, whereas in his late 20s, he suffered incomplete spinal paralysis and he was hospitalised for months at that time and again about 10 years later. His suffering incomplete spinal paralysis made people, including his mother, consider him an ill person.

However, the words disability and illness are still sometimes conflated in Korea, although the two Korean words are completely distinguished each other. From this point of view, disabled people would always be treated as members of society who need to be rehabilitated or recovered, which would make it difficult for them to feel a sense of belonging and to live as citizens in mainstream society. Therefore, some disabled people might seek a society of their own and operate within that arena and live like citizens within that society. For Sanghoon, this arena may mean the field of disability where people are nice to him, as he discussed in the above narrative. Disabled people are often rejected, not only in public life such as in the job market, but they are also hardly accepted as they are in areas of their private life.

Una talked about experiences in her love life which had driven her to give up.

> Una: Disabled women would have disabled women's identities even when they get old. It is certain that this must have something to do with internalised standard appearance—the idea of normalisation? However, only when a counterpart also breaks this perspective can it be connected, because I can never be a 34-24-34, so to speak. However, if a counterpart hasn't removed the appearance value defined by society and hasn't formed a new perspective then I am the only one who has formed this new perspective. This wouldn't work, yeah? When it happened, I thought about the social perspective of women, as a disabled woman, a lot.

Una discussed the standard comprehension of what constitutes beauty by using the idea of normalisation. Due to her counterpart's internalised perception of the standard appearance of women established by the idea of normalisation, it seems that Una has failed in her love life. As she mentioned, she cannot fit the standards of beauty which society usually expects of women. However, her appearance is not associated with her ability or skills which she sets out to develop. Both Sanghoon and Una's cases clearly elucidate that the reasons for exclusion and discrimination against disabled people are not always based on their education and personality. Rather, these are often based on a lack of acceptance by non-disabled people of differences in terms of how disabled people look and act. Non-disabled people often set their own standards and do not accept anything which fails to satisfy this standard. When disabled people are viewed and devalued according to this standard—'the idea of normalisation'—they fail to be recognised and valued as citizens as a result.

5.5.2 Lack of Sense of Belonging

Another interviewee, Joonho, described how he feels when he is involved in relationships with his friends. He also talked about how he is marginalised within society in the following account.

> Joonho: Not only when friends of mine just do well to me. When they ring and visit, drink and talk while they go through a hard time, I feel I am deeply connected to this society and involved, I mean, formally and informally, and I feel that I also constitute a part of this society. On the other hand, in spite of this, occasions when I don't feel like this are the moments when I am disconnected from my social status. For example, when I take the underground or when I walk, ride on wheelchairs through the middle of the streets of the Hong-Ik University area[4], when I do these things, some … some people whom I think superior, who are a bit closer to the standard and normal beauty, when people like this pass me in the streets, honestly, if the people, you know? If they knew me well, it could be different but practically to the people whom I meet on the streets, I am just a disabled person. When this happens, er, something like, you know, if my social role is removed, I think that I can look, very … only, just trivial.

According to Joonho's discussion, disability itself would be the very first and only thing on which to judge and assess disabled people when additional information such as social status is not available. When this happens, the reactions of non-disabled people can discourage disabled people and this could cause them to have feelings of inferiority—experiencing internalised oppression. Joonho divided his life into two realms: one where his social status was revealed to others and one where it was not. His social status seems to play a main role

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[4] This is a trendy area for young people.

for him in terms of living as a member of society. However, his disability, in fact, is crucial for his citizenship, because he would be treated differently because of his disability, in the event that his social status was removed. This means that his disability is the main barrier for him to live as an equal citizen. Joonho also thought that non-disabled people’s appearance was superior and that his appearance looked trivial by comparison.

One interesting point in Joonho’s narrative is that it tells stories that differ from the position presented in Sanghoon’s experiences with his university friends. In spite of Joonho’s disability, he seemed to have equal relationships with some non-disabled friends. However, it seemed that Sanghoon has been somewhat excluded from general relationships with his university friends. One of the reasons for this could be the age difference between Joonho and Sanghoon. There is more than 15 years between them. Heechan, who managed to get the student union involved in the process of his appeal to the university, also had somewhat different relationships with his university friends compared to those of Sanghoon. Joonho and Heechan were in their 30s, while Sanghoon was in his late 40s. It could be assumed that there might be some changes in the societal views held by non-disabled people when they spend time with and get to know disabled people. Attitudes differed according to age in the survey data on Korean citizenship, an issue which was discussed in the ‘Literature Review’ chapter. The survey found that people in their 20s and 30s were more in favour of ‘other’ people and their freedom compared to people in their 40s and older. The discrepancy here in terms of the way in which disabled people are viewed by those of different ages can also be found in another interviewee’s narrative. Una provided the following example, discussing how she lives as a member of society.

> Una: Young people are little bit better, looking at disabled people in a calm manner, but they don’t help. This often happens. However, people in their 40s and 50s talk down and ask me how they can help me, but I can tell how difficult their lives are from their faces and their looks, yeah? They are not bad; they don’t mean anything by it. However, the social convention which permeates

> their minds is that disabled people are weak and somehow they need to help. They approach disabled people from a sympathetic and charitable view.

Disabled people have long been impeded in their attempts to be acknowledged as equal members of society with a full sense of citizenship because of the common social perception of disabled people being within a framework of charity and empathy. It seems that views and social perceptions have changed among the younger generations. However, young people are unlikely to be aware that sometimes disabled people do need help. Of course, the charitable perspective of disabled people affects disabled people negatively, and hinders them from living as equal members of society. However, on the other hand, indifference is not helpful for disabled people to live as equal citizens either. Living as citizens involves interacting with others and sharing their thoughts and feelings, as Joonho explained. He described how deeply connected he felt with this society, where his friends shared their emotions and feelings with him. On the contrary, Sanghoon, who was excluded from business conversations among his university friends, but was welcomed within the disability field, clarified what constitutes a sense of belonging within the disability field.

> Sanghoon: As things go along, boundaries … disabled people who are within the boundary of the idea of IL [Independent Living] … and this movement clearly feels that they are members of society. Society in this case is not the overall society; rather, this is a society which we have made, a network which we have created. In this society, we live emancipated lives. Well, there are hierarchical … class differences, even in here. There are people who earn more money. Although there are people like that, at least existential and psychological stresses because of disability can be resolved. So, among those people, they don’t call each other ‘this idiot’, ‘that idiot’. Rather, they say ‘disabled person Kim’, ‘disabled person Choi’. Disability is like a medal. If the disability is lesser, the person would instead feel diminished. Ha ha ha. Only that slight disability … ? We tease the person, ‘How dare you talk about your disability?’

Although the degree differed from respondent to respondent, disabled people do seem to feel abandoned by mainstream society to some extent. Accordingly, some disabled people instead seek places where they can share their feelings of being abandoned by 'normalised society' and can talk openly about their disabilities, which are considered deficiencies within 'normalised society'. As long as their disabilities are not seen as disabilities, they can live freely. Sanghoon described that they live emancipated lives within the boundary. As members of society, they are able to share their feelings within that society. Not only Sanghoon, but also Joonho emphasised sharing feelings as an important element of feeling attached to society in his narrative. This refers not only to sharing their feelings, but also to being respected as equal members of society. Sanghoon claimed that they do not call themselves 'this idiot' and 'that idiot'. This could infer that there are some places where disabled people are called such derogatory names. If disabled people are called or regarded as 'idiots', it seems that it is not easy for them to live as equal members of society, since they are not respected properly.

Although disabled people have the ability, knowledge and personality to get along with people in society, it seems difficult for them to be accepted as equal members of society and to feel a sense of belonging, unless their differences are recognised and valued. This begs the following question: is it impossible for disabled people to be valued as equal members of society? Some participants discussed how disabled people can be valued as citizens in the following section.

5.6 Ways to be Recognised as Citizens

Some participants suggested some ways in which disabled people could become recognised as citizens by other members of society.

5.6.1 Having a Job and Paying Tax

Younggil suggested having a productive job as a way for disabled people to be better respected as members of Korean society.

> Younggil: I hope disabled people can do productive jobs more. In many cases, disabled people are ... beneficiaries. So not only creating this environment, these conditions, if disabled people pay tax, then self-esteem would go up and they could live with confidence.

Having a productive job and being able to pay tax are not just a citizen's right and duty which are related to economic life. Younggil claimed that disabled people can easily become beneficiaries and are often unable to pay tax. This seems to result in disabled people being marginalised and some non-disabled people even believe that disabled people take advantage of them, as discussed above in Chulsoo's and Heesun's narratives. These social attitudes seem to make it difficult for disabled people to build self-confidence. Indeed, Younggil argued that if disabled people pay tax, it would be a good way to increase their confidence as citizens. Another interviewee, Sanghyun, also emphasised paying tax and participating within society when he discussed the meaning of being a citizen.

> Sanghyun: What our association insists on and advocates for is that we should make disabled people pay tax. The … disabled people are accustomed to receiving too much, but I hate this. Of course, I can't say things about receiving, because the pension right is a right, but I hate that people think this is natural and don't try to come out of it. So, from this point of view, I, well, among disabled people, I think I participate within society pretty well, and I actively participate in, like, voting and then I also report things like illegal parking, something like … I think I participate in society in various ways.

Sanghyun also particularly addressed paying tax in his discussion on the meaning of citizenship and related paying tax to the idea of participation within society. Although he did not clearly specify having a job and making money, he mentioned that ‘disabled people are accustomed to receiving too much’. This might mean that he might have wanted to contend that disabled people need to have a job and make money. It seems that he understands that disabled people would have more opportunities to participate within society and feel a sense of participation within society if they have a job and work in society. Sanghyun also did not associate the idea of having a job and paying tax solely with economic activity. Rather, Sanghyun argued that having a job and paying tax is a way to participate and belong within society. This would probably lead to disabled people being better accepted as citizens. Another interviewee, Heechan, pointed out the importance of roles and duties and also related paying tax and having a job to the roles and duties that mean you are a citizen or member of society.

> Heechan: … a recognised life with roles and duties … If you become a student, you should be able to go to school and should be able to get a job and should be able to vote. Like this, it shouldn’t be different from other people. It is not special because I am a disabled person … so I can do the same things. These kinds of roles should be like that, should be done, yes, should be done. Also, responsibility, it is not like you don’t have duties because you are a disabled person. Tax can be relevant here from a broad concept. From something even like that … if I do have like this, it can sometimes be hard. If I don’t have a job, then the state would give me money, then it could be easy. However, I think if I am a member of society, having proper roles and duties like that would make me feel that I am a member of society.

The fact that Heechan emphasised roles and duties in his narrative indicates that disabled people are often excluded from opportunities to take on roles and fulfil duties that non-disabled people take for granted. Heechan also claimed that although disabled people can obtain financial support from the government when they do not have jobs, having a job and paying tax would be better for them. However, in real life, it is not easy for disabled people to find a job at a high enough level that would entail having to pay tax. First of all, as has been argued by many interviewees, because of exclusion from public education and society it is difficult for disabled people to have the skills necessary to obtain a job and/or jobs are often not offered to disabled people even though they have a sufficient level of skill. Even after gaining a job, not many disabled people secure the job for a long time. However, social welfare is cut off for disabled people when they start to work. Disabled people often have extra expenses due to their disability, so their earnings might not cover their cost of living. All of these circumstances may reduce disabled people's desire to have a job, leaving many remaining in this beneficiary status. In respect of this, Joongsoo raised the question of the state's responsibility for people being citizens and members of society.

> Joongsoo: I think people should fulfil responsibilities and duties, but the state should support people to fulfil responsibilities and duties. Yes, this is the most basic thing.

Joongsoo also highlighted the responsibilities and duties of citizens rather than rights when discussing the meaning of citizenship and being members of society. This can apply to paying tax, which is one of a citizen's basic duties in Korea. However, it is more difficult for disabled people to reach a position where they can pay tax compared to non-disabled people. Therefore, Joongsoo also emphasised the state's responsibilities. Disabled people sometimes need support from the state to reach a position where they can pay tax. Nevertheless, this support is often not properly provided in Korea for disabled people. Indeed, Joongsoo argued that the state has responsibilities to support disabled people in this regard. Failure of disabled people to fulfil their responsibilities and duties might sometimes be a result of the unwillingness of disabled people, but it is often a result of a lack of state support. Everyone has different circumstances, but ways of fulfilling responsibilities and duties are often standardised. This standardisation, stemming from the idea of normalisation, can be part of a process excluding disabled people from enjoying their rights and fulfilling their duties. As long as the state sets out that paying tax is a citizen’s basic duty, people who are not able to pay tax can be marginalised as citizens to some extent.

5.6.2 Re-Imagining of Disabled People in Non-disabled People’s Minds

Heechan contended that disabled people are not currently viewed as citizens within Korean society.

> Heechan: Currently, in their minds they do disability policies or something like these not from the point of view that these are rights which disabled people deserve, but rather they think that these are special treatments for disabled people. No matter whether the amount of money is big or not or whether elements of services are various or not, the point of view itself demonstrates, I think, that this society is still not satisfied that disabled people can live as members of society. This is not related to increasing budgets or the variety of services offered. Although they do some of those things, it is different if they do those things because they think we are also citizens or because they think we are in need due to our disabilities. If they do it like this, would this not be charity? From this point of view, it is not good enough.

Heechan argued that unless all of the services and policies are based on the idea that disabled people are citizens, then the framework would not be sufficient for disabled people to live as citizens. Kangin suggested that disabled people should take part in society and challenge non-disabled people to pay attention to their lives as a kind of solution.

> Kangin: I think society is … ‘give and take’, it is a basic concept. This is not about whether you can play a role or not … even if it’s a small thing … like this … because the relationship is like this. I thought there was a chance for me to expand myself from a disability activist to a social activist. So, when I have

> concerns and interests about local problems, I can also say to non-disabled people that you need to be interested in local and disabled people's problems.

Kangin outlined the importance of active participation within society as a member of society. From his account, it can be found that the disability field is distant from mainstream society. It seems that disabled people's problems are not included within the problems of wider society in which non-disabled people live, such as local problems. So, he put himself actively into mainstream society and has gone beyond the disability field. This enables him to be integrated within society instead of staying only within the disability field.

However, Kangin also highlighted discrimination, which obstructs disabled people from actively participating in society in the following narrative.

> Kangin: Other than institutional discrimination or employment or educational discrimination, cultural discrimination is also huge … so, then discrimination against people like me rather than non-disabled people … discrimination against general disabled people rather than people like me, especially discrimination against people with a developmental disability or people with a mental disability amongst disabled people is still very high within our state.

Kangin raised cultural discrimination as a difficult obstacle for disabled people to overcome as members of society as well as other forms of discrimination. Cultural discrimination is reflected in how people within society think and live. This cannot be resolved only by reorganising some parts of society or amending individual policies or laws. Rather, the whole of society should be reformed and reorganised. Culture is soft but deeply embedded within society over years and decades. Even when the whole of society is restructured and all the policies for employment and education for disabled people are amended, unless the culture of the society changes, discrimination will remain. This problem was also reflected in Heechan's narrative above. Along with physical output, such as policies and economic benefits for disabled people, psychological and cultural ideas embedded within Korean society, such as how disabled people are positioned in non-disabled people's minds, need to be revisited. Unless this social perception is reconsidered, disabled people can only be treated as those who are in the care of non-disabled people and do not fit into society.

As a result, disabled people cannot live as equal citizens within society as a whole. Instead, some disabled people would seek places and areas made exclusively for disabled people, such as the disability field. It seems that there are two societies within this current society: one is for non-disabled people and the other one is for disabled people. The wall dividing the two societies seems to also be very high and solid, so disabled people cannot cross it. Unless people who live in both societies are willing to break the wall, it cannot be broken down. Sanghoon finished his interview by talking about the goals of his work as an activist. One of his final goals is to form a society in which disabled and non-disabled people can live together.

> Sanghoon: So, I hope people can realise that living with disabled people is happy. Not that disabled people are happy in their area, but not happy outside of the boundary; disabled people can be happy everywhere in society.

In Sanghoon's other narrative in this chapter, he explained how happy he is within the boundary of the disability field, because he shares his life with other members of society. When he shares his feelings, he is content with his life and thinks that he lives as a member of society. Sanghoon wants to feel the same things even outside of this boundary. When that happens, he will become a real member of society and become a citizen within society as a whole. From his narrative above, it is not difficult to gather that this is not happening right now in real life. As this remains his final goal, this implies how eagerly he wants this to become reality. This must not be only his goal, but that of most disabled people.

5.7 Chapter Summary

It is very clear from the narratives in this chapter that Korean society is divided into two societies. Disabled people are often discriminated against, stigmatised, misunderstood and excluded from non-disabled people's society. As a result, disabled people often lack the opportunity to gain the necessary discipline and education. Furthermore, disabled people are often abused by others, even family members. This often results in disabled people experiencing difficulties in belonging with other society members. Even disabled people who are educated within the Korean mainstream education system and can get along with people in society are often not accepted as equal citizens so cannot feel a sense of belonging within mainstream society, because disabled people's differences are not recognised and valued in society. Disabled people's differences might be recognised and valued if they fulfil duties and participate in society actively. However, unless non-disabled people, who are dominant in the population, revisit and re-imagine their perceptions of disabled people, disabled people will not be able to become recognised and valued as equal citizens within society. Bearing in mind the definition of citizenship applied for this study, the findings in this chapter clearly show that disabled people in Korea rarely enjoy full citizenship. Their differences and humanity are often not recognised and valued, so they cannot feel a sense of belonging. The next chapter will reveal how the participants defined and articulated QOL.

Chapter 6: Quality of Life

> Younggil: So, there is a high possibility that most disabled people in Korea don't even know what a good quality of life is … I think so. I think that a good quality of life is in an ordinary life. But disabled people don't even know what 'ordinary' means. I think this is the current situation for Korean disabled people. I think so.

6.1 Introduction

This chapter is based on my analysis of the interview data which investigated how the participants defined QOL, what they perceived to be necessary or important elements of QOL, how they perceived their QOL based on their own different experiences and contexts and what they thought of the general lives of disabled people in Korea. However, the participants' discussions about QOL overlapped somewhat with the concept of citizenship, even though the analysis of QOL in this chapter is solely based on participants' discussions relating to QOL. Readers may be confused in some parts of this chapter regarding whether the participants are talking about their citizenship or their QOL. This indicates that the concepts of citizenship and QOL are closely related to each other for disabled people. However, the participants' discussions about QOL are not linked with the concept of citizenship in this chapter; at this stage, QOL and citizenship are considered as separate concepts. Work investigating how the two concepts are related to each other is examined in chapter eight, entitled 'Discussion'.

This chapter is constituted of five sections discussing themes raised as being important for disabled people's QOL, such as social relationships (section 6.2), power (section 6.3), opportunities (section 6.4), life attitude (section 6.5) and leisure (section 6.6), and one section about personal finances (section 6.7), which was articulated by the interviewees in this study in a different way from the findings in previous Korean empirical studies. The chapter finishes with the chapter summary (section 6.8).

Each participant defined what a good QOL means to them. Some of the definitions listed below and further definitions are analysed in the following sections.

> Joonho: A certain amount of time needs to be secured, as well as situations and circumstances that I can control. [Lines omitted.] A person needs to be able to mobilise resources that help to make their life unique.
>
> Youngji: … considering pursuing a life where I can be valued/merited.
>
> Minjae: … one where I can do what I really want to do. It would mean joy, happiness and pleasure.
>
> Joongsoo: … If I am happy even without services … if you have purpose and consciousness ….
>
> Younggil: … one where disabled people themselves can plan, make decisions and ultimately live a life which they decide.

The participants' definitions clearly reflect how they want to control their lives and what they value most in their lives can vary from one person to the next.

Table 3: Themes and Sub-Themes for Quality of life

Theme	Sub-Theme
Relationship	Emotional Exclusion Collective Solidarity
Power	Agency Power
Opportunities	Unequal Opportunities Lost Opportunities
Life Attitude	Positivity Self-Initiative
Leisure	
Personal Finances	

6.2 Social Relationships for QOL

Some participants explained how having a sense of belonging in society can enhance their QOL, but many felt they did not belong in mainstream society. Some suggested alternatives, such as finding places of solidarity where they can belong. This section discusses how disabled people are often excluded from mainstream communities and society and how this negatively affects their QOL.

6.2.1 Emotional Exclusion and Oppression

Joonho discussed the QOL of disabled people in general as follows.

> Joonho: The main reason for low QOL is, I feel, that they are excluded because they are not able to closely participate in society. [Lines omitted.] In terms of space, they have been deinstitutionalised, but still, they can’t participate in

> formal participation, of course, because they don’t have a job, so formal participation is very limited for them. And in terms of informal participation; for example, general relationships, relationships with neighbours … or what else? Also relationships with friends, of course, and dates, they are also very often excluded from informal participation as well. They take part only in a few communities for disabled people. [Lines omitted.] So, well, nowadays … many ordinary people don’t make a family. If they don’t do this, they need to have communities in which they can participate. However, disabled people usually don’t have these communities. And even where they do, usually these communities would just be churches … or just a few communities, and the disabled people are not even closely involved within the communities informally. So then, they are just formal members of these communities. Since disabled people are not deeply involved within communities in an informal way, it seems that there is considerable emotional exclusion. This leads to a very unhappy life. And, although they have vouchers for movies … they have these kinds of things … but … they don’t have people to go with.

Joonho was very clear in explaining the circumstances of disabled people in Korea as members of current Korean society, specifically in terms of participation. He first divided this concept of ‘participation’ into formal and informal participation. He bypassed a more in-depth discussion on formal participation and proceeded directly to informal participation. This is because he believed employment to be a way of reaching formal participation and there has long been a lack of employment for disabled people. This rather reminds us of the lack of opportunities for disabled people in the labour market and reflects how naturally and readily these circumstances are accepted. His discussion about the partial participation of disabled people recognises and emphasises how disabled people have been hindered, or even restrained, from enjoying full participation in Korean society. He focused more on the lack of involvement in informal participation as a primary reason for the low QOL of disabled people. According to his argument, disabled people are often not closely involved in communities in terms of informal participation, although they are formally involved in communities, such as churches and a few other communities. Here, he says ‘just’ churches and ‘just’ a few communities. It seems that he is not satisfied with the communities in which disabled people participate. Possible reasons for this could be the characteristics or range of communities, or that the existing relationships with disabled people are often based on charity and empathy. Whatever the case may be, it can be interpreted clearly that, even in informal participation, disabled people do not seem to be welcome to join a wide variety of communities. He also expanded upon the notion of participation in communities by discussing how disabled people participate in communities either formally or informally. He claimed that disabled people are not even involved in informal participation informally and this results in a low QOL.

Joonho started his argument by discussing the concept of exclusion: ‘they [disabled people] are excluded because they are not able to closely participate in society’. But the opposite can also apply, whereby disabled people are not able to participate in communities because they have been excluded from these communities in the first place. Joonho further supported this idea. He contended that disabled people experience difficulties when it comes to penetrating communities even after being deinstitutionalised. This can lead to disabled people being excluded from communities and can result in segregation. This exclusion results in a lack of participation outside of institutions. The previously mentioned form of exclusion, referred to as institutionalisation, generates a further form of exclusion whereby disabled people lose the opportunity to participate in communities because of the gap between life within institutions and life within communities. This physical exclusion results in ‘emotional exclusion’.

In his narrative, Joonho discussed the severity of disabled people’s ‘emotional exclusion’. This was also described through the stories of friends he had met when living in an institution (this narrative is not extracted for this thesis). These friends had been deinstitutionalised over time as society had changed. However, these friends, who are in their late 20s and early 30s, have little to do and nowhere to go after leaving these institutions. Therefore, they need to stay at home all day and simply do nothing. They feel lonely and disconnected from society. Joonho claimed that this leads to them experiencing not only physical exclusion, but also deep emotional exclusion. He argued in the narrative that he was particularly lucky to have had a good education and employment, but his experience is rare for those with disabilities.

He did not discuss the labour market or marriage as elements affecting the QOL of disabled people. Nevertheless, only lacking in involvement in informal participation would not constitute the primary source of disabled people’s low QOL. A lack of opportunities in the labour market and difficulties in getting married could also be responsible for a much lower QOL. However, it seems these are difficult issues for him to even discuss because of the current low employment and marriage rates for disabled people in Korea. This omission may highlight how severely disabled people are excluded from marriage, the labour market and other forms of formal participation. Some interviewees did discuss the difficulty of getting married as a disabled person and these narratives are presented later in this chapter. Joonho, meanwhile, naturally accepted that disabled people often do not get married.

Another interviewee, Heesun, also emphasised that relationships with people is the most important component of a good QOL.

> Heesun: I think it is people. So, you should be able to live well in harmony with others. For this, you shouldn’t oppress others and shouldn’t be oppressed either. You should feel very free among people. It should be this way, but there are a lot of social causes which means this doesn’t happen. And disability acts as an element of oppression for us who have a disability.

Heesun clearly identified people as a cornerstone in terms of QOL. Interacting with other people is central to her idea of QOL. However, she also suggested the premise of not oppressing others and not being oppressed. This begs the question as to why she did not suggest concepts such as ‘helping each other’ or ‘loving each other’ or ‘respecting each other’, which would be more positive than ‘not oppressing each other’, to ensure harmony, which is clearly a positive term. This leads to some speculation that she might have experienced oppression more than love or help or respect in society or her experiences of oppression might have had a stronger impact on her QOL than other issues. She continued by discussing how disability can become an excuse or reason for oppressing disabled people. It seems that her life has been negatively affected by this oppression in attaining a form of freedom among people and within communities, since she described oppression as inhibiting people from achieving a status of freedom. However, such freedom is a desired status and is significant for her in terms of her QOL.

6.2.2 Collective Solidarity

Heesun discussed freedom in her definition of QOL in the following excerpt.

> Heesun: But the freedom … I can’t be free alone … but only with other people, in relationships with others, I can be free, other external … Something … I mean, if I want to protect myself from factors which affect me, I should end up having power. The power … I should improve my power. But improving power … so … mainstreaming disabled people through something like policies … but, I am thinking of something better than this, since time has already passed, so you should think of alternatives. Having solidarity with people who are like-minded … it is not necessarily a huge amount of solidarity, just with some people, something like collective solidarity. I think this could be a solution.

She also emphasised relationships as an important element determining QOL. She used the words ‘protect’ and ‘power’, which are somewhat contradictory to having a status of freedom. This shows how she and other disabled people have been oppressed in communities. She may have found unequal power distribution in society and therefore she suggested collective solidarity as a way to improve power. This begs the following question: Why did she advocate having relationships with others in collective solidarity, but not in mainstream society? She even suggested collective solidarity as being a better way to improve power than mainstreaming. It seems that she held a negative perspective of mainstreaming for disabled people or may even have considered the idea impossible and suggested the establishment of an independent world instead. She said: ‘I am thinking of something better than this, since time has already passed, so you should think of alternatives’. This means that mainstreaming has already been attempted in Korean society, but didn’t materialise in the manner that she wished. In addition, this may mean that mainstreaming has provided some sources of oppression for disabled people. In another narrative (the narrative is not extracted for this thesis), she recalled her life working as a public official. She described this experience as a life being lived within mainstream society. However, she described how she resigned from the job after three years, after concluding that she could not continue to live a life like that. She recounted how such a life was slowly killing her. This is also described in the next chapter, ‘Disability Movement’, when she discussed how her life changed after participating in the movement. For her, mainstreaming could mean having a job that was usually held by a non-disabled person. However, it seems that she experienced a form of embedded oppression towards disabled people and found that disabled people could not improve their power within mainstream society. This could explain why she suggested collective solidarity as an alternative to mainstreaming.

So the collective solidarity that she desires probably entails a place where people do not oppress each other, especially because of their disabilities. But here, one important feature in her narrative was that QOL sits within a society or collective solidarity, and this is constituted by people. She argued that freedom does not come from being alone. She identified people as a key element affecting her QOL. She also suggested another separate world for disabled people, though this world may be positioned at a distance from mainstream society. Throughout her interview, she discussed that disabled people often had not had the power to enjoy freedom in mainstream society, intentionally or unintentionally, and this can result in having a low QOL.

Another interviewee, Minsoo, talked about his life within mainstream society during his post-graduate studies.

> Minsoo: So, it was not like no one hated me there. If I explain this more adequately, ah, it was like I was with people who were well educated in manners. It was like that feeling. Then, a certain distance existed. Yes, I think it was something like that. Yes, I liked it in some ways. I don't know how I should explain this, but I liked it. I felt comfortable? Because there was nothing I should be particularly worried about. But I also had a fear that if I did something even a little bit wrong, it would be a big mistake. These were more like artificial relationships. Um, of course, at that time, with the exception of one or two people … I have become very, very close to two people as time has passed, even now. One was an international student from China. Er, it seems that this friend also had a similar impression to me. Anyway, I thought I was a minority within the class. I spoke slowly in Korean and repeated what others said when the international student couldn't understand. Among other students … So, classes being taught in English were easier for him. He understood English in the classes. But when there were only students, they talked in Korean. He didn't understand conversation in Korean at all. So, people didn't like this. So I stayed close to the international students. I guess they had a kind of solidarity with me, as people who were excluded from the group.

Minsoo's narrative depicts the existence of a distance between him and his classmates. This distance was expressed in terms of manners. Classmates treated Minsoo with manners or politeness instead of treating him as a close classmate or friend. Manners seemed to be used as a type of tool by his classmates to draw a line between themselves and Minsoo, either intentionally or unintentionally. Minsoo expressed or perceived this distance as being a way of classing him as a ‘minority’ during his post-graduate studies. However, minority does not always signify only that the number of group members is small. Minsoo identified how, for him, a minority group did not only refer to a group with small numbers.

> Minsoo: I think my QOL has been the lowest from previous experiences. It seems that it was the lowest. Er, in every way; honestly, it wasn’t easy financially and I didn’t get any impression that I had been respected much, and what else? As I mentioned previously, I define myself as a minority. This can mean that I am not contented.

While Minsoo listed the various sources affecting his QOL, such as lack of finance and ignorance in society, he explained how the term ‘minority’ can be understood. He discussed that the term minority was an expression of discontent in his life and that the term did not only refer to the number of people in the group. He was involved in a form of mainstream education during his post-graduate studies, but categorised himself as being a minority among his classmates. Minsoo created a form of collective solidarity with the international students who were also excluded from the whole class. He might have been psychologically isolated, although all of his classmates were polite to him. The polite attitudes did not change his perspective or view of himself as being a minority. He was actually comfortable with the artificial relationships, since there was nothing much for him to worry about. However, he felt a distance between himself and the rest of his classmates, except the international students. He might not have been discriminated against in a conventional way, but he must have been excluded from the majority of the class in some ways. He actually used the word ‘excluded’ when he talked about this experience: ‘I guess they had a kind of solidarity with me, as people who were excluded from the group’.

In relation to Joonho’s comments above when talking about informal and formal relationships, Minsoo was involved within the class formally, but not informally. Joonho also argued that segregation creates ‘emotional exclusion’ and this is a primary cause of the low QOL of disabled people. This emotional distance from the majority of the class and from the majority of the people in Minsoo’s life made his life unsatisfactory. On top of this, Minsoo must have realised that he did not have the power to enjoy his freedom as a member of the class, since he was careful about not making any mistakes which would damage these relationships with his classmates.

Disabled people still feel a distance from other members of mainstream society, even though they continue to live within it. This may be reflected in Heesun’s argument above and Minsoo’s experience in terms of creating collective solidarity. This collective solidarity consists of ‘like-minded’ people who could share their emotions, according to Heesun. There would be less or no emotional exclusion within such collective solidarity. Furthermore, Heesun tried to change the position of disabled people within society. Disabled people could gain power in their own lives through this collective solidarity. In her view, disabled people are objects within the mainstream who are oppressed. Therefore, she suggested collective solidarity as a way to ‘improve power’, so disabled people could possess some form of power which would allow them to experience and enjoy liberty and freedom in their lives, which is what Heesun desires to improve her QOL. However, this kind of solidarity could lead to disabled people excluding themselves from mainstream society. Then, this poses the question: What does power really mean?

6.3 Power for QOL

Some interviewees referred to ‘power’, albeit through other words or terms. The following section discusses this reference in more detail.

6.3.1 Having Agency in Your Own Life

Many interviewees discussed the concept of agency as a key source affecting their QOL. The language of one of the interviewees, Una, led to an exploration of what kind of life she wanted to live.

> Una: I have lived because I think that I have been happier after joining the disability movement. I think the reason is the feeling of being alive, having a worthwhile life. When you think you live a worthwhile life, wouldn’t that make you feel like you are alive? And this is also a relationship. This is in a different context of loneliness to that which I have talked about so far. So I think a good QOL is if you can feel you are alive when you live a life, this would be the best QOL. It can be different for each individual. But for me, a good QOL is one in which, if you reflect on your ideals and hopes … and realise these, so to speak, experience self-realisation. Um … although you have desires and dreams that you want to realise, if the dreams are in places that you can never reach, then those would be just dreams … in your dream. But if there are ways and means through which I can move forward to these and make my way towards these, wouldn’t the fact that I am on the journey itself connote a good QOL? And this is worthwhile.

The disability movement involved activity which connected Una to a society where she existed. She also clearly identified that this was a relationship. She may have tried to connect herself to society before joining the disability movement, but it must not have materialised in the way that she had wished for. She began to feel she was alive when she joined the disability movement. When she can realise her hopes and ideals, she feels she is alive through playing her role in society. Her whole argument revolved around living in society and playing a meaningful role within this society. This is a process of fulfilling her inner desires and dreams. This opportunity was given to her only after she had joined the disability movement. It seems that she had not been given this opportunity before she joined the disability movement. She directly compared her life before and after joining the disability movement in another comment.

> Una: I strained to live somehow in the main … non-disabled people's mainstream society, and also had thought about emigrating to the US. I had tried to do things … then I came to choose the disability movement. As I have continued to work in this movement, I have tasted how this is a worthwhile life. This has given me strength and I have come to realise that I am alive. This is a different story from straining to live somehow in non-disabled people's mainstream society. I mean something like fulfilment, activeness and agency. And these provide me strength and also expand the value of life and the scope of thoughts and improve views on society. It is different.

After she had tried to live in mainstream society, she chose the disability movement instead. It seems that she was either unable to find a way of living in the mainstream or she was not welcomed by those people in mainstream society. She clearly articulated that mainstream society belongs to non-disabled people. She was not able to choose the disability movement within mainstream society because, from her perspective, mainstream society is 'owned' by non-disabled people. In her previous narrative, she discussed the desires and dreams which she was unable to attain. These dreams and desires may have sat within mainstream society where she did not belong. It seems there was no way for her to live in the mainstream and/or to have 'fulfilment', 'activeness' and 'agency', which can provide her strength within that mainstream. She became a subject who could reach for her desires and dreams after joining the disability movement.

Una's narrative echoes Heesun's narrative. Una's fulfilment, activeness and agency can be linked or connected to the 'power' described in Heesun's narrative. The strength provided by this 'fulfilment', 'activeness' and 'agency' for Una could constitute the 'freedom' referred to by Heesun. For both Heesun and Una this fulfilment, activeness, agency or power can only be reached outside of mainstream society.

6.3.2 Having Power in Society

Another interviewee, Chulsoo, strongly identified power as a critical component affecting QOL.

> Chulsoo: QOL is, whether some people say I am right or wrong about QOL, a problem of choice, decision making and initiative. However, I am very sceptical about the problem of whether we have power to practise these effectively. So, for now, let’s get rid of whether this is a problem of overall society or not. When you are asked whether disability policies are enacted in the disability field, the answer is no … this never happens.

Chulsoo expanded on the idea of power and discussed agency in terms of choice, decision making and initiative. He also raised the issue of power in relation to agency. Power is directly related to the idea of citizenship, because people who have not fully enjoyed citizenship and are marginalised in society often recognise unequally distributed power. This might be why he explained how power plays unfavourably into the arena of disability in his narrative above. He explained how unequal power is embedded in society in the following account.

> Chulsoo: … for example, let’s say if the amenities which wheelchair users can use for going to the beach are perfectly set; disabled people can go on to the sand and so on. However, there is a kind of taboo with regards to the bodies of disabled people, right? For example, women with severed legs or people with cerebral palsy who use electric wheelchairs. No matter whether there are amenities or not, if the disabled people appear on the beach, people will stare at them. However, this is not a problem of whether access and mobility and other things like these are physically available … in term of physical QOL, blah-blah-blah. You can understand this simply as a problem of awareness, secondly

> as a problem of culture and thirdly as a problem of hegemony. So it will be good if we use the case of women … um … um … So there are policies about women, public hearings, this and that. There are. However, it would feel awkward for men to make comments. There is nothing like men shouldn’t do it, but the feel of being awkward, there are things like this. However, in the disability field it is not like that at all. Rather, non-disabled people talk without constraint and disabled people are busy listening, right? Problems, such as something not being explained in an easy way? So, this is not about the physical environment of movement, access or public transportation which can help disabled people to go to public hearings. However, I think this is, as I talked about previously, about culture, leadership on policy and hegemony about who makes choices and who makes decisions.

Chulsoo argued there is a commonly held view that seeing the bodies of disabled people is taboo. Taboo is a word which is strongly related to concepts such as prohibition, restriction and being forbidden. However, it raises the question as to who has created this view. Disabled people are often not accepted in mainstream society, which has normative expectations of physical appearance and social and cultural behaviours. As a result of these, disabled people are often excluded and devalued. The view that understands the bodies of disabled people as taboo is a form of power which is not about something physically seen. This is more like a hidden social structure and phenomenon embedded in the awareness, culture and hegemony of society. This provides some explanation for Minsoo’s case. Minsoo remembered how his classmates from his post-graduate studies had been polite. However, there was a form of power which pushed him from the majority to a minority group, even though he did not talk about power in his narrative. According to Chulsoo, this is a problem of the awareness, culture and hegemony of society, all of which are not physically apparent.

Chulsoo provided a very clear visual setting, a beach, as an example. The beach is a place where his body, a taboo object, should not be exposed in front of people. This sense of taboo is not physically seen, but, rather, is exerted over the beach. Disabled people and their disabilities become taboo through non-disabled people. This is power, and this power restrains disabled people from practising their freedom to enjoy the beach. The beach might be a place where Chulsoo, who has a disability with regards to his legs, might have wished to go, particularly since he lives in a country which has very hot summers and an expansive coastline. However, his summers, along with those of many other disabled people, may have been restricted by this power. His agency and freedom to decide to go to the beach might have been suppressed by this power. Disabled people are very much marginalised on beaches.

However, according to his narrative, this marginalisation of disabled people is not only carried out in mainstream society, but also within the field of disability. In terms of public hearings, he argued that non-disabled people give their opinions without constraint and disabled people have difficulties in understanding what non-disabled people have discussed because non-disabled people do not explain things in a manner that can be easily understood. There is power of knowledge in the disability field. This power produces an unequal power relationship between non-disabled and disabled people, even within the field of disability itself. Disabled people who have difficulties in understanding can be those with intellectual disabilities and/or disabled people who have not received as much education as non-disabled people have. However, there must be issues of awareness, culture and hegemony which cause disabled people to not be able to be as educated as non-disabled people. Disabled people have lost their voices, even in the disability field, through the power of knowledge and something more than this. Disabled people might not have received as good an education as many non-disabled people, but the experience and knowledge gained by living as a disabled person should be respected. However, these experiences seem not to be respected, even within the field of disability. This explains how disabled people are often placed in a position of ‘voicelessness’. This embedded awareness, culture and hegemony in society regarding disability and disabled people may help to explain why Heesun, Una and many other disabled people have struggled but failed to enter into mainstream society. This, ultimately, often results in disabled people having a low QOL.

Another interviewee, Younggil, also asserted that power is the most important element affecting QOL.

> Younggil: I think the most important element for a good QOL is having power: power, authority, rights—these kinds of things. I have communication lines with people, such as those in the Ministry of Health and Welfare and in the Seoul City Council, who are important people in power. I don't know how to explain it; anyway, people who have power. In the public area, I live a satisfactory life. Then, I think I need to spread the good QOL in the public area … to the disability field … and make it permeate well. So, I am not satisfied in my private life, but if I talk about the public area ... I live a pretty good life. I think I live a good life, but I think there is a high possibility that many problems in the private area would be resolved if I got married. There are a lot of disabled widowers. There are also a lot of … how should I say … not disabled widows ... unmarried disabled women. It is hard for disabled people to get married. I am not afraid, but I don't want the challenge of getting married, to go out with a woman, to have children and have a family. I am not afraid of them, but I don't want to try because I don't want to live a complicated life ... Well, I would also want to get married to a non-disabled woman, if possible. But I know how much time I would need to spend on the marriage and I know how obsequious I should be. There are a lot of pains I would need to bear and endure for such a marriage. I would need to convince the woman … on top of this, I would need to convince her family—father-in-law and mother-in-law. I would need to meet them and I would need to aggressively fight against them. From a common sense view, who would gi … gi … gi … give their sons or daughters to a dickhead? This is a conventional idea, honestly.

Younggil was satisfied with his public life, because he had certain power which he argued to be the most important element of a good QOL. However, he did not explain his power in terms of having power himself. Rather, he discussed this in terms of knowing people who have power outside of the disability field. Power in Younggil's narrative is a little different from the concept of power discussed by Chulsoo and Heesun. In some senses, Younggil's power might mean a connection to the power of the non-disabled people's world or not being excluded from the non-disabled people's world. Power for Younggil is a tool connecting him to the power outside of the disability field, while power for Chulsoo is the drive to overcome the embedded awareness, culture and hegemony regarding disabled people and disability. In considering what power means for Chulsoo, he believed he can be a real member of society and enjoy a world which has no restrictions on his life because of his disability.

In terms of the main topic of QOL, both Chulsoo and Younggil talked about living in a society where there is a barrier between the world of disabled people and the world of non-disabled people. In terms of Younggil's private life, he did not seem to possess power. He did not have a connection to the non-disabled people's world in terms of his marriage plans. He was completely excluded by non-disabled people with regards to marriage. He argued about his exclusion by using a colourful word, namely 'dickhead', in reference to himself and other disabled people through the view of non-disabled people. He degraded disabled people by using such a word as he talked about social convention. He did not experience possession of agency (in the way that Una's language portrayed) or power (in the way that Heesun explained) regarding marriage. He is just a powerless disabled person in terms of marriage, who is suppressed by the awareness, culture and hegemony regarding disabled people and disability. This has diminished his QOL in his private life.

6.4 Opportunities for QOL

This section reviews interviewees' discussions about how disabled people are often excluded from opportunities in real life, in a society where a certain awareness, culture and hegemony regarding disability and disabled people is prevalent and how this exclusion diminished their QOL.

6.4.1 Unequal Opportunities for Disabled People

One interviewee, Youngji, had been rejected from secondary schools, a university and PhD courses where she wanted to study because they all claimed they could not provide the necessary support/facilities for her. She went to alternative schools instead. She argued that there are unequal opportunities for disabled people, which can cause limitations in terms of enjoying a good QOL.

> Youngji: Opportunities should be distributed equally. There are things that can't be done because of disability, but both disabled people and non-disabled people should be allowed to judge themselves on the issue of whether they can do something or not. However, if they are not allowed to do things because of the social system or social perceptions or social standards, their QOL would be very low. So, opportunities should be distributed fairly. And they should decide themselves on issues of whether they can do so or not. So, if they decide that this is not their way, no matter whether this decision is based on their disabilities or their aptitude, this wouldn't affect their QOL much because they have made the decision themselves.

During Youngji's narrative, she was very firm and clear. In her narrative, it seems that disabled people are judged according to their disabilities by the 'social system', 'social perceptions' and 'social standards'. According to her account, it seems that disabled people should gain permission from society to determine what they can do. She recognised that these social issues create fewer opportunities for disabled people in choosing or following their desires. However, it is not clear in her narrative why disabled people need this special permission from society for what they want, particularly as they live in a free, democratic nation. Chulsoo's argument about embedded social awareness, culture and hegemony restraining disabled people from enjoying their freedom is relevant here too. This is about power being exercised in society. It makes disabled people powerless and voiceless within a community and even within a disabled community.

Youngji further argued that the unequal opportunities caused by the 'social system', 'social perceptions' and 'social standards' hold disabled people back from having opportunities to even test whether they can do something or not. First of all, it should not be referred to as 'social standards', since the 'social standards' are not appropriate standards for disabled people who are part of society. The understanding of 'social system', 'social perceptions' and 'social standards' which Jiah referred to would clearly not be the same for everyone. These terms also stem from a normalised concept created by non-disabled people for non-disabled people. Indeed, the 'social system', 'social perceptions' and 'social standards' often push disabled people away from lives which they would be able to enjoy. This affects their QOL in a number of negative ways. Some examples of this are described in Jiah's narrative below. Jiah articulated how disabled people lost opportunities in everyday life.

> Jiah: [Disabled people] are not able to participate in the classes at all.[5] First, if classes are prepared, various disabled people can come to these classes. However, people don't think of this. Also, the underground is a similar story … specifically, that they don't build lifts … shows that they don't realise there are disabled people and old people. And people don't think certain things are necessary for others. Only for non-disabled people … since they are being planned, made and installed by non-disabled people … the rest of the people are excluded.

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[5] She talked about classes for pregnant women provided by communities as an example. In the classes, materials for disabled people, such as deaf pregnant women, were not prepared.

According to Jiah's narrative, in the process of preparing classes and building underground stations, opportunities for disabled people are neglected. Or, opportunities for disabled people may not even be raised within the agenda of those who prepare classes and build underground stations. Jiah described this as exclusion: 'the rest of the people are excluded'. This exclusion probably did not start from when the process of preparing classes and building lifts at underground stations began. It probably started even before this, when disabled people began to exist in society. As a result of this, disabled people are invisible in society. This was even confirmed by interviewees who had acquired a disability during their life. These interviewees within this research revealed that they had not seen other disabled people before they had a disability. Although it is much easier to meet disabled people on the street nowadays, disabled people are still invisible in many parts of Korean society.

Una described how far removed disabled people are from the world of non-disabled people.

> Una: This is a life which makes it very hard for disabled people to try something themselves or to step into self-realisation or anything like that. Yes, for now I am still looking for what I can do rather than asking myself what my dream is. However, even this is not easy … the barriers are too high. So my dream may be this, but I can't do it. So, what can I do? I need to find what I can do. However, people should have had information and their eyes, ears and skin should have experienced these, then they can judge, right? Points of judgement … this is a society which means that opportunities for making judgements are blocked.

Una contended that disabled people do not have enough experiences on which they can respond in an informed manner to the question of what they can do. To illustrate this point, she referred to experiences that should be learned through the eyes, ears and skin. This emphasises how seriously disabled people are blocked in society in a range of different ways. Human beings develop when they experience society and social interaction. However, disabled people are often not provided with such opportunities. Her argument echoed

Youngji’s point that opportunities should be distributed equally and that society should let disabled people decide for themselves what they can do. Una insisted that disabled people do not have the necessary opportunities to experience society, something which would provide more context to their decisions. This may explain the social bias regarding why society feels the need to make decisions for disabled people instead of letting them decide for themselves. Disabled people’s opportunities to learn about society are restricted. Their opportunities to extend their capabilities are often taken away from the outset. As a result of this, difficulties might often be caused or created when disabled people make decisions for themselves. In this way, disabled people are underestimated, resulting in a society of unequal opportunities for them. Disabled people become further excluded from equal opportunities because of the unequal opportunities. In addition, Una argued that they are not allowed to even dream in their lives. Una claimed that such dreams are not possible in a disabled person’s life due to the social barriers that exist.

6.4.2 Lost Opportunities

The lost opportunities in disabled people’s lives may be clarified further by Kangin’s interview. Kangin described how decisions regarding his career were made for him by non-disabled people.

> Kangin: After I finished vocational training at the age of 18, I failed to find a job because I was a wheelchair user. I have two heart-breaking stories. The vocational training was offered at a place, the ‘Seoul Community Rehabilitation Centre’. I went there to learn computer science. The centre was an institution which introduced a team approach. I am not sure you know about this concept of team approach. In the process of assessment, not just individuals or doctors or social workers take part in the assessment. Instead, a team consisting of specialists from various areas do it through the method of a team approach. Vocational rehabilitation specialists, such as rehabilitation doctors, social

workers, special school teachers, physical therapists and psychologists, gather and then do it. Then I applied for computer science at that time. It was 1988 when the 286 computer was replaced by the 386 computer. As I didn't have any education until that time[6], I was told that, although I was good at computers, they doubted that I would be able to learn computers because I was uneducated, and although I was good at computers, I wouldn't be able to get an office job without an education, so I should learn woodcraft, they said. So I learned woodcraft. Then I visited the workplace right before I graduated. Woodcraft was done in a kind of vinyl house. Now, most woodcraft, those being sold in Insa-dong, are made and imported from China. However, at least at that time, the carving of those was a cottage industry in Korea. So, since the labour cost of disabled people was low, they made a kind of hall of residence at a flat nearby or basement, then took half of the salaries for accommodation and gave the rest to the disabled people as salaries. Disabled people using crutches were employed, but, by that time, there were many disabled people with polio. If I went out to protest, the only person in a wheelchair was me. By any chance, do you know the Nodeul night school? It was a group that did protests and there was one person who used a wheelchair. Except for him, there was almost no one else who used a wheelchair. So then, at that time, there were four subjects: computer science, woodcraft, ceramic craft and handicrafts. All the women did handicrafts and people who had some education did computer science. Deaf and moderately disabled people did ceramic craft, since they needed to tread on clay. People who only used their hands, like me, did woodcraft. Although it was a team approach, in practice, they did it mechanically. So, I had applied for computer science, but according to the specialist team approach, I had to do woodcraft. However, it was the same … that I didn't get a job in the end. Then, if I had learned what I wanted to learn, I at least wouldn't be resentful. They

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[6] He did not have any formal education until that time.

> decided what I did, but did not take responsibility. They said I didn’t get a job because my disability was severe. So I decided to study.

Kangin’s first form of social life was decided by these professionals. The idea or concept of a team approach was a method or form of assessment which understood disabled people as objects for whom the professionals would decide what they would do in their life. In this concept of team approach, disabled people cannot have initiative. They cannot even be involved in the process of those decisions at all. The name of the place which offered the vocational training, ‘Seoul Community Rehabilitation Centre’, also infers how they perceived disabled people: disabled people are people who need to be rehabilitated, instead of living as they are. The professionals must have thought that disabled people don’t have the capability to decide what they can do in the future. This explains why the professionals decided for disabled people what they should do in the future. Again, this explains how disabled people are recognised in society, since the centre that works for disabled people perceives them as not having equal expectations to non-disabled people.

Furthermore, most of the subjects offered by the centre, such as woodcraft, ceramic craft and handicrafts entail manual work with low salaries, unless the person can do this work to a high standard. However, the expected quality of work by disabled people must have been low as a result of the working conditions, as described by Kangin. Disabled people are often limited within these low salary workplaces and are treated as people who are capable of learning only these kinds of subjects. Within a society which views disabled people in such a limited way, their dreams are likely to be limited too and their opportunities are again likely to be restricted. However, opportunities, choices and decisions in disabled people’s lives should not be restricted or made by other members of society and this can also diminish disabled people’s QOL.

In Kangin’s case, one bright aspect of his story was that after he had failed to obtain a job through vocational training, he decided to undergo formal education. Through his hard work, he attained undergraduate and master’s degrees and is currently doing a PhD. He is also working as a leader in the disability field. Kangin and some of the other interviewees identified life attitude such as positivity and having self-initiative and independence as crucial principles of QOL.

6.5 Attitudes Towards Life and QOL

This section discusses how the interviewees talked about life attitude, such as positivity and having self-initiative and self-determination, as an element affecting QOL.

6.5. Being Positive about Life

Kangin discussed an individual’s positive thoughts as contributing significantly to QOL.

> Kangin: So a good QOL is [Lines omitted.]… what I am saying is … fundamental bases and close acquaintances … Having good relationships with close acquaintances including families, and next … positive inner thoughts … something like that. So, if I radically summarise this … being contented with a positive mindset and living a challenging life. I think kind of like that. Honestly, economic infrastructure is … for example, people who live with monthly rent want to live in a house with a lease, and people who live in a place with a lease want to buy a house. There are things like that. In practice, economic factors can vary depending on the individual’s view and their background etc. But the most important thing is … I talked about the material basics and relationships previously[7], but I think the most important things are being able to view society on your own positively and living with values or hopes within that society.

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[7] He previously discussed economic necessities during his interview.

From the beginning of his narrative, positivity was stressed. This positivity was expressed in different words and phrases, such as ‘positive inner thoughts’, ‘a positive mindset’ and ‘being able to view society on your own positively’. He also described ‘being able to view society on your own positively’ as one of the most important things in relation to QOL. The concept of ‘being able to view society on your own’ could be interpreted to mean that some people might be in a situation in which they are not even able to see or understand society by themselves for some reason. This could mean that they do not even have opportunities to experience society to understand or see this, or that they view or understand society through other people’s eyes. This insight might have come from his experiences of living as a disabled person and, more specifically, from his experience with professionals under the team approach at the ‘Seoul Community Rehabilitation Centre’. He specifically identified and added positivity to the concept of autonomy. This positive attitude might have helped him to progress even after failing to find a job after his vocational training at the rehabilitation centre. However, emphasising this need for a positive attitude may serve to illustrate how difficult it is for disabled people to have a positive attitude towards their own lives in society.

6.5.2 Having Self-Initiative in Life

One interviewee, Sanghyun, who acquired his disability in his late 20s, discussed QOL in terms of having self-initiative.

> Sanghyun: I think that a self-initiated life means a good QOL, especially if you experience disability. Becoming like this, you cannot help becoming passive and walking around on eggshells, but as I understand, people don’t look at me as a disabled person … like this. Just … it can be thought that other people laugh at me or look at me this way. But it is not like that at all. I have realised this from the very beginning. People just look at me, not disparaging or anything like that. So I think that a self-initiated life can lead to a very happy life. It’s the same in relationships with family members and also at work.

Sanghyun's view in understanding relationships between society and disabled people is a little bit different from many other participants' perceptions. Sanghyun described having self-initiative as an element which disabled people would possess if they were determined to improve their lives, while other interviewees discussed that society should work together to improve the lives of disabled people. Sanghyun understood the barrier to having a self-initiated life as originating from misunderstanding non-disabled people's attitudes, while others understood this barrier as coming from a society dominated by non-disabled people. However, Sanghyun also recognised how the eyes of non-disabled people could represent a barrier for disabled people in terms of achieving a self-initiated life, although he insisted 'But it is not like that at all'.

In the following account, Minjae also strongly argued how having self-initiative can make a difference in a person's life. However, he distinguished between disabled people, categorising them as either people with congenital impairment or those with acquired disabilities. He continued by explaining the differences in attitude between these two distinct groups.

> Minjae: There are differences between those who have acquired disabilities and those with congenital impairment. Those who have acquired disability adapt themselves to society and the different social barriers quickly. However, disabled people within a certain context—those who have been stuck at home for 10 years or 20 years or who have been stuck in institutions—they don't typically have opportunities for education; they don't have chances to develop relationships with people. Because of this, their capabilities are often very low. So, there is not much I can do … so, while I am looking at them, I am so frustrated and think, how can people live like this? However, these disabled people say it is ok. If they say so, it may be ok, but it doesn't seem to be ok. If you are a little bit like this, there would be various ways to live. And the reasons why we learn are that we want to develop and improve ourselves, and we want

> to be even just a little bit happy. If you say that you don't have to learn, then you won't have to learn. However, if disabled people change their thoughts even a little bit, they would live better lives. But they don't. When I see this, and being unable to do anything about it, there are times I feel pity. Yes, it is like that. While they grow up like this, they don't have any plans in mind. They really don't have any special plans. If I ask them what they are going to do and why … the range of choices is limited. For people who have tasted this and that, they have a wide range of choices. However, for people who have only tasted very little or have tried things prepared by others, their range of choices is narrow. They would hesitate and be afraid when you give them more choices. While watching them, there are things I am frustrated about, but whether they are exploited or reviled or whatever … they live within their capability, I think, and that can make them happy as individuals.

Minjae argued that disabled people's capabilities are low due to a lack of opportunity within society. This point differs from those raised by other interviewees. Other interviewees tended to focus on the lack of opportunities for disabled people, not the lack of ability among disabled people. He started his argument by identifying certain life patterns of disabled people by using the description 'being stuck'. In the Korean language there is a clear linguistic distinction between polite and casual language. Polite language forms are used when addressing older people and also when showing respect to younger people or those of a similar age group. However the expression 'being stuck' is clearly and distinctly not a polite expression in Korean. This cannot be used for older people and/or for people whom you want to address with respect. This clearly illustrates how Minjae understood and positioned disabled people who have spent decades at home or in institutions and people with congenital impairment. In other words, he did not demonstrate the proper respect for them.

Through his narrative, he maintained a distance between himself and people with congenital impairment. In the Korean language, the subject of a sentence can often be omitted.

However, Minjae continued to use the term ‘disabled people’. When he discussed disabled people, he clearly described them with the words ‘disabled people’, instead of deleting the subject or simply referring to them as ‘they’, ‘them’ or ‘people’. This may suggest that Minjae identified himself as being different from other disabled people or that he did not see himself as one of them. He also seemed to understand and position himself as someone who was responsible for disabled people’s lives; he said that ‘there is not much I can do … so, while I am looking at them, I am so frustrated and think, how can people live like this?’ This is true to a certain extent as he is a leader within the field of disability who works for disabled people and not only for himself. He is currently a manager of an IL centre and he works to help disabled people and to improve their lives.

However, Minjae acquired his disability and had lived as a non-disabled person for almost 30 years, so he may position himself differently from people with congenital impairment. He may also have his own concept of normalisation in mind, since he had been educated and lived in society in which normalisation was embedded. The life of a disabled person might not look ‘right’ from the point of view of a person who had lived as a non-disabled person for 30 years. Disabled people may appear to him as people who need to be improved.

What he argued may bear scrutiny. Disabled people need to be educated and prepared for their lives. However, we need to revisit the following questions: Why do disabled people become ‘stuck’ and disconnected from society? and Why are they afraid of developing themselves and changing? ‘Being stuck’ may result from being abandoned by a normalised society. Disabled people may be afraid of failing to live in a normalised world as normalised people. In other words, they may be afraid to fail to achieve certain social expectations. So, they might not even want to begin changing or improving their capabilities. Furthermore, they may not be comfortable with all of these things in a normalised world. Indeed, it could be concluded that their timid and passive lives, distinct from motivated and self-initiated lives, may have been caused by a normalised society. At the end of Minjae’s narrative, he stated, ‘whether they are exploited or reviled or whatever’ as a consequence of their unmotivated life. This also shows how disabled people are often still treated in society.

In the following description, Sanghoon responded to the question of how people need to live, while defining QOL.

> Sanghoon: A good QOL is where you live in the way you want to live. This means ... don’t mind others. ‘Don’t mind others’ means that you don’t try to live to achieve the expectations of others around you. You set a goal which you can achieve enough of with 50 to 60 percent of your ability. Then you enjoy your life for the rest of the time. You live in this way.

Sanghoon suggested that a life free from others’ expectations was characteristic of a good QOL. This may serve to illustrate how we live in a society under stress from other people’s expectations. According to Minjae’s narrative above, he seemed to expect a certain lifestyle from disabled people, whilst Sanghyun recommended not misunderstanding others’ views of disabled people. Sanghoon also contended that others’ expectations should not be important in relation to QOL. Sanghyun’s and Sanghoon’s arguments coincide in terms of identifying a need to not empower or validate the views of others, although a clear distinction between the two arguments is that Sanghyun claimed that non-disabled people do not disparage disabled people, while Sanghoon did not discuss how others think, instead suggesting that people create goals or agendas which leave them free from others’ expectations. It is clear that Kangin, Sanghyun and Sanghoon suggested that disabled people’s QOL can only be determined by their own views, their own attitudes and their own life goals.

6.6 Leisure for QOL

In this chapter, more sociological and psychological themes, such as social relationships, power, equal opportunities and life attitude, have been discussed as they were raised by interviewees as important elements for their QOL. However, some interviewees also spoke about the restrictions on their leisure time due to their physical disabilities, thus impacting upon their QOL. It seems that they identified a lack of leisure time in the private areas of their lives, while they acknowledged social relationships, power and opportunities as public issues.

> Joonho: I am confined in terms of space, if I say it in an easy way. So there are days when I want to go travelling, but it is very difficult. You might say 'Go on a local trip', but, first, there are not many places where I can go, and they are usually too crowded at weekends. And there are not many places outside of cities which have facilities. After this, hiking in the mountains, a hobby which is very important to Koreans—I can't go hiking. And as I told you, it is hard to go abroad. Also, there are times I really want to use my body in different ways, like dancing or exercising, but I can't do these things without difficulty. So, I feel very restricted, like my physical energy is locked in. So, I have the basis to live an affluent life intellectually because of the unique social status which I have. However, physically I feel very restricted and confined. Although I really want to learn sports, I don't have the opportunities. I want to dance, but … I feel limited. While my brain is always active and vigorous, my body is completely restricted. This oppresses my life very much.

Joonho insisted that large crowds are a reason for him being unable to travel at weekends. Most places are extremely crowded at weekends, so some people do not go out then. However, they would not say they cannot go, but rather they would say they do not feel like going out on busy, crowded days. The reason for Joonho not being able to go out at weekends is that it is too complicated to use the facilities for disabled people when there are large crowds. Of course, this should not be the case either. However, he seemed to just

accept this reality. Travelling to places that are equipped with facilities for disabled people is a disabled person's right. Moreover, going wherever disabled people may want to go is a basic right. However, firstly, there are not many places that are equipped to facilitate disabled people. Secondly, disabled people might not often be welcome at certain places. Joonho repeatedly stated he felt 'restricted', 'limited' and 'locked in' while describing his lack of leisure, but he did not connect this issue to the public arena. In the beginning of his narrative, he said he was confined in terms of space. He seemed to understand space as a private matter, whilst he understood that he had an enriched life intellectually due to his unique social status. His spatial restrictions could not be solved even with his unique social status. So, he seemed to understand that intellectual problems can be solved within the social arena, whereas spatial issues cannot. However, it seems that the spatial issue is not resolvable unless views regarding disabled people and social perceptions are reconsidered.
Another interviewee, Jiah, also explained limitations with regards to her leisure time.

> Jiah: I can't travel anywhere special because I would need to plan too many things. If I want to go on a trip, I can't just decide on a place and whip off to that place after packing. If I want to go on a trip, before that trip, I need to arrange transportation; after arriving, whom should I ask for help? For the help, which accommodation should I use? And when I arrive at the accommodation, would I be able to use an electric wheelchair or not? I need to prepare all these things before I go. So, it is so tiring to prepare all these things. So nowadays, QOL is limited to watching TV or listening to music at home or leafing through books … not many things … I don't think I have many things in my life which can give me happiness.

According to Jiah's narrative, she inevitably separates herself from the 'universal world' and positions herself in her home for her leisure time, engaging in activities such as watching TV, listening to music or leafing through books. In her leisure time, she is limited and constrained within a certain boundary. She is confined in terms of space, but also in terms of time. She explained that what she wants is to '… just decide on a place and whip off to that place after packing'. This describes a swift action. However, her real life example illustrates how complex and time consuming it can be. Her space, and also her time, is constrained.

However, interestingly, both Joonho and Jiah, who have worked to improve disabled people's lives as disability activists, seemed to accept these limitations regarding their leisure time as personal problems. It seemed that they considered the problems as being caused by their disabilities and, as a consequence, these problems were perceived as very personal things. They did not bring out this issue into the public arena that society has developed. However, due to the lack of opportunities in terms of leisure time, they also lose time and opportunities to become involved within the community. This is clearly not a personal problem, but a wider issue.

Along with Joonho and Jiah, another interviewee, Hojin (who acquired his disability in his late 20s), discussed a lack of physical activity in relation to QOL. He insisted that a low QOL was due to a lack of physical activities, which affected his relationships with others in a negative way.

> Hojin: Since the damage to my body is quite bad, the sphere in which I can move is very narrow. I keep wanting to return to how I used to move in the past … how I used to feel better after being covered in sweat. Since I can't do these things, I have come to feel increasingly restricted. And I haven't been able to find ways to resolve this. How can I explain this? Something in me has not been able to be released, but instead it remains. From this, I think I have my own stress, something which I should be able to release. In the beginning, the sexual problems were also similar … because they were not released or resolved … but I didn't actively seek to solve these problems. This has piled up in me unconsciously and these things which have built up remain in me, unresolved. I

> guess these things may have negatively affected me a little bit, I think, as well as my relationships with people outside.

Hojin also directly connected the cause of his restrictions in movement; for example, the ‘sphere in which I can move’ to ‘damage to my body’. He said that something had been piling up in him and that he had not found a way to solve these problems himself. He kept all of these inside himself. He described these unresolved problems in him as his own stress, saying, ‘I have my own stress’. He did not want to shift both the causes and solutions of these limitations in his activity and the stress attached to this to something else. Therefore, it seemed that he thought he needed to be the person to resolve these problems, since the problems were only his own.

However, another interviewee, Younggil, described similar problems regarding limitation of physical activities in terms of welfare.

> Younggil: … So, the environment for a normal life is a little bit limited, limited quite a lot. We should understand this … like that. So, the culture … if you think from a cultural point of view, I mean … human rights? … let’s cut the crap. Just very fundamentally, why don’t you type in cultural welfare, sports welfare. From a welfare point of view, if non-disabled people go one time, then disabled people should go 0.5 times, or 0.3 times. Let’s look at sports also. Are they able to go to a gym? Disabled people? There is a high possibility that they can’t go because the entrance to a gym would have been built in a certain way. If they want to play badminton or table tennis, space for people in wheelchairs or using crutches should be secured. But do we see this? We don’t. It doesn’t work at all. When gyms are built, there is not only one badminton court, is there? Tens of badminton nets are set. So let’s say 20 nets are set; then five of the 20 nets … the courts … yes, court is right. Five courts out of the 20 courts should be used. Unless our state becomes a good state, there is no way for sports to be accessible for disabled people. This is why there are many obese disabled

> people among disabled groups. I say there is a high rate of having a second disability. It comes from this. Culture, sports, arts; it's all the same. So the … things are not set for disabled people to be able to reach them. As you can only see these things, can't you naturally imagine how things are?

Younggil positioned the leisure of disabled people within the public arena and in terms of welfare, whereas other interviewees above, such as Joonho, Jiah and Hojin, tied the limitations of their leisure to their physical disabilities. He stated that enjoying leisure is a part of normal life, as he described that the 'environment for a normal life is a little bit limited' in the above narrative. This could mean that disabled people are deprived of living a life which non-disabled people take for granted. Disabled people have a right to leisure within their lives; it should not depend on the generosity of non-disabled people. According to Younggil, the benefits of sports, culture and arts are not equally distributed among disabled and non-disabled people. This illustrates how the capacity to enjoy leisure is not simply a personal problem for some disabled people. This is a major issue arising from how society acknowledges disabled people.

6.7 Personal Finances

One of the differences in this study compared to previous Korean empirical studies on disabled people's QOL is that the majority of the interviewees did not go into detail about economic issues and did not consider this to be an important area affecting their QOL, whereas in previous Korean empirical studies, financial status was one of the most frequently raised elements in determining disabled people's QOL. Of course, there were interviewees such as Hojin, Jongun and Minsoo who discussed financial security as an important ingredient for their QOL. Jungun and Hojin raised financial issues as an important element for a good QOL.

> Jongun: First, I think economic factors are very important. And I think you should have good people around you.

> Hojin: … being healthy physically and psychologically. On top of this, financially. I think being in a condition to support what you can accomplish, what you want to do in society, is important.

Minsoo also admitted that economic difficulties were one of the causes of his low QOL in one of his narratives in this chapter.

Nevertheless, many of the interviewees were reluctant to include financial issues as a central element of their QOL. Kangin mentioned economic infrastructure and finance in his narrative about his definition of QOL in this chapter. However, he described financial issues as an aspect which could vary depending on people's views and backgrounds and he drew a line between money and his definition of QOL, even though he was not specifically asked about his thoughts on financial issues. Instead, he considered a positive personal viewpoint, values and hopes as being the most important elements determining QOL. Una also had a similar reaction to Kangin's response about financial issues when she was asked to discuss the important elements affecting QOL. Her first answer to the question was as follows.

> Una: So to speak, I would rather not talk about things such as money and health here …

Thereafter, she explained why values and a sense of self-worth are most important for her QOL. Before she discussed the importance of self-worth in terms of her QOL, she outlined that she could not afford to buy expensive clothes, but could still be happy with cheap clothes and explained that expensive clothes do not make her happy. However, she also mentioned that there are people in poverty who cannot even afford the minimum cost of living. She said her answer might be difficult and painful for such people to hear. She also described how financial problems can vary for different people with different disabilities and at different stages in life. Sanghyun also talked about economic status during his interview and agreed that different people have different circumstances.

> Sanghyun: Of course there are different conditions. People are in need, I am not affluent either, since I need to make money to live. When I get old, if everything becomes too hard, I will be able to become a beneficiary, because this is my right. However, people sometimes do this too quickly.

He emphasised a self-driven life as being the most important component of a good QOL. Furthermore, he expressed a sense of frustration about people who depend on benefits from the government without trying their best to live independently, as he expressed, ‘However, people sometimes do this too quickly’ in the above narrative.

Chulsoo, who had experienced being poor, recounted how he was happy at that time, despite his low economic status.

> Chulsoo: I became happy after I turned 21 years old. I can’t explain how happy I was; I can’t explain. Um, once I had eaten only Ramen [instant noodles] for three months [lines omitted]. I never thought I was unhappy, although I was much better off financially before then.

Eating cheap instant noodles for three months as a meal in Korea would represent that the person is poor; the person does not even have money to buy rice, which is the staple food for Koreans. He tried to explain how his QOL was good, despite his low economic status. He began his activities in the disability movement at 21 years old. He explained in the above narrative how he experienced happiness after he embarked on the disability movement. After the above narrative, he emphasised the value and philosophy of an individual’s life for QOL.

Youngji emphasised the importance of independent living compared to money.

> Youngji: Although the government gives money and says you can live with this, people become unhappy, unless they become independent. This is what sociologists predict, and I also agree with this.

Heesun even warned about the dangers of focusing too much on money.

> Heesun: … in order to improve QOL, one’s life should not be controlled by money, while you should constantly learn how to live with dignity.

Sanghoon answered that money is a necessity for people's QOL, but also warned of the risk of becoming addicted to money.

> Sanghoon: Anyway, you must have money … you need money. If you don’t have money, you need to make how … how … a great amount of effort to survive. You should pour most of your energy into this, making money. So you need money to some degree. However, if your goal is too high and you have too much greed, you would still always need more money, no matter how much you make.

Although it might seem that many participants downplayed the importance of economic issues for QOL, they did not ignore the importance of finances for living. It seems that they were aware of the need for money for living, but wanted to distinguish money from the elements which are important for their QOL.

6.8 Chapter Summary

The participants discussed what they considered necessary to achieve a better QOL and the causes behind having a low QOL. They identified social relationships, power, unequal opportunities, life attitude and a lack of leisure opportunities as the important elements which affected their QOL either positively or negatively. On the other hand, many of the participants tended to downplay the effect of financial issues for QOL.

It is clear that there are often limitations in disabled people's lives because of discrimination, exclusion, decisions being made by other members of society or losing opportunities in the decision-making processes regarding their lives. These limitations diminish their QOL. The participants gave somewhat similar responses regarding their citizenship, which has been restricted because of exclusion in society where their differences are not recognised and valued. The last excerpt of the section on 'Leisure for QOL', where Younggil talked about disabled people's leisure, was a response to a question on how disabled people in general in Korea live as members of society or as citizens. The excerpt was not specifically a response to a question about the QOL of disabled people; rather, it referred to disabled people's citizenship. However, the narrative answered naturally and readily the problems affecting disabled people's QOL. As one of the research questions of this study is how the concepts of citizenship and QOL are related to each other, this will be discussed in depth in the 'Discussion' chapter. Before that, the influence of the disability movement on the participants' citizenship and QOL will be discussed in the following chapter.

Chapter 7: Disability Movement

7.1 Introduction

One of the questions in this thesis investigates how interviewees' participation in the disability movement has influenced their QOL and citizenship. The interviewees were asked to about their activities in the disability movement. This chapter consists of my analysis of participants' answers to the questions about how they became involved in the movement, how their participation in the movement related to their citizenship and QOL, as well as their lives and their goals behind their participation in the disability movement. This chapter begins with the interviewees' accounts that described how they set out their role in the disability movement (section 7.2) and continues to explore how they have contributed to the movement and how the movement has affected their lives (section 7.3). The context of many of the interviews supports the view and demonstrates that their thoughts and perspectives on disability and social issues have been changed and been elaborated upon through their experiences in the movement. Through their experiences in the movement, they have come to acknowledge their disability identity and this has helped them to improve their QOL and to attain their citizenship. This is discussed in the section 'Ascertaining Disability Identity in the Movement' (section 7.4). Before summarising this chapter (section 7.6), the accomplishments of the disability movement and the participants' concerns about the future of the disability movement are discussed in the section entitled 'The Disability Movement in the Past and in the Future' (section 7.5).

The participants talked about their final goals behind their activities in the movement. Sanghoon claimed there were two goals behind his activities in the movement.

> Sanghoon: They [disabled people] can get credit for what they do within their capacity and non-disabled people can recognise what disabled people do. And,

> disabled people can gain a reasonable disposable income. The ... disability movement ... contributes. I also want to contribute to this.

The first goal here is to make society give credit to disabled people for 'what they do' and the other purpose is to offer 'a reasonable disposable income' for disabled people. The former is about socio-psychological facets, acknowledging disabled people's identity and how they should be perceived and accepted within society (disabled people should be respected as they are and for what they do). The latter is focused on social infrastructure and systems that should be secured for disabled people to continue their everyday lives. These two elements are included and embedded in most of the interviewees' narratives that delineate and discuss their participation in the movement.

Table 4: Themes and Sub-Themes for Disability Movement

Theme	**Sub-Theme**
Beginning	Lack of Facilities Other People's Needs Co-Operation
Growth	Working for Others Solidarity
Identity	Realising Disability Identity Finding a Positive Self-Image
Accomplishment & Future	Accomplishment Worries for Future

7.2 Joining the Disability Movement

7.2.1 Lack of Facilities

Sometimes there are very simple and straightforward reasons for action; for example, the building of canals in ancient times. Water is essential to cultivate crops, feed cattle and for people to stay alive. The causes of such actions are not only straightforward, but also indispensable. Many disabled people began to participate in or initiated the disability movement for very simple, but sorely needed reasons. Joonho, one of the interviewees, recounted his first years on his university campus where he started his activities in the disability movement.

> Joonho: Um … I can’t even say it was a movement, but at the beginning … so, in the years when I went to university, not only being excluded privately, but also publicly, I mean, the education, in the education arena, there was nothing, facilities or anything, there was nothing I could do. So, I had to solve the problems right away. So, I began to participate in those activities … it was a start. [Lines omitted.] Anyway, at the beginning, because it couldn’t be helped at that time, I had to go there, but I wasn’t able to go. I had to go to the lecture rooms, but I wasn’t able to go. So, there was no other way than fighting.

When Joonho went to university in the early 2000s, universities were about to start offering admission to more disabled people than before, as a result of the successes of the disability movement between the late 1980s and the mid-1990s. However, as Joonho recalled, he was not able to go to the lecture rooms and this may imply how the infrastructure and services were lacking for disabled people to live on campus. Despite the fact that Joonho, who is a wheelchair user, did not describe this in detail, it can be assumed that there was an insufficient number of lifts or no lifts at all, narrow aisles in lecture rooms and steep sloping roads on the campus. His narrative, ‘there was no other way than fighting’, explains that disabled students desperately needed those facilities and services and emphasises how stubborn the university was in understanding the needs of disabled students. However, it seems that Joonho's demands did not stem from profound insights into disability or searching for answers to questions surrounding disability. Instead, he simply began fighting for his rights to mobility as a student on campus. In addition, Joonho did not want to acknowledge this as a movement action, as he said, 'I can't even say it was a movement'. However, regardless of whether the demands were predicated on great knowledge and deep thoughts or not, the demands were closely bound up with prevalent social views on disability and disabled people. A lack of infrastructure and services for disabled students on campus is not just about technology shortcomings, but is also about the perception of disabled students: how disabled students are understood and perceived at the university. The lack of sufficient facilities in lecture rooms for Joonho as a wheelchair user may imply that the university did not count Joonho as a student who needed to be in the lecture rooms. In this environment, Joonho started his activity in the movement. Another interviewee, Heechan, who went to university in the late 1990s, talked about his university life. The following quotation depicts his perceptions of how universities viewed disabled students and from what perspective their enquiries were dealt with.

> Heechan: I studied special education—if I became a qualified teacher for a special school, it would be easy to get a job, so I did. In the beginning, after I went, I went to the university, but they didn't treat me as a student. If I say, for example, there was nothing like handouts in Braille at all, no textbooks, it was like that when I was at university. So what I remonstrated to the admission office and to the university about was that 'I pay the same amount of tuition'. Nowadays, there is a discount on tuition for disabled people or disabled people don't need to pay tuition, but at that time I paid the same amount of tuition. So I asked, 'Why can't I use computer clusters? Why can't I use the libraries?' So, I got Cs in almost every subject in special education classes, no matter whether I did good or bad, but I got A+s in social welfare classes, which I did as a double

> major. The issues that I raised and insisted upon—the system needed to be changed—bothered the professors in special education. I was a problem student. I was received in this way and it shouldn't be this way.

Heechan's narrative reiterates Joonho's quote about the lack of facilities and services for disabled students on campus. In addition, Heechan also articulated how disabled students and their requirements were perceived by the school. He expressed: 'I was a problem student'. Professors in special education responded to his requests by giving him low grades instead of understanding his difficult situation and supporting him. The reactions from the professors who teach university students on their way to becoming special school teachers in the future reflects how teachers at special schools view disabled students at such schools, since the professors' perspectives on disabled people would probably affect their students' views. This perhaps shows how disabled people are treated and acknowledged by their teachers, even at special schools. Joonho and Heechan did not require anything more than what they needed, such as lifts and handouts in Braille, to continue their lives as students on campus. Their demands were not only related to material support, but were also deeply interrelated with the social view of disabled people, which did not consider them as equal students, and this negatively affected disabled people's lives on campus. When both Joonho and Heechan started demanding material and technical support, it seems that they did not contextualise their needs with disabled people's lives generally or social structures. Instead, they simply requested them because this support was essential in their everyday lives. However, later in this chapter, I discuss how Joonho talked about his goals for the disability movement within the context of disability identity.

7.2.2 Realising Other Disabled People's Needs

The next extract describes how Heechan expanded his life in terms of boundaries of work and has become someone who works for disabled people.

> Heechan: When I was a student at a school for the blind, I didn't know much. However, these were the existing problems that I had to currently deal with, after I went to university and worked in jobs where non-disabled people also worked. So, at the very beginning, what other disabled people were experiencing was not in my interest; the problems I faced, if this is explained in terms of citizenship, were not being respected as a citizen properly. I began to get interested in those problems and raised the issues; I started with my problems and by doing this I became much more interested in the problems of other people.

Heechan explained how he became a person who was interested in the difficulties that other disabled people suffered. He started to fight for his own necessities on campus at the beginning, but, as he repeatedly encountered similar disadvantages to disabled people within society, he seemed to develop his thoughts and ideas on those issues. In his previous narrative, he mentioned that he wanted to be a special school teacher who could guarantee more stable lives. However, as he confronted those problems within society, he stretched his interest into other people's problems and changed direction to becoming an activist, although he had not intended to be an activist from the beginning.

There are also people who began to be involved in the disability movement unintentionally in different ways. Sanghoon is one such example: he got in a van without knowing where it was going and it took him to a place where activists were struggling for their rights. This experience turned him towards the path of a disabled activist. Sanghoon described how he embarked on his involvement in the disability movement.

> Sanghoon: At that time, I was teaching graduate students in public policy at a university. So it was a time when I gave a lecture at night and went to the IL centre to do participatory research during the day time. One day I was asked to get in a van [in the IL centre], so I got in. I got in the van, then ... [Lines omitted.]

> There ... the people in the van were dropped off at a place close to the National Health Insurance Service. Somebody shouted, ‘Let’s go’, then we charged into the building in which the National Health Insurance Service was and smashed and broke things. When I went there ... disabled people in wheelchairs were there. And other disabled people had to occupy the office of the chairman. Yes ... holding the building ... but all of the disabled people were severely disabled people, except me. I was the only one who could at least crawl. By accident, I went to the top floor of the office of the National Health Insurance Service. I think it was on the first floor. I started to become involved in the demonstration without fully intending to. The demonstration was about how electric wheelchairs should be covered by health insurance and medical insurance. At that time, electric wheelchairs were expensive because of a special consumption tax. But in order for disabled people to use them more, to get them more easily, it was insisted that these electric wheelchairs be seen as an assistance device for disabled people. [Lines omitted.] I did these things. After this, I was stuck in a catch-22 situation, so I followed the path of an activist.

An electric wheelchair was not as necessary to him as it was to other people in the protest. This was not Sanghoon’s main interest in his life. So, the special consumption tax on electric wheelchairs did not cause him any difficulties personally, but was considered unfair to people for whom electric wheelchairs were essential for living. The realisation that this was unfair by others who did not need this particular benefit was crucial for people who did need it. His participation in the demonstration probably gave Sanghoon an opportunity to think about the unfairness and speak out against it. Raising their voices was a tool for them to fight back for their rights and take substantial action to make others aware of these issues. As a result of this involvement, Sanghoon began his life as a disability activist unintentionally. Now he is a renowned leader in the disability movement. This explains how people enable the movement to continue and grow and how the movement makes its participants mature at the same time. In this process, the participants in the movement help each other to make the movement expand and they also need each other to attain what they want from it.

7.2.3 Mobilising Other Disabled People

At the outset of their participation in the movement, the participants probably began to realise the importance of social support. In the ‘Citizenship’ chapter, Heechan recounted the time when he mobilised the student union in the process of appealing to his university in respect of his needs. He must have realised he needed help from other students to pursue his goal. It seems that some participants were considering how to reclaim their own rights by mobilising others, instead of building solidarity or helping other disabled people. Joongsoo, a severely disabled person, described how he was satisfied with having personal assistants, a service which had been obtained through the disability movement. He also mentioned other activists with whom he worked in the process.

> Joongsoo: If I don’t have personal assistants, I would pee in my wheelchair and would lie in bed all the time. These are the results of what I have done in the movement and now people are always tied to me. I am very free; it has affected my life very much. It might sound very selfish, but I think I might have fought for myself, because I badly wanted to. The cause of the movement was something like ‘you are killing all severely disabled people’, but on the other side it was also like ‘let me live in comfort, even only me’, although I don’t think I used disabled people just because I want to live in comfort.

Joongsoo had been involved in the protest about personal assistants on behalf of a whole group of severely disabled people, but he confessed that this had been also solely for himself. However, it would not have been possible to make the movement successful by him alone, so he struggled with other people alongside him. As a consequence, he has personal assistants who are always committed to helping him. Joongsoo worked for other disabled people and they also worked with him. Working together for the same purpose represents the strength of the movement. People with whom one works can provide stimulus for activists to continue their participation in the movement. Yet, from the above narrative, it seems that he did not completely realise the importance of the value of his colleagues. Instead, his personal interests seemed to be more important to him at that time. However, the meaning of his colleagues to him now is well expressed in Joongsoo's other narrative, which is quoted later in this chapter. Activists do not only develop ideas regarding disability, but they also build appreciation for their colleagues throughout the movement.

Another interviewee, Minjae, who acquired his disability, found out about the personal assistant service after spending years at home until he accepted his disability.

> Minjae: When the peer consulting leader came from Japan, there were two people who assisted the leader. I naturally thought, 'Ah, they came to do volunteer work'. However, they were not voluntary workers—gaejoin? Gaejo? Gaehoin—they were personal assistants. It was something like that, so I realised that certain disabled people doing peer consulting in Japan live much better lives than disabled people who live in Korea and I thought if we have this, it would be good. It was like that. However, the demanding power of individuals is weak, so the welfare centre set out these kinds of things.

After Minjae acquired his disability, he probably found out that he was in need and could not live without other people's help, which had not been necessary before his accident. It seems that he realised being helped was his right only after he had met the Japanese leader. Moreover, he concluded that demanding services alone was not effective and people who worked within the movement were crucial to achieving these goals. In many cases, disabled people enter the movement to obtain their own needs at the beginning, but later they expand their work to pursue other disabled people's entitlements. Minjae also discussed and debated the state’s role and his thoughts on the disability movement within the context of social construction, which is reviewed later in this chapter.

7.3 Growth through the Disability Movement

This section describes how disabled people’s leaders broaden their thoughts and expand their boundaries of work in the process of their involvement in the disability movement. This section also illustrates how the participants were transformed into people who understand other disabled people’s challenges and support them to solve their problems from people who look for social support and think about how to mobilise other people to accomplish their own goals.

7.3.1 Working for Friends and Working with Others

In the next narrative, Jiah described an instance when she was engaged in protest to fight for the rights of her friend.

> Jiah: … one day one of my friends, she works with me now, when she went to night school, while she was going up in the lift at Cheonho Station—the one which makes the sound beep beep … She fell from the lift and got hurt. So, we went in front of the Seoul metro building and we sat and chanted ‘compensate, compensate’. The officers from the building looked at us in a way that suggested they were thinking, why are these strange people in front of here and what are they doing? [Lines omitted.] The people’s eyes … so the, my pride … getting the eyes ... Who should do this? [Lines omitted.] Then, lifts should be built at all stations in Seoul and low-floor buses should be introduced, buses which disabled people should be able to take with everyone else. It had been about three years, from 2002 until 2004.

First, the lift that Jiah's friend fell from was not a lift which we usually see at underground stations. Before the current lifts were built at most underground stations in Korea, there were steel plates built into the rails on one side of the wall of the stairs at underground stations. These were called 'lifts' and are still used at a few stations. Thus, when a wheelchair user needs to use the lift, he/she needs to make a request to the officers working at the station. Then, the officers control a system to unfold the plate and the wheelchair user goes on to the plate. The officers control the system to move the lifts (actually a plate) to go up and down along the rail on the wall of the stairs. When this lift moves, very loud music plays to make everyone around aware that the lifts are moving to prevent accidents, which could cause injuries. Ironically, the lifts are not safe enough for disabled people. When it rains or snows, the floor of the plates can be very slippery. Some disabled people have been hurt and even killed in accidents falling from the lifts.

Jiah went out to take part in a demonstration for her friend and encountered people staring at her as if she were a strange person. However, Jiah confronted these looks, instead of running away from them. She was determined to fight against non-disabled people's views about disabled people and beat the system by gaining lifts and low-floor buses for disabled people. Furthermore, she fought to win back her pride, instead of fleeing from the situation. She probably figured out that fighting against the *status quo* was a way of regaining her pride and reclaiming the rights of her friend—which were also her rights—that have long been ignored by non-disabled people. Rights for one person can also be enjoyed by other people who live in similar circumstances. Jiah might have had similarly dangerous experiences on the lifts and had bad memories of using public transportation. These incidents might have driven her to protest. It seems that disabled people often sympathise with other disabled people's difficulties, even when the difficulties are not directly related to their own interest. Younggil, who uses a manual wheelchair, discussed the importance of electric wheelchairs in the following narrative.

> Younggil: I am in a wheelchair now. We call it ‘rights to mobility’. We didn’t have any tool for mobility. There were some, but what can people who can’t use their hands and people with spinal cord injuries do? And also, people with cerebral palsy. They can’t push manual wheelchairs. I can at least use my arms and upper body, so there is no problem with pushing a manual wheelchair. Without an electric wheelchair … Have you seen electric wheelchairs? They can’t move without electric wheelchairs. Very basic rights like this cannot be obtained without obsession. I think this is an obsession. So, the rights to mobility have been improved. So, electric wheelchairs were then covered by national health insurance. The rights to mobility began in 2004. This was the beginning of the overall rights to mobility.

Despite Younggil not personally using an electric wheelchair, he understood and agreed on the importance of providing electric wheelchairs for severely disabled people, because he probably knew about the loss and suffering in everyday life caused by the lack of mobility, according to his own experiences. Personal experiences often seem to inspire activists to help other people to pursue their rights, which have been denied for a long time. The process of winning back rights can be understood in terms of citizenship; marginalised people challenge the *status quo* and obtain their rights as citizens, which have been stripped away from them. The process of retrieving citizenship can occur through the form of protest, which entails collective action such as demanding lifts at underground stations and challenging current policies and laws, but can also be continued in everyday life when disabled people are alienated in places such as markets, restaurants and cinemas, which they visit, but where they are not welcome. In the following narrative, Kangin explained what had happened to a disabled person with cerebral palsy who had gone to a beauty salon to get a haircut and described how he and his colleagues went to the beauty salon later to gather some evidence to file a petition.

> Kangin: A disabled person with cerebral palsy in an electric wheelchair in my town went to a beauty salon, but the beauty salon lady swore and shut the disabled person out of the beauty salon. So, we went to the beauty salon to protest and to get some evidence to file a petition to the National Human Rights Commission. Then she changed her story—'No, I was cleaning'; 'I did it because it was before opening time, have a seat here, I will do it now'. She did that.

Sometimes it is difficult for one person to confront society and raise his/her voice against unfairness within society. However, when there are people around him/her who have similar feelings on the issue, then the person will be encouraged to raise his/her voice and the power of their voice will be amplified. The disabled person with cerebral palsy might not have been brave enough to confront the owner of the beauty salon, but Kangin and his colleagues stood by the person and spoke up against the unfairness and the discrimination against disabled people.

7.3.2 Solidarity with other Disabled People

It seems that the participants became more tightly unified and expressed stronger solidarity with people in the disability movement. They were not in a relationship of helping and being helped anymore. The relationships of social support were developed into more intimate relationships with a sense of belonging and solidarity. They counselled together, worked together and became sturdier as individuals and a group. Consequently, they felt a sense of belonging to each other, felt good about their disability communities and realised and accepted their disability identity. This is manifested in the participants' narratives below.

It seems that Kangin had had similar experiences to those of the people with cerebral palsy in the excerpt above, but had not been able to confront the unfairness. Kangin articulated how he developed this attribute after he had started to participate in the movement.

> Kangin: … now I speak up, ‘do this’. I have come to be able to say that you should do this. I originally have positive and strong traits. Nevertheless, through participating in the movement, these tendencies have been elaborated further, so I guess this has been expanded to the area … disability rights.

The disability movement has reinforced Kangin’s positive and strong characteristics, while it seems that he has developed his thoughts and views on disabled people’s rights through the movement. It seems that the participants’ thoughts and perceptions about disability within society have matured and been strengthened by their participation in the movement, whilst the power of the movement has also been enhanced as more sensible and solid participants become involved. As seen in the beauty salon example, the movement has become more cohesive. The process of the protest must have enabled the disabled person with cerebral palsy to speak up and say that the *status quo* is neither fair nor adequate and to win back their rights and citizenship in the future. Furthermore, it seems that a person can become someone who can help other disabled people and fight for their citizenship. In this process, they probably find similar experiences and they can share their emotions and establish solidarity.

Sanghoon echoed much of what Kangin recounted and explained how he dispersed these ideas among other disabled people.

> Sanghoon: … in the past, if I was rejected from a restaurant, I would have taken it. But now it is different. Colleagues who study counselling—we study peer counselling together—would rush and ask for an apology. If lift construction at an underground station is stopped for days, then we would go and ask them to hurry. Then we feel empowered. Ah, we realised that people don’t say ‘idiot, bullshit’ when we gather to work for a cause. We become internalised. I keep barking. I go to lectures. Whenever I give a lecture, I say that you should do this based on these things. And like this, we make things more systemised.

Vulnerability is transformed into bravery through peer work—working together. Sanghoon indicated that people who study peer counselling work together as a source of their power to confront the discrimination against them and to fight for their rights. Furthermore, when they fight together against the rejection and unfairness within society, they would become more powerful, instead of being marginalised or derided as 'idiot, bullshit'. It seems that this is how the movement works and how disabled people who participate in the movement grow through the movement. Colleagues, people who work together in the movement, play an indispensable role in the process. With their colleagues, activists can obtain rights as citizens within society which have been denied.

Joongsoo, who acquired his disability from a disease in his 20s, spoke about how his disability movement participation changed his life and notions on disability.

> Joongsoo: I am happy and delighted. To be honest, if someone gives me medicine to heal me to run, I really wouldn't do it. I have so many things to do in this condition and they are interesting and I also have goals. If I become a non-disabled person then this would be meaningless. Once I had a quarrel with my wife, as I said that I wouldn't do it, but, anyway, this is my identity, I wouldn't do it. First, there are many things to do and I like them. Second, if I go, it would be a betrayal to my friends. I have made so many friends who suffered while we were in the disability movement. To put it crudely, many people died. I don't want to live like that.

Joongsoo developed goals in his life through his activities in the movement and now enjoys his life. He indicated that his colleagues are the reason that he would not give up the movement or his disability. However, in his other narrative (this narrative is not extracted for this thesis), he confessed that he did not go out and stayed in his house for 20 years and tried to commit suicide after his disability emerged. But he was then convinced by a disabled person who was in the movement and he emerged from his solitary life. Joongsoo also recounted, at the beginning of this chapter, that he attended the demonstration about personal assistants and desperately wanted this service, even if it was only for himself. However, here he talked about friendship with his colleagues and indicated colleagues as being a reason behind him being unable to give up the movement and his disability. He is also content with his disability, as he said: 'I am happy and delighted' and 'I have so many things to do in this condition and they are interesting'. Now, he has found a positive self-image and does not have the tragic view of disability which he had 20 years ago. Moreover, it seems that he found and accepted his disability as his identity during his participation in the movement, as he clearly articulated: 'this is my identity'. It seems that this identity enabled him to be a different person from the one who stayed at home for decades and tried to kill himself. This explains how powerfully participation in the movement affected Joongsoo and his life.

7.4 Ascertaining Disability Identity in the Disability Movement

In the 'Citizenship' chapter, Sanghoon explained how people in disability communities respect disability and disabled people. He even reported that 'disability is like a medal' in the communities. Some of the interviewees in this thesis discussed and argued how disability movement participation was interrelated with their identity, how this identity had changed their lives and what the value of identity is. The interviewees related their journey of finding their identity to their participation in the movement. This is discussed in the following sections.

7.4.1 Realising Disability Identity

Joonho selected his disability identity as a reason for his interest in disability issues, whilst Joongsoo clearly articulated that disability is his identity and explained that he does not want to give up his disability in his narrative above.

> Joonho: … the reason that I couldn’t help getting interested in disability problems is that this is about my identity problems.

In another narrative at the beginning of this chapter, Joonho provided his movement actions on the campus as an example of how he set out in his activism. He described the actions as a process of gaining essential support from the university to continue his studies on campus, whilst he was a little reluctant to describe the actions as part of a movement. He probably was not able to contextualise his demand for support for disabled students on campus in terms of his identity at that time. This can be inferred from the above narrative, as he directly relates his disability problems, which challenged him to stay in the movement, to his identity. It seems that the process of pursuing support for disabled students made him believe that the lack of infrastructure was not just about material problems, but was rather about problems regarding their identity that reflected how they were positioned and perceived within society. The following quotation describes how important and valuable his movement actions are to him.

> Joonho: If I wasn’t affected, didn’t do the disability movement … although if I didn’t do it, I would have had a job which wouldn’t be bad. I could have had a better job, because I would have probably spent time more effectively. If I lived like that, I could have derived more income, but I wouldn’t have found a way to explain certain senses of alienation which I continually feel, something like the feeling of alienation in the case of lifts at the underground station, and probably I wouldn’t have been able to understand those. [Lines omitted.] Being involved in the disability movement challenged my social participation. At the same time, I think this gave me some power that held me firmly and prevented me from collapsing or falling apart by consolidating various experiences and worlds.

According to this narrative, Joonho found answers to questions about his sense of alienation by sacrificing a better social status, such as a better job and affluence. During his interview, he recounted his memories of using lifts at underground stations (this narrative is not extracted for this thesis). This is the same type of lift that was explained in Jiah's quotation—a plate running up and down the wall of stairs. He recalled the experience as being very humiliating and shameful. The lift played loud music and he received a great deal of attention from people in the underground station. He was not able to figure out what to do about the embarrassment as a secondary school student at that time. He asked who would want to go out with people who need to take the lift (he was with his non-disabled girlfriend and they were both teenagers). Although he did not clearly articulate it, this was social discrimination and exclusion against disabled people. The discrimination and exclusion may have caused a sense of alienation. The lift was not a problem caused by basic technology, but was more about disabled people's position and how they were treated and seen within society. Participation in the movement gave him an opportunity to understand how society is structured and allowed him to elucidate on the causes behind this sense of alienation. During this process, he must have realised his disability identity as a disabled person. He asserted that he had been empowered internally to stay strong through his participation in the movement.

Another interviewee, Heesun, also noted how her life changed after she began to participate in the movement.

> Heesun: If I didn't do it like this, probably, my QOL wouldn't have been able to be secured even half of half. If I lived as I did before, probably I would have been able to live a better life financially, but psychologically I would have had … my dissatisfaction would have been at boiling point. The unresolved, unexplained … it can't be resolved anyway, but because of the things that can't be explained, my relationships or … and my anger probably would have simmered internally and I would have suffered from heartache. [Lines omitted.] Although I became much older, I also became much healthier because all these things in me could have erupted before.

Heesun said that ‘things can’t be explained’. In Joonho’s narratives above, he also confessed that he would not have been able to understand his sense of alienation without the disability movement. The disability movement must have guided some disabled people to understand society and themselves in the context of social relations and social construction and must have led to the reconstruction of relationships between society and themselves in various ways, such as demanding amendments to policies and laws, challenging current infrastructures for disabled people and reconceptualising the idea of disability within society. This is also why Joonho and Heesun gave up a life which could have secured them a better social status and higher income, but, instead, chose the disability movement. In addition, the disability movement gave Una an opportunity to feel she lives a worthwhile life, as discussed in the ‘Quality of Life’ chapter. I think this sense of worth enabled Una to find a positive image of herself.

7.4.2 Finding a Positive Self-Image

Una’s narrative below delineates what can happen when disabled people do not understand or accept their disability in a positive way.

> Una: Before I knew the movement, I had only wanted not to look shabby when I get older, not to be the one who makes trouble for families, not to be a headache. This was very basically what I wanted. [Lines omitted.] Consequently, the disability movement allowed me to have a much better life than the one I had thought about when I was in my 20s and 30s. The movement gave me an opportunity to clearly realise my sense of worth.

There is no positive connotation to be taken from the words ‘shabby’, ‘trouble’ and ‘headache’. Instead, all of them convey pessimistic overtones. Disabled people are often understood as trouble makers among their family members. This was how Una understood herself before her participation in the movement. However, through her activities in the movement, she has come to consider herself worthy. It could be inferred that a negative view of her disability must have caused her to have feelings of unworthiness about herself. However, her participation in the disability movement has filled a void and has given her a new view of her disability and herself that manifests itself in her improved self-worth. This is what can happen when disabled people understand and accept their disability as their identity in a positive way. She did not clearly explain how the movement helped her to find her sense of worth here. However, it can be inferred that she had not found a way to contribute or show her worth to others before participating in the movement, but it seems that the movement provided a chance for her to prove her worth, as the stark differences in her life before and after participation in the movement demonstrate. This was also discussed in the previous chapter, 'Quality of Life'.

Joonho even argued that disability can be dignified, beautiful and charming in the following excerpt.

> Joonho: I think the message of the disability movement is that although the condition that you are accidently born with is disability, this can still be dignified, beautiful and charming, and can affirm life itself, accepting disability as an identity. From this point of view, the movement is very meaningful. Um … so I have a desire to spread out this stance of the movement within the whole of society. [Lines omitted.] This should also be able to justify severely disabled people's lives—why they were born like this.

The expressions of being 'dignified, beautiful and charming' contrast with the words 'shabby', 'trouble' and 'headache' that were found in Una's above narrative. Joonho must have found a positive self-image as a disabled person. He, who fought for his own needs on campus in the past, now speaks about and fights for other disabled people's identities (including severely disabled people), because he thinks disability is dignified, beautiful and charming. However, it seems that disabled people themselves often do not accept or realise their disabilities as their identity and, furthermore, seldom have a positive self-image as disabled people, as he claimed that he has a desire to spread the message of the disability movement. Yet, Joonho's experience shows how acknowledging disability as one's own identity and having a positive self-image as a disabled person can play a significant role in the person's life and, furthermore, in disabled people's communities.

Jongun, who had attained degrees in different fields and had established a career in the area but studied in the field of disability and worked in the disability area as an activist at the time of interview, articulated her contribution to the disability field.

> Jongun: As I study here [in disability] and get certain results, I can get attention from people here. It is important to feel that I am a person who can contribute something special, not just being a member.

Jongun discussed her contribution to disability issues and seemed to be proud of what she did. People often find a sense of worth by helping others and self-worth and pride are the primary elements of a positive identity. Disabled people often find a positive self-image from their contribution to the process of the disability movement. Another interviewee, Youngji, who made money from a job in the disability area, described how she can contribute within society.

> Youngji: It becomes a reflex. Since I work, there are people following me [personal assistants] and people who help me at home and also people who work for me here [in the office]. So, they can get salaries because of us. Yes, so if one person works like this, people who help the person would also get a job.

Youngji seemed to be proud of having a job, hiring people and paying them money. Disabled people want to contribute and be in a position where they can help others and can be influential as well.

The disability movement has improved social facilities and infrastructure for disabled people and has tried to challenge pervasive views on disabled people and disability embedded in the public and in policies. Meanwhile, the participants have developed relationships with people in the movement and feel a sense of belonging in the disability community, while they have also often realised their self-worth and developed a positive self-image through participation in the movement.

7.5 The Disability Movement in the Past and in the Future

Some interviewees evaluated the disability movement in Korea and expressed their thoughts accordingly. Some of them criticised the politicised tendencies among disability leaders after achieving satisfactory growth.

7.5.1 Accomplishments in the Past

As discussed in the ‘Citizenship’ chapter, disabled people do not only pursue their rights, they also emphasise their duties and responsibilities as citizens. Disability leaders also think about their roles, the validity of the movement and social relations between them and the state. An interviewee, Minjae, also explained the validity of the movement and the state’s role.

> Minjae: … I didn’t go to the movement for a while. Isn’t this an unreasonable demand? What have I done [for society]? I once thought about things like this. However, I, a person, can think like this, but the state shouldn’t have these kinds of thoughts. The state has a role to make people who have more share and people in need to be fulfilled. I think policies that are only for people who have more are not right.

At the beginning of this chapter, Sanghoon argued that disabled people should be respected as they are and for what they do. For this to happen, extra support and services are needed and different views on disabled people must be applied. Minjae argued that these issues are what the state should focus on, and make efforts for disabled people accordingly. These are the rights of disabled people and they also have the right to raise their voices to challenge society and empower disabled people. However, the disabled people’s movement often blocks roads and buildings to protest, and calls for amendments to policies and renovations and upgrades to be made to buildings and facilities. As a consequence, the movement is often seen as amounting to rebels acting for non-disabled people, which creates inconvenience in non-disabled people’s lives. Resistance from non-disabled people sometimes makes disability leaders review their role in the movement, even though all these struggles and controversies have ultimately brought changes and improvements for disabled people. Interviewees assessed their role in the movement and discussed the achievements that had been made in the Korean disability field.

> Sanghoon: … of course, who has power is important. Eh, important. Um ... I don’t know. But whenever we fought for issues related to disabled people, no matter who had the power, the right wing or left wing, it worked out … was solved.

> Hojin: I think things are clearly better compared to 10 years ago. I think, depending on where people think where the limit is, people think differently about whether they should pursue more rights or not. I think there are people who think this is enough and wash their hands of the movement, and there are people who think this is still insufficient and still pursue rights passionately just like they have done in the past.

Most of the interviewees, such as Sanghoon and Hojin, evaluated the achievements of the movement positively. They were satisfied with the results over recent decades. However, they were also worried about the future. As Hojin mentioned, some people who have been in the movement leave when they are satisfied about the improvements made for disabled people, but some interviewees, such as Kangin and Chulsoo, were also worried about the decrease in the number of people and the lack of enthusiasm from the younger generation (these narratives are not extracted for this thesis).

7.5.2 Worries for the Future

In addition, many interviewees also expressed other sources of anxiety.

> Hojin: As I said previously, the charm of independent living is a new life pattern and system which humankind has never experienced before. Severely disabled people enjoy their own lives, full lives, as they are helped by others. This was very fresh to me the first time. [Lines omitted.] From the point of view that this provides and shows new life patterns and new life areas, this is a very important life movement that makes the world more diverse. And I want IL to progress in this way. However, unfortunately, it doesn't. This is not a social movement; rather, this is a movement that simply makes disabled people fit into society.

The goal of the disability movement is not to change or upgrade disabled people to fit into society, but rather to make society view and acknowledge disabled people as equal citizens by accepting the differences in their appearance, attitude and lifestyle. However, Hojin raised a concern about the direction of the movement. If Hojin's argument is proved right, then this begs the question as to why the movement has been led astray after its great achievements. The following narratives might shed more light on this problem.

> Younggil: Let me talk about a negative aspect. Based on these successes, leaders in the disability field, probably including me, have the desire to become a politician. And this is too much.

> Jongun: It would be better if people making policies, and researchers studying identities, do something helpful for everyone, such as making policies and doing research by making use of their identity. However, I think disability leaders in a high position or doing research are not doing well. I feel they are looking after their own interests a lot.

It was not only Younggil and Jongun who discussed the politicising of the disability movement, as many other interviewees also expressed worries about the relationship between disability leaders and politics.

7.6 Chapter Summary

The participants discussed the development of social systems and infrastructure in Korean society for disabled people in recent decades, as well as their own personal growth through the movement. They have realised a disability identity and found a positive self-image through their activities in the movement and have been empowered by this identity. However, some of the participants expressed their worries about the future of the movement. If most disability leaders, not just a few, raise this as a problem in the disability movement, then this needs to be reconsidered carefully. This is probably a time to ponder the direction of the movement for the next generation. As discussed in the previous two chapters, there is still a high and solid wall between mainstream society and the society in which disabled people live. In non-disabled people's minds, disabled people are not positioned and accepted as equal citizens yet. Non-disabled people generally perceive disabled people with an element of stigma and prejudice in their minds. Disability activists might, therefore, need to restart their movement from here, by repositioning disabled people and disability in non-disabled people's minds and society as a whole. Doing so might help to establish a society where disabled people can be accepted as equal citizens.

Chapter 8: Discussion

The purpose of this study is to explore how disabled people in Korea conceptualise their citizenship and QOL and how the two concepts may be related to each other. This thesis also seeks to discover how the participants' involvement in the movement has contributed to their citizenship and QOL. The last three analysis chapters have examined how the participants construct and experience their citizenship and QOL within Korean society and how their involvement in the disability movement has influenced their lives. This chapter synthesises the analysis with literature corresponding to each research question which has guided this study.

8.1 How do Disabled Activists in Korea Speak about, Experience and Conceptualise What It Means to Be a Citizen?

This section, first, examines discrimination against disabled people within Korean society which, in fact, hinders them from living as equal citizens. The thesis continues to probe into how disabled people want to be perceived and live as citizens within Korean society based on the findings of this study using Morris's (2005) concept of citizenship as a framework, which is adopted to understand citizenship for disabled people. Here, it is worth reiterating Morris's concept of citizenship:

> Disabled people's differences and humanity should be recognised and valued, so they can exercise their self-determination, participate in and contribute to society; furthermore, belong in society (Morris, 2005, p.40).

8.1.1 Discrimination against Disabled People and the Idea of Normalisation

In the ‘Citizenship’ chapter, the interviewees clearly articulated that Korean society is a dichotomous society consisting of two societies—one for non-disabled people and the other for disabled people—and pointed out the distance between the two societies. The evidence strongly suggests that disabled people in Korea are not recognised as equal citizens; instead they are discriminated against, excluded from and marginalised within Korean society. Morris’s (2005) concept of citizenship for disabled people emphasises that disabled people’s differences and humanity should be recognised and valued and this is set as a premise of the concept. This prerequisite also evokes the purpose of the UNCRPD, which is ‘to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity’ (UN, 2018). Morris’s concept of citizenship and the UNCRPD discuss that disabled people’s human rights and fundamental freedom have been routinely constrained and their inherent dignity has not been respected, since disabled people’s differences and humanity are not recognised and valued. Eventually, the social perception, not recognising and not valuing disabled people’s differences and humanity, has hindered disabled people from living as equal citizens.

This view, not recognising and not valuing disabled people’s differences and humanity, is deeply predicated on the idea of normalisation. Based on the idea of normalisation, society expects citizens to meet certain criteria such as physical appearance and social, cultural and economic behaviours and ways of being (UPIAS, 1976; Oliver, 1990; Finkelstein, 2001; Urrieta & Reidel, 2008; Oliver & Barnes, 2012) and tends to set a positive image for people who meet the criteria (Wolfensberger, 2011). In contrast, people who do not meet the standard become devalued in society. In this model, society tends to make everyone similar, rather than to accept and appreciate the differences that exist. The idea of normalisation gives disabled people a more negative social image. As a consequence, Jongun was never treated as an equal colleague who had equal ability to her colleagues and her boss treated her like a vulnerable person who could not deal with criticism at work; Chulsoo was treated as an unblessed person by his neighbour; Heesun was perceived as a person who depends on welfare benefit despite her having a job; and Jiah's friends had to confront complaints about them living in an apartment building where non-disabled people live. The participants' stories clearly illustrate how disabled people within Korean society are discriminated against and attempts are made to exclude them from mainstream society. Jackson et al. (1998) maintained that discrimination is actions which are favourable to some people and unfavourable to others, whilst exclusion limits membership within the community (Barton, 1993). The interviewees' stories demonstrate how disabled people's membership within Korean mainstream society is limited due to non-disabled people's 'inappropriate exercise of personal tastes' (Silver, 1994, p.556). In addition, there is a high possibility that the 'inappropriate exercise of personal tastes' would have been influenced by the idea of normalisation.

However, the idea of normalisation itself is equivocal. The standard of the norm is a subjective judgement. Anyone can be either normal or abnormal depending on how norms are defined and implemented. Norms have been continuously changed over the years and are different in different cultures. Then, defining the norm itself is meaningless and the idea of normalisation does not seem legitimate.

8.1.2 How Disabled People Want to Live As Citizens

Morris (2005) utilised three concepts—self-determination, participation and contribution—to understand citizenship in three different ways and as a way for disabled people to become included and to belong in society. The interviewees in the study also discussed the three concepts in similar terms as important elements for their citizenship and described how they want to belong within society and contribute to society as equal citizens.

However, the participants clearly articulated that the ones who must choose where and how to participate in and contribute to society are themselves. There is a noticeable difference between the perceptions of the three components—self-determination, participation and contribution—in Morris's concept of citizenship and the elements in the interviewees' discussions in this study. In the interviewees' discussions, it seems that self-determination acts as a prerequisite for their participation, contribution and belonging in society, rather than being one of the three components. The participants' narratives reflect that they are not often allowed but want to live as self-determined/autonomous people who can choose how/where to participate and belong in and contribute to society. I am not arguing that the concept of self-determination is considered to be less important in Morris's concept of citizenship; rather, I am emphasising how self-determination is an imperative component for disabled people's citizenship in current Korean society. Another difference in the interviewees' narratives is the boundary between participation and belonging, which seems to be a little bit blurred. Disabled people do not want to just participate in society; they wish to participate in society as part of society. The way they want to participate in society seems quite close to the concept of belonging.

The rest of the section examines how the participants discussed the meaning of citizenship and what they want for their citizenship. The participants' discussions will be addressed based on the three components: self-determination, participation and contribution.

8.1.2.1 Self-Determination

Morris (2005, p.6) claimed that self-determination refers to how 'within the wider citizenship debates, there is an assumption that individuals have capacity for free choice and, particularly within the liberal tradition, full citizenship involves the exercise of autonomy'. Disabled people, however, have long been routinely considered as a distinct group who are not rational or autonomous by non-disabled people, as individuals' physical and mental limitations are often embedded in the discussion of disability (Kittay & Carlson, 2010; Goodley & Runswick-Cole, 2014). As a consequence, disabled people are perceived as not being autonomous or being less autonomous (Mégret, 2008). A lack of opportunities for disabled people to exercise autonomy is just evidence of how their differences are not respected and valued, how society insists on the 'sameness' and 'unity' of their citizens and how the idea of normalisation is prevalent within society. Within the human rights approach, each person's differences and humanity need to be recognised and valued as they are (Morris, 2005; Stein, 2007; Quinn, 2009; Degener, 2016). However, in a society where the idea of normalisation is pervasive, disabled people's human rights cannot be ensured, their autonomy would be hardly secured and, furthermore, their citizenship would be endangered.

It is clear how disabled people's self-determination is neglected by non-disabled people from the participants' discussions. The story of Jiah, who confronted the complaints of her friends' neighbours, illustrates how disabled people's autonomy to choose where they live can be threatened by non-disabled people. In a similar vein, Heechan's self-determination to have equal rights on campus as a student was intimidated by professors who gave him low grades. Morris (2005) raised the issue of a lack of sufficient assistance and services along with social barriers such as the misperception of disabled people as the main problem which disabled people face in exercising their self-determination. Heechan fought against the circumstances—the lack of services for disabled students on campus—which made it difficult for him to be autonomous, but the professors threatened him with low grades to force him to give up his self-determination.

In this study, the participants' experiences and stories do not only describe how their self-determination and autonomy have been neglected, but also how they want to be perceived and act as self-determined persons. This is described further below in the discussion on participation and contribution.

8.1.2.2 Participation

Morris (2005) maintained that disabled people are often perceived as people who 'need care' and even do not belong in the community and these views are the main barriers which hinder disabled people from enjoying full participation in the community. In Korea, where Confucianism and nationalism are pervasive (Kim, 1993; Armstrong, 2002; Yoon, 2008), people of difference are not easily accepted within society. It is not difficult to find stories and experiences of how the participants and disabled people are often perceived as people who are different and in need, discriminated against and excluded from the community, so disabled people often do not feel a sense of belonging within Korean society.

The participants discussed their participation within society in terms of a concept close to a sense of belonging. For example, Joonho spoke about how he felt 'deeply connected to this society' when his friends, who were having a hard time, visited him and talked about their lives. His narrative illustrates how he wants to be connected to society emotionally and wants to live 'of' the community instead of simply living 'in' the community. When he lives 'of' the community, he could come to feel that he 'constitutes a part of society', which is a status he is longing for in terms of his citizenship. Sanghoon, who was not able to find intimacy and respect in mainstream society, found the field of disability to be a place where he can belong. The field of disability is a setting where he is not considered as a person in need or an 'idiot' (in his words), but where he is respected as he is and can belong as a member of the community. Furthermore, he can choose and talk about what he wants to do in the disability field, where he can enjoy an 'emancipated life' according to his narrative. The narratives of the participants in this study strongly prove that disabled people do not often feel a sense of belonging within mainstream society and want to have relationships in which they can feel a sense of belonging instead of ones in which they just physically participate in society. In other words, they do not want to just participate 'in' the community; instead, they want to live 'of' the community (being included in social structures and social conventions) (Rapley, 2000; Reinders, 2002).

In Sanghoon's narrative, it seems that he feels a sense of belonging and real citizenship in places where he can act as a self-determined person who 'ha[s] capacity for free choice' (Morris, 2005, p.6). Milner and Kelly (2009, p.56) also found that 'the most highly valued forms of participation were self-chosen activities that people undertook with a degree of autonomy' in a study with participants who were users of a vocational service for disabled people in New Zealand. Wilson (2006) claimed that in order to ensure disabled people’s engagement in social activities, their ‘self-determination’ needs to be secured for the activities. Some of the disabled participants in Milner and Kelly’s (2009, p.56) study claimed that what they are concerned with in terms of community participation is ‘not where but how they participate’. They asserted that ‘the absence of control over the timing or form of participation was experienced as demeaning and disabling’ (ibid.). The participants in Milner and Kelly’s study also maintained that they want to be recognised as community members by other community members and be allowed to contribute to the community. They added that limited expectations of them are ‘the most disabling barriers to community participation’ and that ‘they experienced a sense of belonging’ when their opinions are valued (ibid.). Milner and Kelly (2009) argued that emphasising location in the discussion regarding the social inclusion of disabled people can lead to failure. This is in line with Gilbert et al.’s (2005, p.292) argument that disabled people in the community need to be recognised as having ‘membership of a community of identity’, rather than being perceived as requiring only ‘the identification of a physical environment’.

One of the interviewees, Kangin, described that society is ‘give and take’ and recommended that disabled people need to take part in society. He claimed that he can ask non-disabled people to pay attention to disability problems when he is interested in and works for local problems. Therefore, he actively chooses to take part in society to be included in social structures and social conventions. Based on the participants’ discussions on participation and belonging, it seems that they want to be self-determined persons or they are already self-determined persons and, furthermore, ask disabled people to be self-determined to live ‘of’ the community and feel a sense of belonging.

8.1.2.3 Contribution

Marshall (1950, p.28) contended that ‘citizenship is a status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties with which the status is endowed’. It has historically been believed that enjoying citizens' rights is grounded in the idea of making a contribution to society, such as parenting, working and fighting in war for the nation (Turner, 2006). Morris (2005, p.26), however, maintained that 'disabled people are often assumed to be unable to take on such responsibilities', although 'disabled people make a contribution to the social good as volunteers, parents, and family and community members'.

Many of the participants in this study also emphasised social roles and responsibilities, such as being interested in local problems, having a job and paying tax, as important elements that affect their citizenship. Kangin highlighted social roles *vis-à-vis* the concept of citizenship, while Sanghyun stressed the importance of paying tax and participating actively in society. Heechan directly related citizenship to the idea of being recognised and pointed out roles and duties, rather than rights, as important components for being a citizen, whilst Younggil articulated having a productive job as a way of increasing disabled people's self-esteem and living with confidence by paying tax. Kangin, Sanghyun, Heechan and Younggil did not relate having a job to their economic status, but, instead, emphasised this as an element of their citizenship.

Heechan claimed that having a job is better in terms of becoming a citizen than receiving financial support, although the person can receive support. Gilbert et al. (2005, p.290) also asserted that having a job is recognised 'as an integrating factor and a source of identity and self-esteem' and also an important way to feel a sense of citizenship for disabled people. In order to feel a sense of belonging within society as citizens, carrying out responsibilities as well as enjoying rights is indispensable (Sachs, 1997; Marks, 2001), because fulfilling responsibilities can increase people's self-esteem and, furthermore, make them participate in society more actively (Kabeer, 2002). Therefore, 'feeling responsibility' for the society in which they live is a critical implication for social integration, which is essential for citizenship (Sachs, 1997). On top of this, fulfilling responsibilities, such as paying tax, has been claimed as a basic element of citizenship, at least since Marshall (1950) set out the concept of citizenship.

In Korea, companies which have 50 or more full-time employees must meet a quota whereby 3.1% of their staff must be disabled people (Employment Act, 2020). Companies which do not comply with this law pay a penalty for not recruiting disabled people, while companies which hire more disabled people than required by this quota can receive a grant. Nevertheless, companies often choose to pay a penalty instead of hiring disabled people. In 2014, the employment rate of disabled people in Korea was 36.6% and the unemployment rate of disabled people was 6.3%, which was much higher than the overall unemployment rate of 3.5% in Korea reported by Statistics Korea in 2014 (Kim et al., 2014). Further, the average salary of disabled people was only 46% of the average salary in Korea, according to a report of the Ministry of Employment and Labour for the second quarter of 2014 (ibid.). These data reveal the seriousness of the discrepancies between disabled people and non-disabled people, which results in financial difficulties for disabled people. As per the data, 45.7% of employed disabled people answered that their low salary was their biggest work-related problem. Such a low employment rate and low salaries can make paying tax difficult for disabled people in Korea. The low tax payment rate also results in difficulties for disabled people seeking to live as equal citizens or in them being treated as ‘lesser citizens’ in Korea.

Disabled people in the UK in Jenkins’s (1989) study also expressed frustration about being excluded from the labour market. Disabled workers in Belgium in Jammaers et al.’s (2016) study debated the discrepancy in wages between disabled people and non-disabled people in the same company and covered wage subsidies for disabled people. Some disabled workers in Jammaers et al.’s study insisted that disabled people work as well as their non-disabled colleagues. They thought it was not fair for disabled people to receive a lower salary and for the company to receive a wage subsidy for its disabled staff. In addition, Gilbert et al. (2005) claimed that jobs in niche firms and markets which provide a low salary with low expectations in terms of work quality are only offered to disabled people and described disabled people’s wages as ‘a kind of wage for people who are doing work of a low level’ (p.290). The expected low quality of the work and workplace for disabled people in Korea was also described in Kangin’s narrative about his job search after his training at the

‘Seoul Community Rehabilitation Centre’. These kinds of jobs can contribute to marginalising disabled people and preventing them from being equal citizens.

Morris (2005, p.6) criticised the current policies in terms of emphasising people’s ‘responsibility to make a contribution’, rather than people’s ‘right to make a contribution’ and observed that the concept of the contribution of disabled people is relevant to the debate ‘on the limits to social rights’. She claimed that the value attached to disabled people’s contribution to the economy and society needs to be emphasised by making the necessary resources more readily available for disabled people. One of the interviewees, Joongsoo, asserted that people should fulfil responsibilities and duties, but also stressed that the state should support people to fulfil responsibilities and duties. The International Labour Organization (ILO) promised that: ‘One of the primary goals of the ILO is to promote equal opportunities for women and men, including those with disabilities, to obtain decent work’ (Perry, 2003, Preface). The ILO defines decent work as ‘productive work in conditions of freedom, equity, security and human dignity’ (ibid.). Article 27, ‘Work and Employment’, of the UNCRPD promotes the state to uphold the rights of disabled people to receive equal pay for equal work (UN, 2018). Wickenden (2013, p.15) asserted that the UNCRPD ‘points out that sometimes in order to achieve equality, extra resources (e.g. adaptation, equipment, legal protection, time) must be provided’. The equality that the UNCRPD seeks is based on the idea of the ‘reasonable accommodation’ of the difference of disability, not the idea of ‘equality as neutrality’ (Quinn et al., 2002). The UNCRPD requires states to fulfil the ‘reasonable accommodation’ needed for individuals’ differences in the workplace. However, it seems that the promise of the ILO and the claim of the UNCRPD to the state are not very effective for disabled people in current society, not only in Korea, but also in a broad range of countries as studies from various countries prove.

The participants in the study and literature strongly insist that disabled people want to have a job and contribute to society and to be perceived as equal citizens rather than to receive social support and to be understood as being in need. However, there is still a wide gap between disability policies and practice and this practice lag has left many disabled people as beneficiaries and recipients of services. Meekosha and Dowse (1997, p.60) argued that citizenship for disabled people is merely given ‘lip service’ as part of a ‘normalizing process’. Disabled people are often constantly limited in their participation within society and prohibited, not only from enjoying their rights, but also from fulfilling their responsibilities, because society has been set a guideline whereby duties are only for non-disabled people (ibid.). The idea of normalisation, again, results in disabled people losing opportunities to contribute to society and live as equal citizens. Ware et al. (2007, p.472) claimed that ‘one way of staking a claim to worthiness is by making the social contributions of citizenship’. However, for disabled people, it seems that there is a long way to go in achieving this, as the study found that disabled people are hardly perceived as being autonomous enough to fulfil their duties and the social system and social policies do not fully support disabled people to have a job and keep it.

8.2 How do Disabled Activists in Korea Speak about, Experience and Conceptualise Quality of Life?

This section aims to respond to the second research question. This study utilises Felce and Perry’s (1995) model of QOL as a framework for the concept of QOL. However, Felce and Perry’s model of QOL is not utilised to determine QOL; instead, it is used to understand how the concept of QOL is understood and approached in this study (please refer to the ‘Conceptual Framework’ chapter). Therefore, the definition is not rigidly followed; instead, this study concentrates on individuals’ ‘values’ for their QOL which are emphasised in the model. Before probing into how the participants described QOL, it is worth recalling the definition of QOL applied for this thesis, which is as follows:

> Quality of life is defined as an overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social

> and emotional well-being together with the extent of personal development and purposeful activity**, all weighted by a personal set of values** (Felce & Perry, 1995, p.60, my emphasis).

This section first illustrates how disabled people's QOL can be different from the QOL of non-disabled people. The next sections discuss how disabled people's values and aspirations are reflected in different elements—the concept of autonomy, social context and personal finances—of QOL.

8.2.1 Differences in the QOL of Disabled People and Non-Disabled People

Felce and Perry (1995, p.51) emphasised individual differences in determining individuals' QOL and contended 'externally derived norms should not be applied without reference to individual differences' for an individual's QOL. This is an important view for disabled people who often live in a different situation from non-disabled people within society. Lee (2000), a Korean scholar, also maintained that different domains would be chosen by non-disabled people and disabled people as important elements for determining a better QOL for each group, although the same domains are considered in studies on QOL. He argued that culture and leisure activities would likely be chosen by non-disabled people, whereas rights to mobility would probably be selected by disabled people as important elements for their QOL. This implies that individual differences exist in determining QOL and the areas lacking in individuals' lives could affect their QOL.

It is evident that the interviewees in this study and disabled people in Korea are often deprived of opportunities to make choices and take initiative in their lives in mainstream society. The parts of their lives that suffer from the lost opportunities in mainstream society often become their aspirations for a better QOL. The aspirations are usually ones that most non-disabled people in Korean mainstream society enjoy and take for granted in their everyday lives, such as informal participation within the community, enjoying freedom and feeling a sense of self-worth within mainstream society and equal education opportunities. Furthermore, the elements raised as being important for QOL could also sometimes be the same for disabled people and non-disabled people, but they would be articulated in different ways. For example, some of the interviewees in the study, such as Joonho, Jiah and Hojin, talked about the importance of leisure for their QOL. They argued that lack of access to facilities for disabled people is the barrier to them enjoying leisure. However, non-disabled people, for whom leisure is important for their QOL, would not discuss it in terms of lack of access to special facilities. Therefore, discussions regarding QOL by non-disabled people should not be generalised to disabled people's QOL. Furthermore, it would be better for disabled people to discuss issues and concerns affecting their QOL themselves. However, in a previous Korean empirical study on disabled people's QOL, some of the questionnaires about intellectual disabled people's QOL were completed by the parents of disabled people, instead of by disabled people themselves (please refer to Roh and Hwang, 2010). Most of the empirical studies on disabled people's QOL in Korea have utilised questionnaires prepared by researchers, instead of interviewing disabled people directly. This may be the reason why 'social support', which was frequently found to be important for disabled people's QOL in previous Korean studies, was not mentioned by any of the participants in the study. Instead, the participants discussed belonging with other disabled people within disability communities. The result of Kim's (2000) study proved there is a substantial gap between what disabled people want for their QOL and the opinions and thoughts of their parents and disability professionals in terms of what disabled people desire for their QOL.

8.2.2 Autonomy for Disabled People's QOL

8.2.2.1 Lack of Autonomy in terms of Disabled People's QOL

Felce and Perry (1995), furthermore, argued that the assessment of life domains in an individual's life is interpretable only in relation to the individual's 'values' and 'aspirations' (p.58) and claimed 'individual's personal autonomy to maintain and change their quality of life is a paramount consideration' (p.56). However, as has been discussed, disabled people in

Korea are rarely considered autonomous people. One of the interviewees, Chulsoo, claimed that QOL is ‘a problem of choice, decision making and initiative’ and raised the question of whether disabled people have the ‘power to practise these effectively’. This is in line with the argument that the power of disabled people to enjoy their rights within society is often exploited due to the pervasive unbalanced power distribution within society (Meekosha & Dowse, 1997; Sibley, 1998; Gilbert et al., 2005; Morris, 2016).

The view that understands disabled people as less autonomous or not autonomous often positions them with the status that the community is responsible for them. According to Gilbert et al. (2005), for disabled people participating in the community, somewhat ambiguous situations occur. These ambiguous situations are produced because the community often feels a ‘responsibility’ to disabled people, instead of a feeling of intimacy (p.292). One of the interviewees, Joonho, discussed that when disabled people participate in the community, they only participate formally in limited communities and these limited types of communities ‘would just be churches … or just a few communities’. The churches and the few communities would probably be the communities that would feel a ‘responsibility’ to disabled people according to Gilbert et al. Joonho also contended that disabled people’s low QOL is deeply related to their exclusion from informal community participation. He argued that disabled people want to be involved in the community informally, but it is difficult for them to do so; therefore, the lack of informal engagement ultimately causes disabled people’s QOL to be low. According to Joonho’s argument, disabled people are able to neither choose the communities in which they want to participate nor decide how they want to participate in the communities, either informally or formally. It is evident that the lack of autonomy in disabled people’s lives causes their QOL to suffer. There are many more cases in this study which demonstrate how disabled people’s autonomy is neglected in society and this results in their QOL being low. For example, Kangin lost the chance to make a decision regarding his future career at ‘Seoul Community Rehabilitation Centre’; Youngji was not able to make a decision about where to study; and Una does not have the power to take the initiative to live a life that provides her with self-worth in mainstream society.

8.2.2.2 Lack of Studies Including the Concept of Autonomy for Korean Disabled People's QOL

The concepts and ideas which encompass control over disabled people's own lives—making choices, taking initiative and autonomy—have also been found to be important areas in previous research on disabled people's QOL (please refer to Albrecht & Devlieger, 1999; Haigh et al., 2013; Iriarte et al., 2014). Nevertheless, it is rare to find Korean empirical studies on disabled people's QOL which encompass the concept of self-determination or similar concepts such as the concept of autonomy. However, in Park's (2000) study, which was discussed in the 'Literature Review' chapter, disabled people cited the component of 'self-determination and problem-solving skills' as the tenth most important component for their QOL amongst 67 components, whilst the component was ranked 48th and 51st by disability professionals and disabled people's parents respectively. This may lead to an assumption that the scarcity in the number of Korean studies including self-determination for disabled people's QOL might be a result of the research method. Most of the Korean studies were conducted using questionnaires and, consequently, researchers' perceptions could more easily be reflected in selecting the variables affecting disabled people's QOL, and the researchers were not often disabled people.

In Korean studies, 'social support', instead of self-determination, has appeared rather more frequently as an important domain for disabled people's QOL (Paik, 2003; Kim & Kim, 2005a; Kim, 2007a; Jung & Kim, 2009; Nam et al., 2011; Kim et al., 2016). 'Social support' is an imperative element not only for disabled people's lives but for the lives of all human beings. However, that 'social support' was frequently raised and found as a significant domain for disabled people's QOL might imply that disabled people in particular need more social support or disabled people are easily perceived as people who need social support instead of people who are respected as living autonomous lives, or it could be both. I argued in the 'Literature Review' chapter that the set of statements used to gauge disabled people's 'social support' could equally be bracketed under other terms, such as 'social relationships' or 'social network' or 'sense of belonging'. It seems that naming the set of statements 'social support' itself assumes a kind of prejudice, which suggests that disabled people only need support, instead of being autonomous people who can enjoy social relationships.

8.2.3 Importance of Social Context in QOL

The frequent occurrence of 'social support' as a significant domain in studies on disabled people's QOL reflects that they are also social animals; social relationships are important in their lives. The important components discussed by the participants in this study concerning their QOL also reside within the social context and social environment, such as how disabled people want to participate in the community informally, how Heesun is willing to live in harmony with other people and enjoy freedom amongst them, how Una wants to feel self-worth in society, how Una and Chulsoo want to possess agency or power amongst people and how Youngji wishes to live in a social environment which offers equal opportunities. Hojin even related dissatisfaction due to a lack of physical activities to negative relationships with others, whilst Sanghyun suggested a self-initiated life as an attitude to life which could help disabled people to participate actively in society. It seems that it is not precise to understand participants' QOL without bearing their social lives in mind.

The participants' discussions pertaining to their QOL were about deprivation in their social lives and delivered their reflections on how they want to live and participate in mainstream society as equal members of society. This could explain why QOL scholars emphasise the prominence of social domains in defining QOL (Diener & Suh, 1997; Raphael et al., 2001; Salvador-Carulla et al., 2014) and, furthermore, why Gasper (2010, p.351) argued that the concept of QOL is 'more to refer to context and environment'.

8.2.4 Personal Finances for QOL

When Felce and Perry (2005, pp.58-59) emphasised ‘values’ and ‘aspirations’, they provided an example to explain how individuals’ differences in terms of values can affect their QOL differently: ‘size of income (the objective measure) may contribute little to quality of life for a person whose values are nonmaterialist’. This probably explains why most of the interviewees who have fought for disabled people’s rights and citizenship, which are a more valuable aspiration to them, tended to downplay the effects of personal finance for their QOL. The interviewees did not go into detail about personal economic issues and did not consider this to be an important area affecting their QOL, although they acknowledged the necessity of a certain level of money for living.

Lee and Song (2014) found a lower level of sense of happiness and life satisfaction amongst people in Korea who chose money as one of the two most important values in their lives (please refer to the ‘Conceptual Framework’ chapter). The finding that materialism has a negative effect on people’s QOL had already been found in previous studies in different countries (Ryan & Dziurawiec, 2001; Kasser & Ahuvia, 2002; Deckop et al., 2010; Karabati & Cemalcilar, 2010). Richins and Dawson (1992) asserted that people who have a tendency to materialism set money as the centre of their life and their life goals; thus, they are often deprived of opportunities to fulfil the intrinsic value of their lives. Deckop et al. (2010) also claimed that materialists might not be able to satisfy other parts of their lives, while they try to attain financial accomplishment. Kim (2014) also found that materialists in Korea have a tendency to compare themselves to other people; furthermore, to people of a higher financial status. This allows us to understand how materialists are hard to satisfy in life and have a lower QOL. The interviewees in this study have something more valuable than money in their lives, which they have been longing for and have tried to accomplish over the last decades. Some of the interviewees were even reluctant to compare their aspirations with money. As Felce and Perry claimed, it seems that an individual’s QOL can only be determined by the person's values and aspirations in their lives and each individual's values and aspirations can be different.

However, Lee and Song (2014) also found a higher average level of happiness and life satisfaction for households in the higher income level. This could imply that financial standards not only improve living conditions but also provide a range of opportunities and choices which people can control and which enable them to enjoy their lives (Wilkinson & Marmot, 2003). In addition, a positive relationship between personal income and QOL has been found in previous studies (Johnson & Krueger, 2006; Oshio & Kobayshi, 2010; Choi & Moon, 2011; Nam et al., 2012). From this point of view, the finding that money has a positive effect on disabled people's QOL in previous Korean empirical studies seems to be reasonable and relevant, since most Korean empirical studies on disabled people's QOL have examined the relationships between economic issues and QOL based on pre-selected domains.

Lee and Song (2014), therefore, contended that the effect of income on people's QOL cannot be fully explained only in terms of material conditions and environment, but rather needs to be approached in terms of how economic issues are understood by the person. They also claimed that academic research on how the value of money affects people's QOL in Korea is very rare. This suggests a high possibility that previous Korean studies on disabled people's QOL did not explicitly discuss the value of money and did not examine how disabled people contextualised money for their QOL in various ways. In contrast, the interviewees in this study contextualised important elements with value and their aspirations for their QOL. The interviewees, instead, talked about having a job, income and paying tax in terms of contribution to society and citizenship instead of economic issues for their QOL. This implies that the participants in the study tended to understand income and personal finance as a means to improve their conditions to affirm their citizenship, instead of as a material element which can affect their QOL. Previous Korean studies have also proved that disabled people who have a job and economic activities experience higher social inclusion (please refer to Kim, 1998; Kim, 2005; Bac, 2005). Furthermore, Jang (2005, p.102) claimed that the agenda of poverty needs to be considered from various social aspects, such as social exclusion and cultural and psychological alienation of people in poverty. Some participants discussed the need for a certain level of finance for living, although they differentiated money from the elements which are important for their QOL. All these make it apparent that personal finance is still important for disabled people's lives but needs to be understood from various social aspects instead of only being considered within the economic aspect.

The participants' discussions about their contribution to society were focused on having a job and paying tax, along with social roles. In addition, many of the participants mentioned money and personal finance while discussing their QOL, although they were not specifically asked about their views on the issues for their QOL. This may reflect how issues of money and personal finance are embedded in depth in people's minds in Korea and considered paramount by many citizens in Korea (Chang, 2002).

How the participants spoke about the concept of citizenship and the idea of QOL has been examined in the sections above. The next section probes into whether the concepts are related for disabled people and how the relationships can be explained.

8.3 Do the Two Concepts of Citizenship and Quality of Life Speak to Each Other in Everyday Life and Theory?

8.3.1 The Role of Citizenship for Disabled People's QOL

Morris (2005) argued that in current society disabled people's differences and humanity are often not recognised and valued and this results in disabled people being hindered from living as equal citizens in society. Based on the participants' accounts, it has been found that disabled people in Korea are often viewed as being the embodiment of vulnerability, the 'offspring of the unblessed', beneficiaries of state funding, and as people who do not belong in society instead of being perceived as equal citizens. This is not much different from the discussion; prejudice and misunderstanding about disabled people influenced by Confucianism, prioritisation of the economy and the importance of the military in Korea have compounded the strong sense of discrimination against disabled people (Jung, 2002). As a consequence, disabled people are often deprived of opportunities which citizens are usually able to enjoy, then the lost opportunities become important values and aspirations which could improve their QOL. Therefore, it has been found that the important values and aspirations for disabled people's QOL are no more than how they would like to live as equal citizens in mainstream society, such as enjoying relationships within the community, having equal opportunities in society and enjoying leisure without experiencing a lack of access to facilities. This is in line with Felce and Perry's (1995) model of QOL. According to Felce and Perry, the model of QOL which does not regard individuals' different life conditions and applies 'externally derived norms' is less appealing. For disabled people's QOL, it seems that the model of QOL which does not regard their lack of citizenship and applies non-disabled people's QOL—who take citizenship for granted—is less appealing. Felce and Perry emphasised the significance of an individual's aspirations and values in determining the person's QOL. It seems that the participants' values and aspirations for a better QOL would be inexplicable unless their lives and, especially, their lack of citizenship within mainstream society are understood.

I discussed the interviewees' narratives regarding how the lack of opportunities for leisure and physical activities in their lives diminished their QOL in the 'Quality of Life' chapter. The last excerpt in the section was Younggil's narrative. He condemned Korean culture and sports infrastructure, which does not distribute the benefits from culture and sports equally amongst disabled people and non-disabled people. As I disclosed in the chapter, Younggil's narrative was his response to a question concerning how disabled people in general live in Korea as members of society or as citizens, instead of an answer to a question related to the concept of QOL. Younggil understood the issue of the lack of benefit from culture and sports for disabled people in terms of citizenship and raised the question of whether Korean society understands disabled people as equal citizens, whilst Joonho, Jiah and Hojin accepted the limitations in enjoying their leisure time and physical activities, which decreased their QOL, as personal problems. This poses the question of whether deprivation in disabled people's lives, which reduces their QOL, can essentially be resolved within the boundaries of the subject of QOL so disabled people can have a better QOL.

Many of the individual participant's stories and opinions regarding their citizenship and QOL also raised the same concerns. For example, Jiah harshly condemned Korean society, which excludes disabled people from the decision-making process and argued that the exclusion diminishes disabled people's QOL. Meanwhile, she recounted her experience of when she confronted community members who complained about the inconvenience of living with disabled people in the same building and an occasion when a young man said 'this bus is not for disabled people', and argued that disabled people are often considered as being different in the community from non-disabled people in the 'Citizenship' chapter. It seems that Jiah's wish to be included in the decision-making process can rarely be accomplished in current mainstream society where disabled people are often considered as being different from non-disabled people and expected to live in a separate arena. Another example is Joonho's argument. Joonho raised the issue of disabled people's lack of informal participation as a source of their low QOL. In the 'Citizenship' chapter, Joonho stated that disabled people are often isolated in society and excluded from education. He claimed that, as a consequence of this, disabled people 'are often not able to give any information' and it is difficult 'to get attention from others'. In his discourse, he depicted disabled people as people who would rarely be welcome to join communities, whilst he focused on the issue of disabled people's lack of informal participation as a source of their low QOL. It seems that the fundamental causes of disabled people's low QOL are not embedded in their weak relationships with community members, but grounded in mainstream society where disabled people are excluded and not given equal opportunities. This implication may lead to the presumption that disabled people’s low QOL could hardly be improved unless they are included and live as equal citizens in mainstream society.

8.3.2 How Autonomy Links Disabled People’s Citizenship and QOL

Morris (2005) and Felce and Perry (1995) both emphasised the significance of self-determination and autonomy for exercising citizenship and enjoying a good QOL. The findings of this study manifest that disabled people in Korea are rarely considered as autonomous people but they want to belong in and contribute to society as self-determined people. Being deprived of opportunities to practise citizenship as autonomous people often results in disabled people’s QOL suffering. In contrast, it seems that some of the participants live as autonomous people, practise more citizenship and enjoy a better QOL. For example, Sanghoon, who is considered pitiful or ill in mainstream society, recommended that people should not ‘mind others’ and live ‘in the way you want to live’. This could infer that Sanghoon is currently living the life that he recommended and this is the type of life that autonomous people live. In addition, Sanghyun and Kangin also pointed out a ‘self-initiated life’ and ‘being able to view society on your own’, which are concepts closely related to the concept of autonomy, as a vital element for their QOL. Sanghyun talked about paying tax as a way of explaining what citizenship means to him, but criticised some disabled people as being accustomed to receiving social welfare, whereas he identified having a self-initiated life as leading to a good QOL. This can be interpreted in two ways. First, paying tax instead of receiving social welfare from the government can be a way to exercise a self-initiated life, which leads to a good QOL; or second, he lives a self-initiated life, so he becomes close to a status where he can have a job to pay tax, which is a way of attaining citizenship. Similar implications can be arrived at in terms of the relationship between Kangin’s definition of QOL and the description of how he lives as a citizen. Kangin claimed that the most important thing affecting QOL is viewing society on your own positively and living with values or hopes within that society. He discussed being interested in local problems as a way of expanding his role as a disability activist to become a social activist. This was in response to the question of how he lived as a citizen. Kangin's definition of QOL and living as a citizen can also be interpreted in two ways. The first way is that as he expands his role from a disability activist to a social activist, he can experience society more independently and live with more values or hopes. The second way is that when he experiences society by himself and lives with values and hopes, he becomes interested in problems in the local area, so he becomes a social activist. In either interpretation of Sanghyun's and Kangin's discourses, it is evident they live autonomous lives. It seems that many of the interviewees had already become autonomous. This is discussed further in the following section.

This chapter has discussed how disabled people live as citizens within Korean society, what they want for their QOL and whether their citizenship may be related to their QOL. It has been found that disabled people are often discriminated against, excluded from and marginalised within Korean society. This often happens because non-disabled people's perceptions of disabled people are routinely based on the idea of normalisation. As a result of this, disabled people are often prevented from participating in and contributing to society as equal, autonomous citizens. The limitations in exercising citizenship, eventually, diminishes their QOL, because what they want for their QOL is a life which they can enjoy, when they live as equal, autonomous members of society. Therefore, this means that not only may disabled people's QOL be improved when they are perceived as equal citizens and may exercise their citizenship, but also that disabled people may exercise their citizenship while they fulfil a good QOL. In other words, when citizenship in mainstream society is assured for disabled people, they can enjoy a better QOL, and that disabled people can enjoy a better QOL can mean that they access citizenship.

8.4 What is the Impact on Both Citizenship and Quality of Life of Being an Activist and Part of the Disability Movement?

The question for this section was developed by interviewing disabled activists in the process of examining disabled people's citizenship and QOL. This section is synthesised to illustrate the process by which some interviewees have achieved citizenship and a better QOL through their involvement in the disability movement. It was also found that their disability identity plays a prominent role in the process of attaining citizenship and refining QOL.

8.4.1 Embarking on the Disability Movement

Disabled people in Korea embarked on the disability movement in 1988 by publicising their wretched environment and living conditions and demanding the new acts along with challenging existing laws, as the core value of the movement was rights and the movement continued until the mid-1990s (Kim, 2005; Yoo, 2005a). This movement achieved some improvement and accomplished some of their goals. This resulted in more opportunities for disabled people to enter public society in education and labour at a certain level (Yoo, 2005a). As a result of this, Joonho and Heechan were able to enrol in university more easily in the late-1990s and early-2000s. Nevertheless, they became aware of pervasive discrimination against disabled students on campus and had to challenge the lack of facilities and the way of understanding disabled students. First, they claimed their rights to study. Joonho, who is a wheelchair user, asked for his rights to mobility on campus, since he was not able to access lecture rooms due to the lack of facilities on the campus, which was built without consideration for disabled people. Heechan asked his university to prepare text books and handouts in Braille. Facilities enabling students to attend lectures and the provision of readable textbooks and handouts are fundamental and essential rights of students, which need to be prepared and provided by universities. Disabled students gathered together with other students who experienced the same difficulties or agreed on the universities' unfair treatment of disabled students and fought for their rights. Joonho said, 'There was no other way than fighting'. Joonho and Heechan's actions on campus are in line with Beckett's (2006, p.749) argument that disabled people tend to focus on protecting and enhancing existing rights when they understand that power is in the hands of the ‘opponent’. They embarked on their involvement in the disability movement as they struggled for their rights to study—which is a basic right for students—against the universities, which possessed power.

Beckett (2006, p.744) contended that the key concern of disabled people in the disability movement is ‘their exclusion from the ideals of citizenship’ and they fight against the barriers causing exclusion as the main focus of their activities in the disability movement. Ellison (2000) also asserted that citizenship is at the heart of contemporary social movements and stressed ‘engagement’ in the context of society as the most significant feature of citizenship. ‘Engagement’ in Ellison’s argument for citizenship is related to the concepts of recognition, belonging and relationships emphasised in inclusive citizenship discussed in the ‘Conceptual Framework’ chapter. This is, furthermore, related to Morris’s (2005) concept of citizenship for disabled people. Joonho’s and Heechan’s differences and humanity were not respected and valued by the universities; thus, their rights, such as attending classes and reading textbooks, were not ensured. Therefore, Joonho and Heechan were probably not able to participate in and contribute to their classes as autonomous students; furthermore, this probably hindered them from being ‘engaged’ and belonging with other students in their classes. As a result, they gathered with other disabled students who faced similar difficulties on the campus and shared their experiences with them. The groups of students began to challenge the universities to pay attention to their current situations and claimed their rights on the campuses as equal students. Exclusion from the ‘ideals of citizenship’ and a lack of a sense of belonging in society also led other interviewees to begin their involvement in the disability movement, as some interviewees, including Sanghoon, Minjae and Jiah, shared their stories, as outlined in the ‘Disability Movement’ chapter. However, when they embarked on their involvement, it was for a relatively simple reason, such as attaining an existing basic right for their own needs.

8.4.2 Being Citizens in the Disability Movement

People who recognise the inflexibility of the standards to become a mainstream citizen often seek and develop places or communities where they feel a sense of belonging (Hall, 2005). Such places are considered their ‘safe havens’ (Parr, 2000) and/or ‘oases’ (Philo et al., 2005). Some participants suggested collective solidarity as a solution for their exclusion from mainstream society. Heesun suggested ‘collective solidarity’ as a place where she can feel free amongst people, as people and freedom are essential for her QOL. Minsoo thought of himself as a minority during his post-graduate studies at university, which he saw as representative of mainstream society. The term ‘minority’ was a means of expressing dissatisfaction with his life. He, therefore, created a form of collective solidarity during his post-graduate studies with international students who were also excluded from the class.

Collective solidarity for Una meant the disability movement where she can feel a ‘sense of worth’, which is a crucial element affecting her QOL. Una found her self-worth through participating in the disability movement by realising her dreams and experiencing self-realisation. She was previously worried that she would become a source of trouble and a headache for her family before participating in the movement. Putnam (2005, p.190) claimed that the disabled person who finds ‘a strong sense of positive self-worth’ often relinquishes ‘internalised oppression’ caused by ‘negative stereotypes and attitudes about disability’. Una’s life has changed from one where she barely tried to live in the mainstream to one where she can enjoy her self-worth and realise her dreams. Sanghoon found the disability movement to be a place where he can even be proud of his disabilities. Collective solidarity and the communities of disabled people represent an arena where Heesun can enjoy freedom among other people, where Una found her self-worth and where Sanghoon can feel a sense of belonging.

8.4.3 Realising a Disability Identity

Swain and French (2000, p.569) argued that the group identity developed through the disability movement has reinforced the development of an ‘affirmative model’, which ‘is essentially a non-tragic view of disability and impairment which encompasses positive social identities’. This is well represented in the interviewees’ narratives. Sanghoon claimed that ‘disability is like a medal’ in disability communities. Joonho even argued that disability can be ‘dignified, beautiful and charming’ and this is a message of the disability movement. Swain and French further asserted that the ‘collective identity’ amongst disabled people’s organisations makes it ‘feel exciting being part of a social movement which is bringing about tangible change’ (p.577). Interviewees such as Sanghoon, Una, Heesun and Joonho seem to be proud of the disability movement and their involvement in the movement. Marmarosh and Corzzini (1997, p.70) claimed that ‘social identity theorists argue that individuals maintain a positive social identity and use this social identity to protect and enhance their personal self-esteem’. This might explain how Una, who had a negative self-image such as being a headache for her family, has found self-worth through her involvement in the disability movement.

It evident that some interviewees, such as Joonho, Heesun, Sanghoon, Una and Joongsoo, now have a positive view of the disability movement, disability and themselves. Shakespeare (1996) acknowledged the prominent role of disabled people’s community and the disability movement for their identity. Furthermore, he pointed out that promoting a ‘positive disability identity’ is one of the benefits of the disability movement that the social model of disability has applied (Shakespeare, 2013, p.220). There is also a notion that the shared disability identity in the movement has had ‘a crucial role’ in developing the movement and been ‘a powerful and creative force’ to continue the movement (Watson, 2002, p.513). Beckett (2006, p.747) also maintained that there is at least ‘collective identity’ and ‘overall solidarity’ amongst disabled people in the disability movement, although there might not be ‘total agreement’ on ‘a positive “disability identity”’. Joonho articulated the reason for his interest in disability problems as being problems about his identity. Finding his disability identity helped him to understand society and to address the problems which could not have been solved or explained without participating in the movement. Such problems, if left unsolved, could have led to a continuous ‘feeling of alienation’ for Joonho and ‘dissatisfaction’ for Heesun. Instead, participating in the movement gave Joonho power ‘that held [him] firmly and prevented [him] from collapsing or falling apart by consolidating various experiences and worlds’, made Heesun healthier as she no longer had heartache and provided an opportunity for Una to realise her sense of worth. Joongsoo even claimed that he would not take medicine, even if one was available that could heal him, because disability is his identity. They found their identities through their participation in the disability movement. According to Joonho, the message of the disability movement is that ‘although the condition that you are accidently born with is disability, this can still be dignified, beautiful and charming and can affirm life itself, accepting disability as an identity’ and sharing the idea is one of the main goals of his involvement in the movement.

However, Joonho did not say disability *is* dignified, beautiful and charming; instead, he insisted that disability ‘*can* still be dignified, beautiful and charming’. This implies that there must be a view that disability is not dignified, beautiful and charming. Additionally, there is a possibility their lives might not be affirmed sometimes, as Joonho claimed that ‘can affirm life itself’. This assumption is supported by the purpose of the UNCRPD, which is to promote respect for disabled people’s inherent dignity. If there was respect for disabled people’s inherent dignity, this would not be the purpose of the UNCRPD. Ikaheimo (2010, p.81) asserted that respect is an attitude of valuing the individual’s personhood, which makes someone a person and is also a fundamental attitude to establishing an interpersonal relationship, seeing others in terms of a response to what the other is. Kittay (2008, p.145) argued that the relationships which bring ‘a series of appropriate emotional and moral responses’ play a constitutive role in people’s identity. However, Fraser (1997) observed that certain groups of people’s personhood are denied by society as a form of injustice predicated on hegemonic cultural definition. Jung (2002, p.41) contended that the ‘personhood of people with physical disabilities’ in Korea, where agriculture was the main industry before modernisation, has been ignored and denied, because the ability to work physically in an agricultural society has been an important criteria of personhood. In addition, disabled people in Korea are often considered unnecessary people who cost an unfair price to the nation, where a healthy body is required to sustain the nation's military power (Hong, 1997). However, Joonho claimed disability 'can still be dignified, beautiful and charming and can affirm life itself'. It seems that the participants in the study realised a disability identity through participation in the disability movement and their view of disability identity, which affirms themselves, is not tragic but positive.

8.4.4 Being Empowered as Autonomous Citizens

Kabeer (2002) argued that individuals feel a sense of solidarity when they can identify with others and work together for their recognition as members and for their collective claim for justice. Putnam (2005, p.193) contended that disabled people in the disability movement who understand disability is not an individual's negative characteristic believe that better 'policy alternatives' are possible, so engage in 'political action'. People involved in collective actions have a desire to adjust policies in terms of their language and tone for different purposes, which could advance disabled people's QOL in society (ibid.). As a result, they call for funding, building and/or rebuilding of social infrastructure as well as rectification of legal and administrative guidelines for disability policies, as they become empowered and act like active citizens who call for social justice.

The interviewees who had realised a disability identity and found a positive view of disability and themselves through the disability movement had become empowered. Sanghoon talked about a power balance in the process of resolving the problems and concerns pertaining to disability and disabled people in the 'Disability Movement' chapter. From the narrative, it seems that Sanghoon understands that the power to resolve the problems related to disabled people and disability has been shifted to the disability movement and/or disabled people. In the 'Disability Movement' chapter, Sanghoon expressed that, 'If lift construction at an underground station is stopped for days, then we would go and ask them to hurry'. Constructing lifts in underground stations is a result of the disability movement. As disabled people struggled for their rights to mobility in Korea, new lifts have been built and stations have been renovated or rebuilt in order to build lifts. In another excerpt he described that he would return with his colleagues if he was rejected from a restaurant and clearly articulated 'we feel empowered'. Kangin also illustrated a similar story of when he went to a beauty salon with his colleagues because the beauty salon had refused entry to a person with cerebral palsy in an electric wheelchair. They went to the beauty salon 'to protest and to get some evidence to file a petition to the National Human Rights Commission', since the National Human Rights Commission is an agency for modification of the Anti-Discrimination Act for disabled people. The Anti-Discrimination Act is an accomplishment which the disability movement made after a seven-year struggle. The interviewees, empowered after they found a positive view of disability and themselves, pursued new laws and policies and claimed further improvement for disabled people in society and became autonomous citizens, not only in the disability community, but also in mainstream society.

Lister (2003, p.6) claimed that citizenship is not just an outcome, but a process of struggling to acquire rights. Kabeer (2005, pp.21-22) described 'societal' understanding of the citizen 'as someone who belongs to different kinds of collective associations and defines their identity from participation in activities associated with these different kinds of membership'. The participants attempted to challenge unequal society and bring about change regarding their exclusion. It is about 'the collective struggles of excluded groups, which have historically driven the process of social transformation' (p.22). Kabeer argued, further, that collective actions develop and deepen a sense of agency, whereas agency is 'about the capacity to choose and act, but it is also about a conscious capacity, which is important to the individual's self-identity' according to Lister (2003, p.39). Isin and Wood (1999) claimed that people's sense of identity plays a prominent role in their sense of agency and in exercising it. It seems that agency and identity help reciprocally to develop each other and provide support to expand and strengthen citizenship. Shakespeare and Watson (2001, p.562) argued that it is not necessary for disabled people to identify themselves with an impairment and deficiency, but they 'can identify in terms of social oppression, resistance, solidarity and pride'. The interviewees who had realised their self-worth and felt a sense of pride about their disability through the disability movement established their self-identity and were empowered. It seems that their self-identity is not negative, but positive. They also became autonomous people who have the capacity to choose and act and claim their rights. They now attain citizenship and are satisfied with their lives more than before they participated in the disability movement.

8.5 Chapter Summary

It has been found that disabled people in Korea are not often perceived as equal citizens by non-disabled people. These views often prevent disabled people from enjoying their lives in mainstream society. That they cannot live as equal citizens in mainstream society ultimately diminishes their QOL. In order for disabled people to live as equal citizens in mainstream society and fulfil their QOL, the premise in the definition of Morris's (2005) citizenship—'disabled people's differences and humanity should be recognised and valued'—seems to be a prerequisite. Furthermore, it has also been found that improved citizenship or QOL for disabled people can each improve the other, whilst a sense of autonomy is an imperative concept in establishing disabled people's citizenship and improving their QOL. It has also been found that involvement in the disability movement has helped to ensure that some of the interviewees feel a stronger sense of citizenship and it improves their QOL. They were empowered and became people who can choose and act by realising a disability identity and finding a positive view of disability and themselves through involvement in the disability movement. Now they work with other disabled people and are developing the movement more powerfully to claim further rights for them and other disabled people to live as equal citizens.

Chapter 9: Conclusion

This last chapter aims to reflect on findings and learning which have emerged whilst conducting the research and analysing the data. First, section 9.1 briefly summarises the research findings. Section 9.2 follows by discussing the contribution of this study to the body of knowledge on disabled people's citizenship and QOL and the relationship between them within Korea society. The limitations of the study are discussed in section 9.3. This chapter continues to my reflection on this study (section 9.4), while finishing with a conclusion (section 9.5).

It is worth revisiting the research questions here:

1. How do disabled activists in Korea speak about, experience and conceptualise what it means to be a citizen/citizenship?
2. How do disabled activists in Korea speak about, experience and conceptualise quality of life?
3. Do the two concepts of citizenship and quality of life speak to each other in everyday life and in theory?
4. What is the impact on both citizenship and quality of life of being an activist and part of the disability movement?

9.1 Research Findings

This study found that non-disabled people's perceptions of disabled people often result in disabled people being discriminated against and denied the opportunity to belong in and contribute to mainstream society within Korean society, whilst belonging in and contributing to society as autonomous people is found to be a way to exercise citizenship. It is also evident that disabled people are often deprived of opportunities to make choices and take initiative in mainstream society, since they are often not perceived as equal autonomous citizens. This results in disabled people being prevented from accomplishing what they wish to in mainstream society, such as enjoying freedom, realising self-worth, having agency, living a self-initiated life and enjoying leisure time. The parts of their lives that suffer due to the failure to accomplish what they want in mainstream society often become their aspirations for a better QOL. Nevertheless, what they want is no more than that which non-disabled people often enjoy and take for granted in mainstream society. Therefore, when disabled people are perceived and live as equal autonomous citizens, they can have a better QOL. In addition, that disabled people can enjoy a better QOL can often mean that they are exercising citizenship. It was also found that having self-determination and autonomy is imperative for disabled people in exercising their citizenship and improving their QOL. It seems that some of the participants became empowered to raise their voices, claim their rights and live as autonomous people since they realised a disability identity and found a positive view of disability and themselves through their involvement in the disability movement. This resulted in them being able to experience citizenship and to have a better QOL.

9.2 Contribution of This Study to Knowledge

This study contributes to knowledge on disabled people’s QOL within Korean society. As discussed in the ‘Literature Review’ chapter, the number of studies on the QOL of disabled people in Korea is relatively small and the QOL of disabled people still does not receive much attention as a research subject (Park, 2000; Park, 2009b; Lee, 2014b). Lee (2014b) even argued that the lack of studies into disabled people’s QOL could itself be a cause of disabled people’s low QOL in Korea. This study has built up a depth of understanding of disabled people’s lives and their QOL and how they think about what QOL is. This has been possible because this study gave disabled people the opportunity to explicitly talk about their lives and their QOL and their opinions about what a good QOL is. This is different from previous Korean empirical studies, which often used questionnaires to investigate relationships between certain domains in disabled people's lives and their QOL. One of the important findings regarding disabled people's QOL in this study is the role of concepts and ideas which encompass control over disabled people's own lives—making choices, taking initiative and the concept of autonomy for disabled people's QOL. This finding also reinforces Felce and Perry's (2005, p.56) argument that an 'individual's personal autonomy to maintain and change their quality of life is a paramount consideration'.

This study has also contributed insights into how disabled people's QOL may be related to their citizenship. It was found that disabled people's aspirations for a better QOL are those things that most non-disabled people in Korean mainstream society enjoy and take for granted. In other words, what disabled people want for a better QOL concerns the circumstances of how they are perceived and can live as equal citizens within Korean society. This is the very first study which examines how disabled people's QOL may be related to their citizenship within Korean society.

In addition, this study also contributes to knowledge on the concept of citizenship within Korean society. As discussed in the 'Literature Review' chapter, the concept of citizenship for disabled people has been neither articulated sufficiently nor suitably investigated in Korean literature. However, recently, the need to understand disabled people from the perspective of the concept of citizenship has been claimed by an array of researchers in Korea (Kim, 2008; Yoo, 2011; Cheon, 2014; Kim, 2014; Shin et al., 2013; Shin et al., 2016; Shin et al., 2018). In listening to participants' stories and opinions directly in the study, it was possible to gain first-hand accounts of disabled people's lives as citizens within Korean society, how they live as citizens, what prevents them from obtaining full citizenship and their hopes and wishes for their citizenship.

Furthermore, this study has applied Morris's (2005) concept of citizenship for disabled people as a framework to understanding disabled people's citizenship in Korea. Morris developed the concept of citizenship based on the UK's 'political debate on citizenship', but the participants' narratives demonstrated similarities between the environment and society in which disabled people in Korea live and the circumstances which disabled people in the UK face in their everyday lives. This study provides insight into how Morris's concept of citizenship, which was originally developed for disabled people in the UK, can be adopted in studies on disabled people's citizenship in other countries. This study helps to comprehend non-disabled people's views of disabled people and how disabled people are marginalised in a similar manner in the two different countries, although the two countries have few connections in terms of culture, region and history.

9.3 Limitations of the Study and Recommendations for Future Research

Schur (1998) claimed that disabled people who recognise the importance of the social and environmental issues embedded in disability tend to develop more of a disability consciousness. Meanwhile, Hahn (1997) assumed that people who have a strong self-image and recognise the social effects on their disability tend to be involved at the highest level of disability activism. Since the interviewees in the study are activists in the disability field, they might have different personal attributes to other disabled people and their ways of thinking about problems may differ from disabled people in general. Additionally, the participants in the study have been educated to a higher education level than disabled people in general in Korea and all had a job. This might also have influenced the findings of this study. Moreover, all of the interviewees were physically disabled or blind in this study. As a result, issues pertaining to people with other disabilities might not have been included in this thesis.

Therefore, carrying out studies concerning disabled people's QOL and citizenship with different groups of disabled people from various environments and people with different disabilities could prove worthwhile steps for future research. Furthermore, I noticed differences in the understandings of disabled people and social phenomena between the two groups (participants with congenital impairment or who had acquired disabilities at an early age versus participants who had acquired disabilities in their 20s and 30s), although the differences are not clearly illustrated in this study. It seems that it would also be worthwhile to conduct separate studies on the different groups to provide more detail. I did not observe gender differences in analysing the data of this study, but it may be beneficial to conduct studies based on different genders. It may also be valuable to utilise a range of qualitative research methods and, furthermore, emancipatory research, since qualitative research methods and emancipatory research have not been employed much until now on this subject in Korea.

One more limitation of this study is that non-disabled people's views on disabled people as citizens was considered only through disabled people's understanding of non-disabled people's perceptions and behaviour. As I have argued, it is imperative to listen to the direct voices of those whom we want to examine. In order to understand non-disabled people's views on disabled people, it is necessary to conduct studies which explore the views and opinions of non-disabled people directly. It is also worth conducting the studies with a range of methods which can interrogate their honest voices, since there is a possibility that non-disabled people would be reluctant to discuss their negative perceptions of disabled people.

9.4 Reflection on the Study

This study provided me with an opportunity to come to recognise disabled people as people living within society with me and to become familiar with issues about disabled people and disability. This is a noticeable change in me, since I had not been very aware of disabled people living within society until I ran into a man at an underground station, as explained at the beginning of the thesis. From the very beginning in conducting this study, I have faced challenges. I first had to become familiar with the vocabulary, concepts, theories and philosophy embedded in both disability studies and social science. Especially as I studied in the UK, the culture and language were another challenge which I had to face in the process of learning. Even when I thought I understood the ideas and concepts, I experienced difficulties in using and applying them in my writing. This might have happened due to my lack of understanding of disability as a subject and my perception, which I developed over time when I was not very aware of disabled people. In addition, it might have also happened because I did not understand the nuances of the English language and the culture differences between the UK and Korea. Some expressions which I intended to use to criticise society, in fact, seemed to sound as though they condemned disabled people. However, one thing is clear: that I became aware of paying attention to the expressions and words which I use and to try to understand social phenomena from a range of perspectives. In addition, conducting this study was a path to reshaping myself from an objectivist and positivist to a social constructionist and interpretivist. From a social constructionist's point of view, it would have been better to frame the research questions in this thesis to focus on understanding how reality is constructed, such as how disabled people and their lives are constructed within Korean society. Nevertheless, in this thesis, I set the questions to examine disabled people's citizenship and QOL and to seek if there were relationships between them.

When I interviewed disabled people for this study, it was the first time I had met disabled people in person. Interviewing the disabled activists was a privilege for me. As they are leaders who are knowledgeable about disabled people's lives from different circumstances and about the Korean disability field, I was able to learn about not only disabled people's lives in a range of different environments, but also social phenomena and tangible causes behind the phenomena in the disability field. During the interview process, I came to admire the participants' resilience in a society in which they are often discriminated against and marginalised, and from which they are often excluded, and their pride, which they had earned through their struggle and hardship. At the end of this research, I began to contemplate ways in which this thesis could help to improve disabled people’s lives and what would be my next step in working with disabled people to challenge society to make it better for them.

9.5 Conclusion

This thesis has found that some of the participants who have realised a disability identity and have a positive view of disability and themselves have attained their citizenship and enjoy a better QOL, whilst non-disabled people’s perception of disabled people based on the idea of normalisation is a main barrier to disabled people enjoying their citizenship and a better QOL. These two findings offer a useful insight into solving the question of how disabled people’s citizenship and, furthermore, their QOL can be improved.

First, this thesis encourages disability scholars and policymakers to scrutinise the perception of disabled people in policies, public documents and the media and to revise the current perception of disabled people. The UN challenged the medical model embedded in the Korean Welfare Act (UN Human Rights, 2014). There is a high possibility that the medical model and the idea of normalisation pervasive within Korean society might have an influence on the perception of disabled people in other disability policies. If the UNCRPD, which is the human rights convention for disabled people, and the findings from this study are applied in the new perception and the new perception is widely accepted within society and adopted in policies, public documents and the media, there is a high possibility that disabled people could be recognised as people who not only ‘possess inestimable inherent self-worth but are also inherently equal in terms of self-worth, regardless of their difference’ (Quinn et al., 2002, p.16). Furthermore, I propose to focus on enabling disabled people to attain a positive view of themselves and their disability, and it is my intention that this study informs that vision in the future. Further studies, such as ‘how disabled people see themselves’ and ‘how disabled people can achieve self-worth’ need to be conducted and a range of programmes and policies might need to be created and revised in the process. Nevertheless, it is important to emphasise that the most imperative factor is that disabled people must be respected as autonomous people who wish to decide where to participate in society and how to contribute.

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Appendix A: Examples of Search Results for Korean Literature

Generated Date: 3, Dec. 2018

Data Base	Terms	Number of Results
RISS	Disabled People & QOL	2249
	Disabled People & Citizenship	195
	Disabled People & QOL & Citizenship	22
	Disabled People & QOL & Social Inclusion	169
	Disabled People & QOL & Social Integration	593
	Disabled People & QOL & Social Participation	818
KISS	Disabled People & QOL	269
	Disabled People & Citizenship	16
	Disabled People & QOL & Citizenship	4
	Disabled People & QOL & Social Inclusion	21
	Disabled People & QOL & Social Integration	40
	Disabled People & QOL & Social Participation	53

Appendix B: Ethics Approval Letter

School for Policy Studies

University of
BRISTOL

8 Priory Road
Bristol BS8 1TZ
Tel: +44 (0)117 954 6755
Fax: +44 (0)117 954 6756
bristol.ac.uk/sps

24 April 2015

Hyunhee Park
School for Policy Studies
University of Bristol
8 Priory Road

Dear Hyunhee

Title: 'Quality of Life and Citizenship of Disabled People in South Korea
Reference: SPSREC14-15.A15

The School for Policy Studies Research Ethics Committee has reviewed your application with regard to this project and we have received your responses to our requests for clarification. As such I am happy to provide REC approval for this project.

Please do not hesitate to contact me if you have any queries.

Yours sincerely

[redacted]

(on behalf of)

Beth Tarleton
Chair of the SPS Research Ethics Committee

Appendix C: Consent Form (English)

University of BRISTOL

Consent form
(For study on the Quality of Life and citizenship of disabled people in South Korea)

Please initial boxes	**Yes**	**No**
I confirm that I have read and understood the participant information sheet for the study above and have had the opportunity to ask questions.	☐	☐
I understand that my participation is voluntary and I can change my mind until August of 2015, without giving reason.	☐	☐
I agree to take part in a digitally recorded interview.	☐	☐
I understand that the information gathered during this interview will be included in a PhD Dissertation and work related to the dissertation.	☐	☐
I understand that anything I say in the research will be confidential, and that my name will not be used in any report or publications.	☐	☐
I agree to Hyunhee Park processing this information about me.	☐	☐
I understand that my information will be anonymous. In the case where my name would be used, an alias will be used instead.	☐	☐
I understand if I disclose harm or potential harm and abuse to myself or others, then the researcher would have to pass this on to someone who could help me.	☐	☐

Data Protection Act
I understand that data collected about me during my participation in this study will be stored in a password protected file on a personal computer and university computer storage system, and that any files containing information about me will be made anonymous. My consent is conditional upon Hyunhee Park complying with the duties and obligations under the Data Protection Act. ☐

Contact address:

Telephone number:

Email address:

Name (please write in capitals) Signature
Date

Appendix D: Participant Information Sheet (English)

Participant Information Sheet

(For study on the Quality of Life and citizenship of disabled people in South Korea)

I am a PhD student who studies disability at the University of Bristol in the United Kingdom. I do research on quality of life of disabled people and also on how disabled people perceive their status as citizens in Korea. I want to hear about the opinions and experiences of disabled people in Korea. The reason that I especially want to listen to your opinion is that you are one of people who has worked for a better quality of life for disabled people in Korea through your work in a disability movement and/or in the process of developing anti-discrimination law. I assume that you have more in-depth thoughts and opinions about the quality of life of disabled people in Korea and being a citizen as disabled person in Korea. Your opinion might help improve the quality of life of disabled people in Korea in the future, if this study can contribute to developing plans and policies for disabled people in future. If you decide to participate in this study, I will look forward to hearing about your experiences and your opinions. I will come to the organization (or centre) at a convenient time for you. This time will be discussed with you before the interview via the contact number which you provide in the consent form. The interview would take about an hour, and with your permission, would also be recorded. The interview record will be analysed by me under the supervision of my supervisors. Analysis will be presented in my thesis in English. A summary of the data analysis will be produced in Korean at end of study. This report will be sent to you by email or post (whichever manner you prefer).

All information collected from the interview about you will be kept anonymously and kept confidential in any form, including within my PhD dissertation, the report which will be sent to you and all related documents. In the case where your name would be used, an alias will be used instead. However, any data which is collected during the interview will be kept confidentially, unless information regarding harm and/or abuse to others and/or yourself is disclosed during the interview. The data will be stored in a folder on my personal computer and university computer storage system which are safely locked with encryption. Your signed consent form and interview record will be kept for 10 years.

If you don't want to take part in this study, your decision will be fully respected. However, if you decide to participate, I will look forward to hearing your experiences and opinions.

If you need any support or any supporting facility for doing the interview, please let me know. Assistance will be provided in any way you wish. If I am unable to provide support in the specific manner you request, I will discuss any alternative support with you in advance to hopefully find a suitable alternative.

Please email or call me if you would like to participate in this study and agree to the consent form.

My name is Hyunhee Park
Email:
Mobile :

If you have further questions about this study, feel free to contact me or my supervisor

Supervisor
Dr. Val. Williams
School for Policy Studies, University of Bristol, 8 Priory Road, Bristol, UK, BS8 1TZ.
Email:

Appendix E: Consent Form (Korean)

University of BRISTOL

인터뷰 동의서
연구: 한국 장애인의 삶의 질과 시민권에 관한 연구

해당 되는 곳에 서명 해 주세요

	그렇다	**아니오**
나는 위 연구에 대한 인터뷰 설명서를 읽고 이해 하였으며, 연구에 대한 궁금한 점을 연구자에게 물어 볼 기회를 가졌음에 동의 합니다.	__________	__________
나의 참여 의사는 온전히 나의 자율에 의해 결정 되었으며, 2015 년 8 월 까지 나의 참가 의사를 아무 조건 없이 바꿀 수 있음을 이해 합니다.	__________	__________
나는 나의 인터뷰가 녹음 되는 것에 동의 합니다.	__________	__________
나는 나의 인터뷰 내용이 박사 학위 논문과 논문관련 연구에 사용 되는 것에 동의 합니다.	__________	__________
나의 인터뷰 내용은 모두 비밀로 보호 될 것이며, 나의 실명은 어떠한 연구 결과나 출판물에도 사용 되지 않을 것임을 이해 합니다.	__________	__________
나의 모든 정보는 익명이며, 만약의 경우 연구 결과나 출판물에 이름이 사용 될 경우 가명이 사용 될 것 임을 이해 합니다.	__________	__________

University of BRISTOL

	해당 되는 곳에 서명 해 주세요	
	그렇다	**아니오**
나는 나의 관련 정보와 인터뷰 내용을 연구자 박현희가 사용하는 것에 동의 합니다.		
인터뷰 중 당사자나 다른 사람에게 상해나 학대 내용이 드러날 경우, 연구원은 이 내용을 도와 줄 수 있는 사람에게 의논 할 것 임을 이해 합니다.		

정보 보호법
나는 인터뷰 중 수집된 나의 모든 자료와 나의 관련 정보는 연구자의 개인 컴퓨터와 학교 컴퓨터에 암호로 잠겨 진 파일에 저장 되며 모든 파일은 익명으로 표기 될 것임을 이해 합니다. 나의 인터뷰 참가에 대한 모든 동의는 연구원 박현희가 정보 보호법에 의거한 모든 사항을 준수 하였을 때에 한합니다.

서명

주소:

핸드폰 번호:

성명 **서명** **날짜**

Appendix F: Participant Information Sheet (Korean)

인터뷰 설명서
연구: 한국 장애인의 삶의 질과 시민권에 관한 연구

안녕하세요 저는 영국에서 장애학을 공부 하고 있는 박사 과정 학생인 박현희 라고 합니다. 저의 관심 연구 분야는 장애인들의 삶의 질 이며 저의 박사논문 연구 주제는 장애인들의 삶의 질과 관련하여 한국의 장애인들이 한 사회의 일원으로 한국 사회에서 어떻게 자신들을 이해 하고 살아 가는 지에 관한 것입니다.

이 연구를 위하여 선생님의 귀한 의견과 경험을 여쭙고자 이렇게 편지 드립니다. 특별히 선생님께 인터뷰를 여쭙는 것은 선생님께서 한국에서 장애인들의 삶을 위해 일하시며 장애인들의 삶의 질과 장애인이 한국 사회의 일원으로 살아가는 것에 대한 깊은 이해와 통찰이 있으리라 사려 되어 귀한 시간 여쭙습니다.

인터뷰는 1 시간 30 분에서 2 시간 정도 걸릴 것으로 예상 되오며 선생님의 허락 하에 모든 인터뷰는 녹음 될 예정입니다. 인터뷰 시간과 장소는 선생님께서 편하신 시간에 원하시는 장소로 제가 찾아 뵙겠습니다. 인터뷰 내용은 담당 교수님의 지도하에 분석 되며 논문은 영어로 작성될 예정 이오나, 모든 연구가 끝난 후 연구 결과의 한글 요약 본은 이메일이나 우편으로 선생님께서 원하시는 방법으로 보내 드릴 예정 입니다.

논문, 보고서 그 외 모든 관련 출판물에 선생님의 실명은 사용 되지 않으며, 모두 익명으로 표기 될 예정 입니다. 인터뷰 중 선생님 당사자나 다른 사람에게 상해나 학대 내용이 밝혀 지지 않는 이상 모든 인터뷰 내용은 비밀이 보장 되며 모든 자료와 인터뷰 내용은 익명의 파일로 제 컴퓨터와 학교 컴퓨터에 암호로 잠근 파일에 저장 될 것 입니다.

서명하신 인터뷰 동의서와 녹음된 인터뷰는 10 년 동안 보존 될 예정 입니다.

만약에 인터뷰에 참가 하시고 싶지 않으셔도 그런 선생님의 의견을 충분히 존중하고 이해 합니다. 하지만, 인터뷰에 참가 하여 주시기로 결정 하시면 선생님의 소중한 의견과 경험을 꼭 듣고 싶습니다.

인터뷰를 위해 필요하신 사항이 있으시면 말씀 해 주세요. 선생님과 협의 하에 필요하신 방향으로 지원 해 드리도록 하겠습니다.

이 연구에 인터뷰로 참여 하시기로 결정 하시며 인터뷰 동의서에 동의 하시거나, 다른 궁금하신 점이 있으시면 아래 저의 전화나 e-mail 로 연락 주시면 감사 하겠습니다.

연구자: 박현희
전화:
e-mail:

만약, 이 연구에 대해 제가 답해 드리지 못한 더 궁금 하신 점이 있으시거나 불만 사항이 있으시면 아래에 있는 저희 지도 교수님께 연락 부탁 드립니다.

지도 교수: 윌리암스 교수님 (Dr. Val. Williams)
주소: School for Policy Studies, University of Bristol, 8 Priory Road, Bristol, UK, BS8 1TZ.
e-mail:

Appendix G: Interview Schedule

Interview Period: 10, June - 19, Aug. 2015

No	Date		Day	Time	Interviewee
1	June	10	Wed.	2:00 PM	Chulsoo
2		12	Fri.	9:00AM	Kangin
3				2:00PM	Yongji
4		15	Mon.	1:00PM	Heechan
5		16	Tue.	1:00PM	Heesun
6		17	Wed.	10:30 AM	Yonggil
7				3:00PM	Jongun
8		19	Fri.	1:00PM	Sanghoon
9		24	Wed.	10:00AM	Sanghyun
10				4:30PM	Hojin
11	July	6	Mon.	3:00PM	Minsoo
12		7	Tue.	10:00AM	Joongsoo
13		10	Fri.	10:30 AM	Minjae
14		27	Mon.	2:00PM	Jiah
15		29	Wed.	11:00AM	Una
16	August	19	Wed.	6:00PM	Joonho

Appendix H: Participants' Information

Name	Gender	Age	Education	Congenital* /Acquired	Type of Disability	Field of Work (At the Time of Interview)
Chulsoo	M	47	Post-Graduate	Congenital	Physical	IL
Heechan	M	36	Post-Graduate	Congenital	Visual	IL/ Culture for the Disabled
Heesun	F	53	Post-Graduate	Congenital	Physical	Disabled Women's Network/Writer
Hojin	M	45	Post-Graduate	Acquired	Physical	IL
Jiah	F	54	Secondary	Congenital	Physical	Solidarity of Disabled People
Jongun	F	30	Post-Graduate	Congenital	Physical	Culture for the Disabled/ IL
Joongsoo	M	58	University	Acquired	Physical	IL/Business
Joonho	M	33	Post-Graduate	Congenital	Physical	National Agency
Kangin	M	45	Post-Graduate	Congenital	Physical	IL
Minjae	M	49	University	Acquired	Physical	IL
Minsoo	M	37	Post-Graduate	Congenital	Visual	Business for the Disabled
Sanghoon	M	49	Post-Graduate	Congenital	Physical	Education for the Disabled
Sanghyun	M	54	Post-Graduate	Acquired	Physical	Disability Organisation
Una	F	52	Post-Graduate	Congenital	Physical	Disabled Women's Organisation
Yonggil	M	49	Secondary	Congenital	Physical	Disability Organisation
Yongji	F	58	Post-Graduate	Congenital	Physical	Publishing for the Disabled

*Congenital: Includes people who acquired their disability at an early age.