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**The Influence of National Context on Future Care Provision Planning for Korean Parents  
with Children Living with Disabilities: A Cross-National Study**

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*A thesis submitted in partial fulfilment of the requirements for the degree of PhD Social  
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## **Abstract**

A pervasive concern of ageing parents or family member with adult children living with disabilities is planning for their future. This topic is essential to address as it is highly likely that people living with disabilities living at the family home who do not have an alternative support network beyond their family members, will become dependent on some sort of formal care service. The cultural background and geographical location of all families have a substantial influence on service provision, treatment, processes, and future care planning processes.

The aim of the study is to explore how country contexts shape the plans and possibilities for future care provision of Korean parents with children living with disabilities in New Zealand and Korea (Korea, in this thesis, means South Korea). To gain a deeper understanding of Korean parents' plans, experiences and perceptions around future care provision for their children living with disabilities, a qualitative approach was employed to collect rich and lived information from participants. Using purposive and snowball sampling, a total of 36 participants were recruited and interviewed: both Korean parents of children living with disabilities and professionals working with them (10 professionals and eight parent participants from New Zealand; and nine professionals and nine parent participants from Korea). The collected data were analysed through conventional analysis methods.

Drawing on the findings of the study, the researcher concludes that future care planning is still 'in process' in both Korea and New Zealand contexts. Korean parents living in Korea and New Zealand all expressed deep concerns and anxiety related to planning for their children's future care, yet lacked concrete plans and substantive practice. The findings of the study suggest that the strong familism culture prevalent in Korea is creating a 'Self-Service' model of welfare in Korea, where parents have to, actively and directly, be involved in almost every aspect of care provision for their children living with disabilities. This makes it demanding to provide adequate care on a daily basis, leaving no, or limited, time and space to plan for future care

provision. The strong familism embedded within Korean culture creates dilemmas among migrant parents living in a host country when planning for their children's future care provision. It is also evident that Korean parents living in New Zealand perceive the state service system as a 'Safety-Net', which may lead to state dependency for some parents living in New Zealand. Nevertheless, planning for future care provision for Korean children living with disabilities in New Zealand is perceived to be significantly impacted by cultural barriers, including a lack of culturally appropriate services and provision of information for Korean parents, pressure of independent living, lack of understanding around service system, and language barriers.

The study suggests a development of a 'Korean Model of Welfare' or the 'New East Asian Model of Welfare' through state-level involvement in encouraging, empowering, and strengthening independent family functioning while reflecting the traditional characteristics of cultural values. Such a model is intended also to stimulate family functioning among the Korean parents living in New Zealand to minimise the level of state dependency evident among some parents.

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## **CHAPTER 1 Introduction**

### **1.1 Background of the Study**

Families have very deep concerns and anxieties around what might happen to their family member living with disabilities once they cannot continue to provide care (Bowey & McGaughlin, 2007; Morgan, 2009; Prosser, 1997). Yet, it is argued that the current and future care provision and needs of people living with disabilities living at home under parental or familial care is an overlooked area (Bowey & McGaughlin, 2007; Prosser, 1997; Taggart, Truesdale-Kennedy, Ryan, & McKonkey, 2012). This topic is essential to research as it is highly likely that people living with disabilities living at the family home who do not have an alternative support network beyond their family members will become dependent on some sort of formal care service. This section provides an overview of a number of issues related to planning for care provision in the future for Korean immigrant families in New Zealand, and Korean families living in Korea.

The cultural background and geographical location of all families have a substantial influence on future care planning processes. Social phenomena and the meanings attached to them are continuously being accomplished by social actors and such social actors can be seen as an emergent reality in a continuous state of construction and reconstruction instead of as a mere external reality (Bryman, 2001). Knowledge and meaning are developed through human practice and are being constructed through interactions between individuals and the world around them (Crotty, 1998). Thus, experiences of people from the same ethnic and cultural backgrounds have the potential to differ between people living in the country of origin and migrants due to different social actors (i.e., language, the culture of the society, people they interact with, etc.). Hence, the national and cultural contexts of the two countries selected for this present study enable discovery of possible explanations for differences and similarities and lead to a deeper understanding and a greater awareness of the socially experienced reality of future care planning.

It is highly likely that many, if not most, migrants experience difficulties around the migration and resettlement processes. Language barriers, along with other cultural differences, can cause them to face a range of challenges (Cho, Singer, & Brenner, 2000; Welterlin & LeRue, 2007; Wong et al., 2004); raising children living with disabilities can be extremely difficult in the host society. Korean immigrant parents of children living with disabilities might face ‘dual challenges’ not only as an immigrant but also as a parent of a child living with disabilities. It is evident that often the attitudes of ethnic minorities around disability differ from the values embodied in the host society’s health care system (Danseco, 1997; Ryan & Smith, 1989; Wong et al., 2004). Moreover, as evident in studies (Bywaters, Ali, Fazil, & Wallace, 2003; Fatimilehin & Nadirshaw, 1994), ethnic minority families with children living with disabilities commonly experience immediate or additional barriers to equality of treatment and equality of opportunity compared with those families from the majority population.

Despite all the challenges faced as immigrant parents with children living with disabilities, studies revealed that they might perceive the host country as providing better service and environment for their children living with disabilities (Cho et al., 2000; Choi, 2014; Kim-Rupnow, 2001). For instance, in a study comparing experiences of Korean mothers and Korean American mothers with children living with disabilities unanimously reported that the United States was a better place to raise their children living with disabilities than Korea, mainly due to different public attitudes and the availability of social services (Cho et al., 2000).

With the general understandings around planning for future care provision and how it may differ between Korean immigrant parents and Korean parents in Korea, the next section introduces the aims of the study.

## 1.2 Research Aims

A pervasive concern of ageing parents or family members with adult children living with disabilities is planning for their future (Bowey & McGaughlin, 2007; Freedman, Krauss, & Seltzer, 1997; Heiman, 2002; Morgan, 2009; Prosser, 1997; Taggart et al., 2012). National context and the cultural principles embedded within the given society are argued to have a significant influence on how individuals living with disabilities are supported and treated. The primary aim of the study is to explore how the country contexts shape the plans and possibilities for future care provision of Korean parents with children living with disabilities in New Zealand and in Korea. The comparison between these countries is critical for this study as the two selected countries present differing systems of welfare and cultural principles, which allows a comparison to be made between the socially experienced reality of future care planning between Koreans living in countries with distinct national and cultural contexts.

Further, the present study also attempts to ensure that the voices of the most vulnerable groups are heard. The study intends to gain an understanding of the parents' worries and desires around their children's future care and the supports they identify as valuable in their planning process as well as their children's future care provision, with a view to making valuable and useful recommendations for service design and delivery that accommodate the specific needs of people living with disability and their families in both countries studied.

Contemporary services for people living with disabilities are influenced by how disability is understood theoretically. It is increasingly apparent that the world faces challenges around the environment, economic, and politics that will almost undoubtedly have an impact on the lives of every individual. Thus, our ability to produce knowledge in the real world around how to address such issues may determine our survival in this world (Oliver & Barnes, 2012). Hence, getting a real understanding of the lives of people living with disabilities and their families is essential, which Oliver and Barnes refer to as producing knowledge in the real world. Such real world knowledge can be gained through consulting with people whose lives are affected. Policy

makers should ensure such consultations take place before making critical policy decisions. Policy makers, as well as service providers, have various ways to hear the voices of the service users to assist in decision making; these ways include systematic research.

As Shakespeare (2006) argues, there is a need for more information or evidence in disability studies. This study attempts to contribute to this need for new knowledge in the sector and comparative research which would be valuable in shaping care provision, practice, and policymaking through providing an intellectual background of the concepts, orientation and empirical generalisation of the issue to inform policy. It is important to understand that the predominant use of social research is not around the application of the specific data and findings to specific decisions, rather, it is used by decision makers as a source of information, ideas, and orientation to the world (Hanney, Gonzalez-Block, Buxton, & Kogan, 2003; Tseng, 2012; Weiss, 1977). Hence, the aim of the present study in public policymaking and service provision is not around problem-solving, yet it is around providing a forum for decision makers to think about the issue and to define the problematics of the current situation to gain new insights and perspectives to set the agenda for future actions. Such use of the data is not direct, deliberate, and targeted, yet it has the power to lead gradual changes in the whole focus of debate over the issue. In other words, as new data and concepts emerge, their cumulative effect can change the conventions decision makers abide by and reconstruct the goals and reprioritise the practical policy sphere (Weiss, 1977).

### 1.3 Research Questions

To explore how the country contexts shape the plans and possibilities for future care provision of Korean parents with children living with disabilities in New Zealand and Korea, listed below are the questions that drive the proposed study:

What are the plans of Korean parents in Korea and migrant Korean parents in New Zealand for future care provision of their children living with disabilities?

How are plans, perceptions and experiences around future care similar and/or different in the two different countries selected? How do culture and country contexts shape the plans and possibilities?

#### 1.4 Rationale

This present cross-national research attempts to make a comparison of people from one culture living in two different countries to explore differences and similarities of the socially experienced reality of future care planning between Koreans who immigrated and those living in Korea. This enables us to gain a deeper understanding and a greater awareness of the effect national and cultural contexts may have on Korean parents' future care plans for their children living with disabilities. Hence, this study is significant for its potential contribution, both at national and international levels, to assisting policy makers to design service models with an appropriate mix of formal and informal supports that the parents of children living with disabilities find useful in meeting the long-term care and well-being needs of their children. Also, it attempts to make valuable and useful recommendations for social work service design and delivery that accommodate the specific needs of people living with disability and their families.

Furthermore, it adds new knowledge in a global context to the existing pool of literature around the challenges of being a parent of an individual living with disabilities (Hewlett & Hewlett, 2011; Morgan, 2009; Weaver, 1999) and brings to light the specific support needs of people living with disabilities and their families. It also adds to the current debate around the role of the welfare state in supporting people living with disabilities (O'Brien, Caritas, & Welfare Justice, 2010; Oliver & Barnes, 2012; Rummery, 2002; Shakespeare, 2006).

## 1.5 Methodological Considerations

As the study aims to gain a deeper understanding of Korean parents' plans, experiences and perceptions around future care provision for their children living with disabilities, a qualitative approach was employed to collect rich and lived information from participants. Using purposive and snowball sampling, 36 participants were recruited among Korean parents of children living with disabilities and professionals working with them (10 professionals and eight parent participants from New Zealand; and nine professionals and nine parent participants from Korea). Professionals were recruited to provide professional views around how much Korean parents are prepared for care provision, what kind of services are being identified as valuable by the parents, and the perceived challenges and difficulties in terms of future care planning for Korean parents. Data were collected through face-to-face, semi-structured interviews. Note: the word 'interview' in the study captures all conversations in both individual and group interviews. Although the study initially did not intend to conduct group interviews, two group interviews were carried out as this was strongly requested by the participants. However, although we met as a group, the interviews were conducted to gather individual experiences. Each participant was asked all scheduled questions equally and the researcher was able to capture each individual's experiences and perceptions around future care provision planning. The group interview setting may have altered the gathered data but this is not considered to be significant as the focus was on the individual participants, not the group. The collected data was analysed through a conventional content analysis method using NVivo™ software.

This study is conducted by 'an insider researcher'. I am a Korean living with disabilities. When I was aged four, I was hit by a 15-tonne truck in Korea and lost my left arm. This accident has changed my entire life and affected my beliefs and values on disability. It is my strong hope, therefore, that the present research will contribute to adding knowledge in the sector, lead to improvements in service provision for people living with disabilities and their families, and make recommendations for policy makers on support models that would affect the lives of



people living with disabilities and their families. The benefits of being an insider include having greater knowledge and understanding of the context of the research, the ability to blend into situations without disturbing the social setting and to present authentic understanding of the culture through speaking the same language, and provide easier access to, and acceptance from, the members of the group studied. There were, however, some challenges associated with being an insider researcher, such as: the potential of being too subjective and inherently biased (Greene, 2014; Hodkinson, 2005; Kanuha, 2000; Unluer, 2012). These benefits and challenges of being an insider researcher are explored in greater depth throughout the ‘Methodology’ chapter.

## 1.6 Structure of the Thesis

This first chapter of the thesis provides a brief background to the study and an outline of the aims and the rationales for conducting this research. The next chapter presents a critical overview of the literature on the topic. It is organized into three main sections, including Core Concepts of Disability, Cultural Consideration, and Provision of Care. Chapter three outlines the methodological and ethical considerations of the study, including discussions around the research design, sampling, data collection, analysis, and methodological limitations. Chapters four and five provide detailed discussions of the findings from the data and their meanings, looking specifically at differences and similarities of the socially experienced reality of future care planning between Korean parents who migrated to New Zealand and those living in Korea. Chapter four is divided into three major sections: Options for Future Care Provision, Reasons for Lack of Planning, and Systemic Issues. Aspects to Consider when Planning for Future Care Provision, Needs, and Self-Service are then discussed in the subsequent chapter. Under each heading a number of sub-themes are identified. In chapter six, the major issues identified in the findings are discussed. Two primary themes, Future Care Planning: In Process, and Looking to the Future: Issues to be Resolved, are explored in depth. Finally, the thesis returns to the research questions and offers conclusions and recommendations.

## **CHAPTER 2 Literature Review**

This chapter aims to provide a critical overview of the literature around the influence of national context on future care provision planning for Korean parents with children living with disabilities. The chapter is organised into three major headings: Core Concepts of Disability, Cultural Considerations, and Provision of Care. The chapter discusses disabilities in broader and wider societal contexts, followed by cultural considerations around disability with a specific focus on how these are understood and perceived in the Korean context, and then explores the provision of care which is largely influenced by both how disability is perceived in societal and cultural contexts. The Core Concepts of Disability section begins with a discussion around the definition of disability which explores how disability ‘should’ be defined, impairment and disability, and the use of language referring to people living with disabilities. The section then continues into the discussion around the different models of disability and where New Zealand and Korea stand in terms of legislation and disability approaches.

The following section, Cultural Consideration, provides an overview of the impact of culture in terms of how disability is perceived, understood and treated. Discussions around how disability is understood in the Korean cultural context and attitudes towards disability in Korea then follow. Then specific cultural impacts for migrants caring for children living with disabilities are briefly outlined. Finally, the last heading, Provision of Care, outlines the shift in paradigms of disability, specifically around the shift from institutional facilities to community-based living, followed by an overview of disability services and systems in Korea and New Zealand. The discussion then leads to a brief explanation of the issues of ethnic minorities around residential provision. The final section of the chapter begins with the discussion around planning for future care which comprises discussions on the current situation, the significance of future care planning, reasons behind parents’ low involvement in future planning and how this process can be especially challenging for ethnic minorities. Different types of care provision, namely formal and informal provision of care, are subsequently

discussed. Finally, the section provides an overview of disability services in Korea and New Zealand. There are some cross-overs and links between the areas explored, but the section is organised in order to make it manageable for the reader.

## 2.1 Core Concepts of Disability

### 2.1.1 Disability

The ideologies and meanings attached to the models of disability are explicitly informed by how disability is defined. There are various ways to define disability. This section is structured to provide a brief overview of the use of the definition in practice as well as the academic discussions around this through providing a discussion over how the international disability organizations capture and define disability; how it is defined in the two countries studied; the critical debate around the distinction between impairment and disability; the constant debate around ‘people with disabilities’ and ‘disabled people’; and finally, how they will be phrased for the purpose of the present study. Discussion around how disability is defined and engaging actively in the process of searching for a working definition of disability (both in practice and academia) is an essential part of this study as human beings give meanings to aspects surrounding their social world and orientate their behaviour towards them depending upon the meanings given to them. Nevertheless, such behaviours are not only reflected in everyday interaction but are also translated into policies (Oliver & Barnes, 2012).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) uses one widely recognised working definition of disability which fits with the social model of disability discussed fully later in the chapter. Article 1 of the UNCRPD (United Nations General Assembly, 2006) states that persons with disabilities include “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with barriers

may hinder their full and effective participation in society on an equal basis with others” (p.1). The International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2002), defines three different levels of human functioning: body, the whole person and the whole person in a social context. According to their definition, disability is the outcome of the interactions between conditions of individuals’ health and contextual environment factors. It is a biopsychosocial model of disability integrating both the medical and social models of disability, which defines disability as an umbrella term encompassing limitations and restrictions on three levels of human functioning (i.e. impairment, activity limitation and participation restrictions).

Looking specifically into how disability is formally defined in the two countries studied, in Korea, the Anti-Discrimination Against and Remedies for Persons with Disabilities Act 2007 defines disability as “an impairment or loss of physical or mental functions that substantially limits an individual’s personal or social activities for an extended period”, and the Employment Promotion and Vocational Rehabilitation for Disabled Persons Act 1990 defines it as “those who because of physical or mental handicap, are subject to considerable restriction in their working life for a long time”. The definition provided by the Welfare Law for Persons with Disabilities 1989 under Article 2 follows: “For purposes of this Law, persons with disabilities encompasses those people with physical disabilities, visual disabilities, audio-lingual disabilities, mental retardation or other mental defects who have suffered substantially in his/her daily living or social life due to disabilities”.

In New Zealand, the New Zealand Disability Strategy defines disability as:

Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments... Disability is the process which happens when one group of people create

barriers by designing a world only for their way of living, taking no account of the impairments other people have. (Ministry of Health, 2001, p. 3)

Further, Statistics New Zealand (2013) in their Disability Survey provides the following definition: “disability is defined as long-term limitation (resulting from impairment) in a person’s ability to carry out daily activities. The limitations identified were self-reported or reported on behalf of the disabled person by their parent or primary caregiver” (p. 2).

The use of the two words ‘impairment’ and ‘disability’ in the preceding legislation reflects a fundamental debate in the literature where there is an ongoing debate around the distinction between impairment and disability. Shakespeare (2004) noted that relationship between disability and impairment is very complex. According to the Union of the Physically Impaired Against Segregation (UPIAS, 1976), ‘impairment’ refers to bodily function, and ‘disability’ is the disadvantage or restriction of activity as a result of a contemporary social organization which excludes people with impairments from participating in mainstream social activities.

Shakespeare (2004), however, argues that distinguishing between impairment and disability is not effective. According to him, impairment and disability are on one single continuum and are not two distinct social phenomena. He noted that impairment is never just a biological problem, but it is created, defined and understood within a social context. Along the same lines, Oliver and Barnes (2012) noted that most people living with disability do not differentiate between disability and impairment. Rather, they argue that “both impairment and disability are ‘produced’ as individual and medical problems within capitalist society at both the national and international level” (p. 31).

Distinguishing impairment and disability is a complex matter. In reality, anyone can be dis-abled’ by society as a result of certain trait an individual holds. In other words, any individual

in a given society may be ‘un’-abled to do something or participate in activities due to his or her gender, ethnicity, religious, class and so forth, hence dis-‘abled’. Yet, in our current society, ‘disability’ directly reflects physical, attitudinal and/or societal barriers caused or created by bodily, mental, or sensory impairments. The word ‘disability’ nowadays is widely acknowledged as a universal word that captures both bodily impairments and social experiences that are caused by impairments. While bodily ‘impairment’ alone cannot capture the socially experienced disablement, disability on its own, in the sense of disadvantage or restriction of activity and participation that are socially created, also has the potential to fail to fully acknowledge the medical conditions of people living with disabilities. Thus, in this research, impairment and disability will not be distinguished into two different social phenomena.

Depending on how we define disability, people living with disabilities could be perceived differently. The two very predominant phrases in this era and in a constant debate are ‘people with disabilities’ and ‘disabled people’. Oliver and Barnes (2012) argue that “to accept the label ‘people with disabilities’ is to accept that disability is an individual rather than a social problem” whereas they view “‘disability’ as a social creation” (p. 6). As Oliver and Barnes noted, people should not simply accept that disability is an individual problem. However, such strong sole emphasis on disability as a social creation has a danger of ignoring the medical conditions of disabled people. As Shakespeare (2006) argues, it would be as equally dangerous for disability studies to ignore questions of the body and impairment as medical sociology to ignore issues around socio-politics.

In fact, in my master’s thesis (Choi, 2014), I have used the phrase ‘people with disabilities’. It is arguable that the use of phrase ‘disabled people’ is favourable as some say people do not ‘have’ disability; it is the society that disables them by creating barriers that obstruct full participation in society (Ministry of Health, 2001); I use the term ‘people with disabilities’ to refer to people ‘living’ with disabilities created by society and their bodies. If use of the term ‘disabled people’ is to be encouraged in the current era with its strong emphasis on society

having the greatest influence on people's lives, the argument is that the person takes up the passive role leaving only a small amount of power, if any, for the person to be the driver of their own lives as people living with disabilities. The phrase 'disabled people' describes the person with a passive voice. A passive voice places people living with disabilities in a position where they have no power to control what has been done to them rather than being active agents. In this way, society basically defines people with disability, and they are 'given' their status as identified by the society which then again leaves them minimum power to define themselves. Although not many people would want to be identified as disabled or to be living with disability, it is time for people living with disabilities to stop to think that we are the 'victims' of our society. There is a need to stop being the passive identities where something gets 'done' to us, but become the active drivers of lives and social changes.

From studying a range of different literatures and debates around the terminology, I have come to an understanding that my use of the term 'people with disabilities' may also not fully comprehend who and how I would like to identify as 'people with disabilities'. My initial aim was to capture people with impairments and faced with social barriers. Yet, I have concluded that some readers may read it as people who 'have' disabilities and place disability as more of a medical and personal problem level. Thus, for the purpose of this study and for lack of better term, I will use the phrase 'people living with disabilities'. I believe it captures both bodily, mentally, and sensory impairments as well as the social barriers while avoiding negative connotation. It is also believed that the phrase comprehends the complex relationship between impairment and disability through capturing both bodily impairments and social experiences that are caused by impairments without distinguishing the two.

### 2.1.2 Models of Disability

Traditionally, in the literature, there have been two principal frameworks for understanding disability. One is known as the medical model of disability, and the other as the social model.

From a medical model perspective, disability is explained as an individual's problem where people living with disabilities are the victims of personal tragedy or circumstances. The emphasis of the medical model is on prevention, diagnosis, cure, treatment and personal adaptation (Burke, 2008; Swain, French, & Cameron, 2003). In other words, the model considers disability as an individual problem and often relates to the functional limitations of the person's body and conditions of deficit which are perceived to be in need of individualized medical treatments. The model is often criticized as it overlooks the needs of people living with disabilities (Burke, 2008; Swain, French, & Cameron, 2003). The model was linked with institutional care provision and, until the 1980s, people living with disabilities were isolated from their families and communities, segregated away into hospital-style residential facilities (Bradley, 1994; Walmsley, 2005).

Contrariwise, the social model of disability considers disability as a product of social relations and socially experienced reality which is socially constructed through interactions between people living with disabilities and people who are not (Munford & Bennie, 2009), as well as the wider social and physical environment people live in. The model argues that disability is aggravated by environmental and attitudinal barriers that are socially constructed, and thus the context of disability goes beyond the individual (Burke, 2008; Oliver, 1996). This model argues that such socially constructed barriers prevent people living with disability from living independently and participating fully in society. Hence, the model stresses eliminating barriers that are present in a society, while providing an environment where people living with disabilities are able to enjoy ordinary everyday life just like other people who are not living with disabilities. The social model of disabilities provided a momentum for de-institutionalization of people living with disabilities, and since the 1980s, a great investment in alternative community care provision took place (Bradley, 1994).

Though the model had great influence in the elimination of negative public attitudes and social barriers as an inspiring initiative in disability practices, it can be criticised for its neglect of impairment at an individual level and for separating impairment from disability (Read, 2000,



cited in Burke, 2008; Shakespeare, 2006). To take up more fully the argument noted earlier, Shakespeare (2006) argues that the social model fails to correspond to the daily life experiences of people living with disabilities, many of whom experience mental and physical difficulties, as well as exclusion and social barriers (Shakespeare, 2004). As Shakespeare noted (2010), people are disabled by both society and their bodies. According to him, disablement is caused by the interaction between intrinsic individual elements (for example, impairment) and the extrinsic structural elements such as societal barriers. Shakespeare argues:

Social modellers would claim that “medical modellers” assume that “people are disabled by their bodies”, whereas they say instead that “people are disabled by society, not by their bodies”. I would argue that “people are disabled by society and by their bodies”. (Shakespeare, 2006, p. 56)

Thus, he argues that it is necessary to have an interactional or relational understanding between the social and the medical approaches. This discussion will be explored further later in the chapter.

It is essential to understand that the social model itself is often related to recognition that people living with disabilities have the same human rights as people living without disabilities (Landmines Survivors Network, 2007). It is respected that the human rights approach has emerged aiming to respond to the international challenges associated with the oppression of people living with disabilities. The principle of human rights, including the first article of the Universal Declaration of Human Rights (UDHR): “all human beings are born free and equal in dignity and rights” and that every individual is entitled to the human rights without distinction of any kind, are the cornerstones of this approach and, as noted earlier, the UNCRPD incorporated this approach in 2007. Such an approach focuses on empowering people living with disabilities and their advocacy groups as well as individual choice and support (Bradley, 1994; Harpur, 2012).

In 2007 and 2009, New Zealand and Korea adopted the UNCRPD, and it was ratified in the following year. Hence, all new policy and legislation in New Zealand and Korea must be aligned with the UNCRPD which aims 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” (Harpur, 2012, p. 2). This embraces the social model which intends to achieve a fully inclusive society. Hence, the fundamental basis of the current New Zealand and Korean disability approach is the combination of a human rights based approach and the social model.

## 2.2 Cultural Considerations

### 2.2.1 Impact of Culture

McCallion, Janicki, and Grant-Griffin (1997) noted that culture represents custom, beliefs, values, structures, behaviours, and identities by which a group of individuals define themselves. (Note that culture in the present study is used in a quite specific way, referring to the ‘ethnic’ cultural background of individuals.) Culture is a significant aspect of our lives that is learned and shared. According to Sotnik and Jezewski (2005), human beings learn culture from people with whom we interact, beginning at the time of our birth (or even before birth). One’s cultural values and principles that are learned and shared have a significant impact on how they people conceptualise both who they are and the world around them. These culturally inherent values and beliefs are then reflected in the ways in which they perceive themselves and others, behave, and interact with others. Thus, it is arguable that how disability and care giving are perceived is tightly linked to one’s cultural values.

Culture has a significant impact on the construction of the concept of abnormality. The belief and notion that people living with disabilities are atypical, limited, or marginal compared to what defines humans are believed to be constructed on cultural grounds (Lupton & Seymour, 2003, cited in MacArthur, Sharp, Gaffeny, & Kelly, 2007). As an example, a cross-cultural study around parental attitudes and beliefs around learning disabilities (mental handicap) revealed that attitudinal differences and service utilization patterns among the white population and Asian families were found to be more related to religious and cultural differences rather than individual characteristics of the child living with disabilities or their parents (Fatimilehin & Nadirshaw, 1994).

Culturally conceptualized frameworks of impairment and disability affect the ways in which people see themselves and the world around them. They have an impact on the manner in which individuals in their world, including members of family and community, interact with them, and become the basis upon which societies implement programmes and policies that affect many aspects of their lives, directly or indirectly (Groce, 2005). Groce (2005) argues that societies have a tendency to group people together with specific impairments and frequently show very distinct ways of responding to people depending upon the kind of social interpretations that underlie their specific disabilities. Individuals with impairments are not only identified as distinct from the general population, but that value and meaning are attached to the types of impairments.

According to Mardiros (1989), understanding parents of children living with disability starts with understanding where disability stands within the given society. As many researchers have claimed, different societies have different paradigms for understanding disability (Bywaters, Ali, Fazil, Wallace, & Singh, 2003; Hassiotis, 1996; Shah, 1996; Wong et al., 2004). Across and within many demographic variables, including educational levels and culture, religious belief, and socioeconomic status, the concept of disability diverges (Cho et al., 2000; Sotnik & Jezewski, 2005). Individuals from different cultural and ethnic backgrounds may perceive, cope, and manage caring for their children in different ways. For instance, Westbrook, Legge,

and Pennay's (1993) study around attitudes towards disabilities in a multicultural society with six different ethnic groups discovered differences in ethnic community attitudes towards people living with different disabilities. It is also important to acknowledge that the same ethnic community may attach different significance and grant different rights and status to people with different types of impairment. In other words, specific intellectual or physical attributes are valued or devalued in particular societies. Hence, in predicting how well an individual with impairments will live in a given society, the personal attributes a society values are very significant.

Groce (2005) argues that, in predicting how well a person with impairment is treated in a given society, even for immigrants, belief about how disability is caused is significant. Cultural explanation around why impairment occurs help define how poorly or well people with impairments are treated in societies. Cultural belief systems regarding disability is evident to have an impact on parents' perception around causation and treatment. For example, according to Ryan and Smith's (1989) study around parental reactions to developmental disabilities in Chinese American families, Chinese belief systems around health and illness were apparent in the parents' concepts around causation and treatment. Their (1989) study revealed that a number of Chinese parent participants in the study regarded the cause of their child's disability as punishment for a violation of an ethical, cultural or religious code. Nevertheless, it is evident through studies that many parents with East Asian cultural background believe that total recovery is achievable (Danseco, 1997; Wong et al., 2004). Many parents remain hopeful that one day a cure will be discovered or a miracle will happen and that the condition of the child's disability is only temporary (Danseco, 1997). According to Wong et al.'s (2004) study on Chinese parents raising children living with disabilities, the focus of raising a child living with disabilities was on treatment for recovery rather than on issues around training. Likewise, Raghavan, Weisner, and Patel (1999) discovered that South Asian families were comparable in their hope and desire that the impairment of their child would somehow get better as time went on.

Hence, differences in beliefs may have direct implication for their approaches towards treatment. In other words, there are diverse ways that families may view disability and individuals with impairments (McCallion et al., 1997; Welterlin & LeRue, 2007), which is likely to influence the degree of service needs and family's willingness to accept different services (McCallion et al., 1997). For example, people who hold the belief that the disability is caused by supernatural powers tend to feel depressed or helpless, or blame themselves or their ancestors for the disability. They have a tendency to seek little help and leave things to fate. Moreover, Groce (2005) discovered, in some immigrant communities, they believe improving their present lives lessens the amount of suffering they ought to endure, thus compromising the possibility of a higher level of existence in their future lives. Those with a more scientific education believe that conditions of disability may be cured with appropriate medical intervention, and actively seek medicine, surgery or therapy from health professionals. While the causes of disabilities within Korean culture and society are discussed in greater detail in the following section of the chapter, some Koreans use herbal medicines, acupuncture and other remedies as intervention options of treatment. Furthermore, there are people who are spiritually orientated who consider Western medicine as an effective treatment option, but who still offer prayers and practise religious rituals to recover physical and mental health (Kim-Rupnow, 2005).

Further, as is evident through studies (Danseco, 1997; Ryan & Smith, 1989; Welterlin & LeRue, 2007; Wong et al., 2004), often the attitudes of ethnic minorities around disability differ from the values embodied in the host society's health care system. For instance, the dominant culture in the United States is based upon a set of values and beliefs that define the mainstream idea of a 'quality of life' that includes principles of self-resilience, independence, and personal choice. However, it is possible that immigrant families may not share the same principles as United States parents and professionals (Welterlin & LeRue, 2007). Such differences may lead to ineffective treatment and dissatisfaction for both the providers and service users (Welterlin & LeRue, 2007; Westbrook et al., 1993). Westbrook et al.'s (1993) study discovered that significant mismatches occur between the expectations and attitudes of people from different ethnic communities and people who are embedded in mainstream health care programmes.

Thus, studies (Bailey et al. 1999; Bywaters et al., 2003; Welterlin & LeRue, 2007) argued that there is a need for service providers to understand and respond to the attitudes and knowledge of families, to work alongside families' beliefs, and to ensure that the provided services are not Eurocentric. According to Westbrook et al. (1993), research has shown that the cultural background of health professionals trained in Western medicine has a significant influence on how they react to patients with disabilities. There is a need for professionals to have awareness that the cultural background of a client with disabilities and their families has significant implications for their expectations.

Nevertheless, culture and its significant impact on wider social welfare, broadly considered, should also be considered. In other words, there is a close link between culture and the social model of disability discussed earlier that needs to be articulated. As explained earlier, the social model of disability considers disability as a product of social relations and socially experienced reality which is socially constructed through interactions between people living with disabilities and people who are not. In turn, culture represents customs, beliefs, values, structures, behaviours, and identities which have an impact on the manner individuals interact with others in the society. Culture also is reflected as the basis upon which societies implement policies and programmes. In other words, culture is a fundamental aspect of what constructs a society, impacting on social relations and the social reality of individuals within a given society. One's customs, beliefs, values, and identity, hence one's culture, are reflected in the ways in which they behave and interact with others, accordingly constructs social relations and experiences. To illustrate this further, as discussed above, different societies have different paradigms for understanding disability as people from different cultural backgrounds are likely to hold different beliefs and values, and perceive and understand disability in different ways. Hence, the interactions between people living with and without disabilities, which constructs social relations and reality, are likely to differ according to the cultural values and principles that are embedded within the given society. Hence, culture and social models of disability are tightly interrelated.

This section of the discussion looked at what culture is, the impact that culture has on how people construct what disability is, and the effect it has on how people living with disabilities are treated as well as the interactions between people living with and without disabilities within a given society. The section provided a discussion around the impact culture has on the concepts of abnormality, impairment and disability. It also provided an explanation for how culturally conceptualised understandings of disability and impairment may affect how people perceive themselves and world around them, and thus impact on the manner people interact with others. The discussion articulated that different societies have different paradigms for understanding disability and that people from different ethnic and cultural backgrounds are likely to understand, perceive, treat, cope and manage care provision differently. Making reference to a number of other studies, this section of the chapter explained how the perceptions, experiences and attitudes of ethnic minorities around disability issues may differ from values embodied in the host society's health care system. Finally, the section looked at how culture and the wider social framework of welfare are tightly interrelated. The discussion provided in the section around the cultural impact on disability is vital for the present study as it sets out the basic understanding of the impact of culture from the very individual interactional levels to the much wider social framework of welfare.

Now, with the more general understanding of what culture is and the impact of it on disability, the next section aims to provide a more specific discussion around the impacts Korean culture has on disability.

### 2.2.2 Disability and Korean Culture

Too often in the West, 'Asians' are lumped together as if they are a homogeneous group. This oversimplifies 'Asia', which is an extremely diverse continent in terms of race, cultural religious traditions, colonial legacies, homogeneity/diversity, economic development, language and so on – much more than 'Europe'. Within Asia, there are differences depending

on whether we focus on Japan, India, Korea, Iran or China and sometimes it is not possible to even generalise across different cities and provinces within one given country (Hofstede, 2007). However, for the purpose of the study, the continent of Asia is divided into *four* Asias (South, Central, Southeast, and East), while the thesis focuses largely on East Asia. Hence, unless otherwise stated, the term ‘Asia’ is used to refer to East Asian countries, including Mainland China, Mongolia, North and South Korea, Japan, Taiwan, Hong Kong, and Macau, which all share common cultural roots going far back into history. Note also that discussion around familism, which is a major concept of the thesis, is offered as a part of Korean culture later in the section. Furthermore, the chapter initially focuses solely on Korean culture but later covers the material from New Zealand to draw upon the similarities and differences between the two countries.

The history of disability in Korea is argued to be parallel with Western histories in terms of experiences around stigma, how disability is interpreted as moral punishment, and institutionalisation of people living with disabilities (Kim, 2006). While disability policies have been thought to enhance the lives of people living with disabilities through modernisation and Western influences, some sought to read Taoist, Buddhist and Confucian principles concerning the body and disability as the signs of traditional attitudes towards people living with disability before modernisation. Some of these commentators generalise such principles as ‘benevolent’, ‘humane’, and ‘holistic’ compared to Western maltreatment of people living with disabilities (Kim, 2006).

It is essential to pay close attention to the significance of the influence of Korean cultural values on parenting and supporting children living with disabilities. It is argued, though traditional Korean values are impacted by diverse different factors, the most prevailing one is clearly Confucianism (Hyun, 2001; Park & Cho, 1995). It is acknowledged that Confucianism has been powerful in shaping the structure of the family and communities, as well as the behavioural patterns in Korean society (Park & Cho, 1995). According to the Confucian



philosophical principles, the composition of society is hierarchical, based on each individual's moral capacity and self-discipline (Hyun, 2001). As Hyun (2001) noted:

To ensure harmony and order in the family and in society, one must abide by filial piety as the cardinal value. The Confucian code of conduct also prescribes the principles for the major interpersonal relations, including those between: ruler and minister, parent and child, older and younger brothers, husband and wife, and between friends. Wisdom, responsibility, and benevolence descend from the former (superior), and obedience, loyalty, and respect are expected of the latter. (p. 205-206)

From research exploring Chinese cultural influences (Holroyd, 2003) – which is also largely influenced by Confucianism – on parental care giving obligations towards children living with disabilities, it was concluded that parents of children living with disabilities go beyond the demands of mere duty. The study claimed that in such circumstances, compared to the obligations of parents with children living without disabilities, parents with children living with disabilities may voluntarily give of themselves in ways for which few cultural guidelines or expectations exist (Holroyd, 2003). Such an excessive sense of obligation was apparent in my previous study around experiences and perceptions of Korean parents with children living with disabilities in New Zealand as well. For instance, parents had a strong preference for having their children under their care as long as they can, even if their children reach adulthood (Choi, 2014).

Kim-Rupnow (2005) conducted a study examining Korean concepts of disability and attitudes towards disability. According to him, there are two major disability concepts that have influenced Koreans over generations. The first one is based on the idea around a supernatural agent. From Buddhist tradition (imported to Korea in the very early days when Buddhism was introduced around the fourth century AD), some believe that lifelong disability is a type of punishment for something they did in the past, or the actions of their parents, or even their

ancestors. Later, when Christianity was introduced into Korea, the concepts of ‘God’ and ‘devil’ were first introduced to Koreans. Confined only to Koreans who are Christians, a particular view was presented in which they regard disabilities as “punishment from God or the curse of the devil for their sins” (2005, p. 119). This often results in suffering from denial, helplessness, withdrawal, shame, and depression. The second conceptualised belief is that disability results from the mother’s carelessness during pregnancy, including violating certain taboos and the failure of nutritional practices while pregnant.

Although contemporary Korean citizens increasingly consider the cause of disabilities to be genetic defects or diseases, it was apparent in Kim-Rupnow’s (2005) study that Korean society still has mixed perceptions regarding the causes of disability. Recent studies on Koreans’ attitudes towards disabilities claimed that past researchers tended to focus on negative attitudes towards disability and explain the higher level of stress and guilt demonstrated by Korean mothers by highlighting a culturally deep-seated conception that associates disability with karma<sup>1</sup> (Cho et al., 2000; Park & Chung, 2014; Schumm & Stoltzfus, 2011). However, Korean parents are increasingly less likely to display traits of self-blame and they resist prejudice (Park & Chung, 2014). Differences in parental interpretations of the causes of disability also emerged among Korean parents and American Korean parents (Cho et al., 2000). Korean parents attributed causes to their own behaviour, such as mistakes in early parenting or carelessness during pregnancy. On the other hand, 63% of Korean parents who migrated to the United States attributed the causes to a divine plan that ultimately would benefit the family. Here, it is evident that the causations referred to by Korean migrant families are closely linked with Christianity, which contrast largely with the Buddhist concepts referred to above. Such results may have been influenced by the fact that Christianity is the most popular religious belief among Korean Americans.

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<sup>1</sup> A Buddhist ethical concept referring that all our actions are conditioned and have consequences.

Moreover, in contrast to Western cultural ideology where autonomy, uniqueness, and independence based on internal attributes (such as emotions and thoughts) serve as the principal guide for cognition and behaviour, in East Asia (including in Korea), the predominant cultural ideology, is social conformity and interpersonal connectedness (Hyun, 2001; Kim-Rupnow, 2005; Park & Cho, 1995; Shin, 2002). Shin (2002) noted that Korean culture is believed to be collectivist in its nature –this emphasizes the values of family, meeting expectations of family through obedience, and conformity to the rules of society. Such ideology fosters an interdependent self-construct which is driven by relational and contextual information to guide cognition and behaviours. It is argued that such a social conformity emphasis in collectivist cultures may result in greater social stigma. This occurs as individuals’ ‘otherness’, ‘impairment’ in this case, makes it hard for them to conform to society, hence their being treated differently, marginalised, and isolated. It is suggested that the social stigma of living with disabilities is more likely to be extended to other in-group members than in comparatively individualistic cultures. Also, in East Asian cultures such as Korea, preserving harmony within an individual’s social environment was a powerful motivator in life, and it is argued that people from this cultural background would potentially define a high quality of life as one in which harmony is preserved and achieved (Hofstede, 1984). Hence, in Confucianism, individuals’ interests, desires and minds may be only carefully expressed or willingly suppressed to maintain harmony within their social groups. At homes, as well as at schools, children are expected to learn ways to adjust their behaviours, and become sensitive to others’ minds in order to maintain harmony and interpersonal relationships (Choi & Kim, 2003; Haight, Kayama, Ku, Cho, Lee, 2016). In such a context, people living with disabilities who are unable to perform their expected roles, or whose impairments cause discomfort to others may be marginalised (Haight et al., 2016; Hyun, Kim, Kang, & Nam, 2012; Nakamura, 2006; Paik, 2001).

Further, it is also perceived that such collectivist communities are less likely to have benefited from the advanced modern medicine or adopted scientific explanations for disabilities (Westbrook et al., 1993). For example, Westbrook et al.’s (1993) study in Australia discovered that supernatural explanations for disabilities have been communicated more frequently by

collectivist communities. People in collectivist communities also displayed variation around help-seeking behaviour; they were found to be more dependent on family around problem-solving rather than searching for outside sources for support, and they rely on family members to support them in care provision for their family members with impairment, whereas individuals from more individualistic cultures would be more inclined to depend on professionals (Shin, 2002).

It should be noted here that some of the cultural impacts discussed above may also apply to the New Zealand context. For instance, favouring family responsibility is also evident in New Zealand society and had been evident throughout history (Milner, 2008). There are a number of underlying similarities in the situation of Korea and New Zealand, including how New Zealanders also have a tendency to blame parents for their child's disabilities in the grounds of parental development and other possible reasons for blame. The discussion around family responsibility in New Zealand is explored in further depth later in the chapter; this section is hence focused solely on the impact of Korean culture on disabilities.

#### 2.2.2.1 Familism

Korean social security programmes and public services have been neglected for decades under growth-orientated developmentalism (Chang, 1997), and social policy in Korea has only recently come to the fore as a response to perceived social problems (Shin & Shaw, 2003). The welfare state in Korea is facing diverse pressure and challenges due to changing social, demographic and economic circumstances: prevalence of the service economy; labour market flexibility; weakened family function and an increase in non-traditional families; low fertility rates; and the most rapid ageing population among OECD countries. Such challenges listed are recognized as 'new types' of social risks. The 'old' social risks such as poverty, disability, ill health, retirement and unemployment have not disappeared due to inadequate or insecure welfare, and now these risks intertwine with the so-called 'new risks'. Hence, the welfare state

of Korea is currently facing a number of complication and tasks to resolve (Kim, 2009). This is particularly concerning for the present study as, in the midst of ‘new’ social risks, namely weakened family function and increase of non-traditional families, and the ‘old’ risks, lie children living with disabilities and their families without a concrete plan for their future.

As discussed earlier, Korea retains a very strong cultural tradition and repeated affirmation of the practices and values of Confucianism (Shin & Shaw, 2003), where family interdependence, individual self-help and filial piety are emphasised as social virtues (Phillips & Jung, 2013). According to Phillips and Jung (2013), familism in Korea can be directly related to the historical values of Confucianism. Familism has been broadly discussed in the context of welfare typologies and is perceived particularly relevant to East Asian welfare states – conceptualized as sharing Confucianism ethical values and social norms (Phillips & Jung, 2013). Familism is a concept that emphasises the family over any other groups or individuals in a given society (Yang, 2002). Note that, in Confucian tradition, ‘family’ means an ‘extended family’ and not the ‘nuclear family’ we imagine today. In traditional Confucian society the concept of ‘individual’ was very weak while ‘clan’ (which includes everyone sharing the same family name) was the central source of identity.

Yang (2002) states that familism and the values attached to it can be identified as one of the aspects that represent the traditional values of Korean society (Yang, 2002). It is believed that family values in Korean society, where interconnectedness among family members is exceptionally strong and family-centred thinking is predominantly emphasised in all social relations, has a great influence on other aspects of people’s lives such as the meanings attached to the values, ideologies, and consciousness that the members of the society construct and hold. In Korean society, based on the value of familism, it has been considered as an unquestioned duty to care for, nurture and support family members (Yang, 2002). Consequently, Korean society traditionally places responsibilities for individual welfare on families. Such responsibilities include: raising children, caring for elderly parents, and providing emotional and material support for members of the family.

As Yang (2002) states, the welfare system of each country can be perceived as a product shaped not only by the political formation, economic development, and socio-cultural background of the country but also by the public consciousness of the nation's welfare state. Welfare consciousness is developed in relation to the value and relevance that constitute the basis of the society in relations to the country's historical and cultural background. It reflects the values, beliefs and attitudes towards the welfare of the members of the society. In other words, welfare consciousness is built on the basis of traditional ideas and values that form the foundation of the society, or in relation to traditional ideas and values. Conclusively, *welfare consciousness* is a term that collectively refers to the ideas, values, and attitudes towards the welfare system that the members of a society have on the basis of society's historical, political and economic situation. It is not *fixed*, but is a value system that changes over time and as a result of wider social changes (Yang, 2002).

The findings of Yang's (2002) research suggests a clear, high level of relation between familism and welfare consciousness in Korea. In other words, how people in Korea perceive welfare provision is highly related to familial responsibility over any other groups or individuals. Such a clear relation with familism and the welfare consciousness of Korean society can also be evident from a number of other studies (Chang, 1997; Phillips & Jung, 2013; Shin & Shaw, 2003; Yang, 2002). Yang (2002) argues that the welfare consciousness of Korean society is continuously progressing, yet such familism values that are shared by Koreans have been criticised in Korea for their emphasis on the responsibility of family regarding social welfare. In this regard, familism becomes a tool to reduce and minimise the functioning and provision of national levels of welfare (Chang, 1997; Yang, 2002).

The strong cultural tradition and the practices and values of Confucianism in Korean society, discussed above, are also evident in its relationship with the way social policy has been addressed (Shin & Shaw, 2003). According to Shin and Shaw (2003), the development of social policy in Korea is believed to be continuously facilitated by Confucian values. In current

Korean society, citizens are under strong moral and political pressure to sacrifice individual interests for family unity that is unconditional, to keep familial problems within the family, and to withdraw from resorting to governmental and social measures in an effort to meet familial needs.

It is argued that that the welfare system in Korea has been improved, and it has been changed to emphasise the responsibilities of the state and society rather than individual responsibility more than in the past (Yang, 2002). For instance, the School Meals Act 1981 was introduced in Korea, where the state and local governments provide administrative and financial support, to provide and enhance the quality of school meals, contribute to the physical and mental development of students, and to elevate their dietary quality. However, while Yang (2002) states that the value of familism has weakened, it is still found to continuously have its relations to the level of awareness about the welfare system held by members of the Korean society.

Chang (1997) argues that families are recognised as a major policy target in East Asian countries, which includes Korea (Chang, 1997). According to Chang, in family welfare, support from family members become the main source and objectives of policy implementation. According to him:

... if the state depends on sound support among family members to protect children, the elderly, the handicapped and other types of dependent people, family support is not only a private virtue but also a political goal. (p. 24)

The family support obligation rules, specified in Civil Law and the National Basic Livelihood Security Law, could be a great example of Korean policy where the *family* is obliged to provide the service first and foremost, *not the state*. In other words, the ‘obligatory providers’, who are the lineal blood relatives between two generations and his/her spouse, hold responsibilities for

providing support for other family members in need. Only when the person in need has no obligatory provider, or has obligatory providers that are unable to provide support, or is unable to receive support from obligatory providers, and has income below a certain amount, are people eligible to receive support from the state. This system has particular implications for the present research as the system has a significant impact on the process of future care planning, especially for families who are barely making ends meet yet do not meet the eligibility requirements to receive state level supports. The system places the family where they cannot be independent from each other but must be interdependent on each other, hence planning for future as well as current care is largely influenced by these family support obligation rules.

Chang (1997) criticises that public assistance and service for familial needs have been neglected for decades, while policy discussions around ‘family welfare’ are predicated on the state dependence on self-support by families in maintaining its (the state’s) minimal commitment towards welfare. He further comments:

If the official emphasis on family welfare in Korea takes the family as the objective of public welfare and purports to provide all the necessary resources for materially stable and psychologically harmonious family life, it is certainly a timely approach. However, if it sees the family mainly as a means of inexpensive social welfare for reducing the fiscal burden of the state, not much can be expected in overall improvement in the well-being of the Korean population, or in quality improvement in the country's labour force. This is a crucial, but too often neglected, distinction. (Chang, 1997, p. 36)

Cho (2001) also argues that, despite the rapid growth of the economy of East Asian countries, the welfare state remains underdeveloped. According to this author, in East Asian countries welfare is provided for individuals in need primarily by the family rather than the state. He notes that welfare services and systems of these countries operate under the East Asian Welfare Model or the Confucian Welfare States that are unique to these countries and are rather



different from the Western models of welfare. Similar to the criticism made by Chang as stated earlier, he also observes that countries providing welfare under such models, shaped by Confucian traditions, cannot expect the rapid expansion of welfare policy that is evident in European countries. Yang (2002) makes similar comments and is highly critical that such familism, placing responsibilities for caring, nurturing and supporting children and elderly on family members, affects the formation and understanding of welfare consciousness of the citizens, and further restricts the level of welfare state development (Yang, 2002).

As discussed throughout the section, the close relevance of familism in the view of who holds responsibilities for welfare provision is clearly evident in Korean society (Yang, 2002). Her study revealed that, in terms of who holds welfare responsibility in different areas of social issues, familial responsibility was identified to be preferred over state responsibility in the areas of poverty and elderly care. However, in the cases of people living with disabilities and issues around unemployment, participants in the study expected higher state responsibility than familial responsibility. In the areas of welfare provision for persons living with disabilities, females, and children of families without parents, the view that the primary responsibility lies with the government is predominant. Further, from the findings of her research, the need for non-familial responsibility for people living with disabilities has been argued most strongly by the participants compared to any other groups. In other words, it was discovered that the citizens of Korea who participated in her study perceive people living with disabilities as a primary group of people that the state should take responsibility in providing support and services for. It was also evident that more institutional and social involvement were needed for these populations. She argues that such results can be seen as a result of the attempts and consensus to shift disability from private responsibility to public responsibility (Yang, 2002).

As is evident throughout the discussion, it is clear that Korean culture has a unique impact on how disability is perceived, understood and treated in Korean society. With Confucianism playing a powerful role in shaping the structure of the family and communities, family interdependence, individual self-help and filial piety has been emphasised as a social virtue in

Korea. Familism, in particular, is argued to have a great influence on the aspects of Korean people's lives including the meanings attached to the values, ideologies, and consciousness Koreans construct and hold. Caring for, nurturing and supporting family members are considered as an unquestioned duty for Koreans. Therefore, with Korean society traditionally placing responsibilities for individual welfare on families, and current welfare systems and policies in place being perceived as state dependence on self-support by families, it is highly likely that such familism will have a considerable amount of influence on future care planning for children living with disabilities for Korean families. The values of familism do not only have the potential to have an impact on families living in Korea, but also on Korean families living outside Korea as values embodied in the host society's health care system are likely to differ. For instance, in New Zealand, although familial involvement is much encouraged in care provision, a lot of systems and services are perceived to support independence of their children, which may create a level of dilemma for Korean parents from cultural backgrounds with a strong emphasis on familism.

### 2.2.3 Attitudes Towards Disabilities in Korea

Studies conducted about Korean people's attitudes towards disability revealed that traditional Korean culture carries negative attitudes towards people living with disabilities (JoongAng Ilbo, 2001; Kim-Rupnow, 2001; Park & Chung, 2014; Shin & Crittenden, 2003; Shin, 2002). A survey conducted to examine Korean's attitudes towards disability (JoongAng Ilbo, 2001) concluded that strong negative attitudes have not changed at all over the 15 years between 1984 and 2000. Shin and Crittenden (2003) argue that, although Korea has adopted Western and modern values in many respects, traditional attitudes and ideas towards disabilities are significantly resistant to the changes following modernisation and perceived to have persistent and enduring negative effects on the well-being of both people living with disabilities and their families. A more recent study conducted by Park and Chung (2014) also revealed that, although Korea has endorsed a series of legislation and mandates to expand opportunities for children living with disabilities, disability is still perceived with prejudice and stigma. Korea's legislative efforts to ensure discrimination-free education has resulted in an increase in the

number of social services for families and opportunities to receive public education. Yet, experts criticise that such an improvement in quantity has not essentially led to changes in social climate as attitudes and perceptions towards people living with disabilities remain biased and negative (Park & Chung, 2014).

According to Kim-Rupnow (2005), the majority of Korean people tend to avoid people living with disabilities – this results from uneasiness connected to not knowing what to do. It is argued that “when helping a person with disabilities, some people usually overprotect or overcompensate, which only serves to frustrate those they are trying to help” (Kim-Rupnow, 2005, p. 121). Thus, Korean people living with disabilities are highly likely to experience isolation (Kim-Rupnow, 2005).

Shin and Crittenden (2003) argue that Korean mothers of children living with disabilities were affected more by the attitudes towards disabilities and by the traditional values of Korea than by the actual children themselves. Their study revealed that Korean mothers were much more stressed than American mothers. They argue that, beyond the stress the child could cause, Korean traditional values tied with a negative attitude towards disability may have a very strong negative influence on the stress Korean mothers experience (Shin & Crittenden, 2003). Another cross-national study (Cho, Singer, & Brenner, 2003) also revealed that Korean Americans experienced that the United States is more accepting of people living with disabilities and had more knowledge about disabilities compared to people of Korean origin. They also believed that non-Koreans had higher levels of tolerance towards the challenging behaviour of people living with disabilities. Differing public attitudes and perceived tolerance in the United States were the major reason behind the unanimous acceptance among Korean American mothers that the United States was a better place to raise their children living with disabilities than was Korea.

The National Report of Korea on the Convention on the Rights of Persons with Disabilities organized by National Human Rights Commission of Korea (National Human Rights Commission of Korea [HRCK], 2014) stated that, although the central government and local governments are providing education, conducting public campaign advertisements, and distributing guide books to raise awareness on disabilities for school students, workers, and the general public, the results of the Survey on the Recognition of Discrimination against Persons with Disabilities (Ministry of Health and Welfare, 2010) indicated that 67% of the respondents (persons living disabilities) reported persons living with disabilities frequently face discrimination in Korea, and 49% answered they have never heard of the Anti-Discrimination against Persons with Disabilities Act 2007. The results of the 2013 Survey on the Economic Activities by Persons with Disabilities undertaken by the Korea Employment Agency for the Disabled also suggested discrimination and prejudice against persons with disabilities were the biggest reasons, in 17.9% of cases, for them to fail in landing jobs. Although pursuant to the Act on Welfare of Persons with Disabilities, under the Act on Employment Promotion and Vocational Rehabilitation for Disabled Persons 1990, the state, local governments and business owners are obligated to provide education to employees to raise awareness on people living with disabilities, there are no penalties when this provision is neglected.

#### 2.2.4 Influence of Immigration on Care Provision for People Living with Disability

Migrants often face social, cultural and economic barriers which are likely to limit access to health care services (Welterlin & LeRue, 2007). Many migrant families have different beliefs and values when compared to native-born people of the country. They may have specific views on what constitutes disability based on their own unique cultural and social background. They may not share the same principles of normalisation of the country they migrated to (Welterlin & LeRue, 2007). Consequently, it is argued that the impact of culture on service utilisation and caregiving is often changed by immigration. For instance, studies (Bywaters et al., 2003; Fatimilehin & Nadirshaw, 1994) reveal that ethnic minority families with children living with disabilities (which include migrant families) commonly experience immediate or additional barriers to equality of treatment and opportunity than those families from the majority population. Adherence to cultural values may pose some complex challenges. As a result,

minority cultures, willingly or unwillingly, give up their own ethnic values, behaviour, and customs for those of the majority (McCallion et al., 1997).

Learning and gaining access to services can be difficult for any parents raising a child living with disabilities, however, those who are not members of the mainstream culture are likely to find such processes especially challenging (Bailey et al., 1999). It is likely that they may lack knowledge around navigating their ways around health care services. Navigating health, medical and education systems can be a daunting duty for many immigrant families and individuals (Welterlin & LeRue, 2007). It is possible that members of diverse cultural population that are in need of the most care may be receiving the least amount of service as a result of lack of knowledge and awareness (McCallion et al., 1997). A study conducted by Bailey et al. (1999) reveals that families of the host society both anticipate and experience fewer barriers in gaining access to health services than families of other ethnic groups. Westbrook et al. (1993) claimed that migrants are often unfamiliar with, or unaware of, the different types of service available. It appeared in an Australian study (Royal South Sydney Hospital Rehabilitation Centre, 1980) that Anglo-Australians living with disabilities are more likely to receive and fare better in rehabilitation than people from other cultural backgrounds. Further, in the study conducted by Wong et al. (2004), it was revealed that lack of knowledge and information was common among East Asian parents, despite parents' educational levels (Wong et al., 2004). Westbrook et al.'s (1993) study suggested that awareness of available services may encourage parents to seek support rather than hiding their children living with disabilities at home.

Hatton and his research team also noted that family carers from minority ethnic communities, which includes migrant families, have the tendency to be at substantially higher risk of poor mental health and well-being than parents of the host society (Hatton, Emerson, Graham, Blacher, & Llewellyn, 2010). They note that minority ethnic membership often tends to co-occur with a greater likelihood of experiencing a poorer socioeconomic position. According to their research, families from minority ethnic communities were viewed as being more likely to

experience reduced human capital for example, not using the language required by the services and reduced understanding of the adult living with disabilities) and reduced social capital (for example, little support from service systems and local communities), both potentially made more likely by the poor socioeconomic position of ethnic minority families in terms of housing, employment and income. They argue that these factors combined result in reduced well-being, family functioning (for example, in physical health, worry, distress, and negative influence on the household), as well as less optimal parenting styles among ethnic minority families caring for children living with disabilities (Hatton et al., 2010).

Language is a critical constituent of an individual's social context and the meanings attached (Crotty, 1998). Hence, living in a society where different language is used from the country of origin may have an impact on their knowledge, experiences, and perceptions around raising children living with disabilities as language barriers can create anxiety around seeking and engaging with services (Cho et al., 2003; Choi, 2014; Danseco, 1997, 1997; Hassiotis, 1996; Wong et al., 2004; Ryan & Smith, 1989).

#### 2.2.4.1 Korean Migrant Parents in New Zealand

The Korean migrant population is the fourth-largest Asian group residing in New Zealand. The number of Korean migrants in New Zealand has increased significantly from 1991 to 2006 (Statistics New Zealand, 2013). Their key motivations for immigration are noted to often include higher quality of life in a clean and beautiful natural environment, and to provide a better educational environment for their children, rather than economic betterment. As Epstein (2006) states, Korean migrants are generally characterised as well educated, middle to upper-middle class and relatively wealthy. However, as with many other migrant groups, Korean migrants are often faced with challenges regarding language barriers and lack of cultural knowledge. It is highly likely that many, if not most, migrants experience difficulties in migration and resettlement processes. Language barriers, along with cultural differences, can

cause them to face a range of challenges. It is believed that these challenges often limit their employment opportunities, access to social services and social networks for migrants settling in New Zealand (Morris, Vokes, & Chang, 2007; Yoon, 2003).

In addition, while raising children living with disabilities can be extremely difficult for any parent. Korean immigrant parents of children living with disabilities might face ‘dual challenges’ not only as immigrants but also as parents of a child living with disabilities. From my previous research (Choi, 2014), the language barrier was identified as one of the biggest challenges in raising children living with disabilities in New Zealand. Limited English proficiency meant that Korean parents were faced with issues around seeking information, engaging with support services and communicating their desires and needs freely. Mistrust or lack of trust towards professionals and service providers was evident in many areas. Feelings of anxiousness around lacking knowledge about available services and having limited understanding of how the general health care system operates were perceived to be significant issues for Korean parents caring for children living with disabilities.

Another major finding of the study was that Korean migrant parents in New Zealand often perceived themselves as passive recipients who have to adjust and conform to both the services and to wider society. The study concluded that this is likely to be related to the notion of professional supremacy. In Korean culture, it is assumed that professionals have knowledge and thus greater power over clients. This was found to have a substantial influence on how Korean parents perceive themselves whilst engaging with social services. Parents often perceive themselves as passive recipients, and consequently exercise less power over services provided. As Dixon (1996) noted, “in the past, patients and family members were expected to trust the professionals with whom they interacted” (pp. 126-127). However, as with the findings of Mir and Tovey’s (2003) study, such feelings of powerlessness seem to lead Korean migrant parents in New Zealand with children living with disabilities to feelings of inability to influence or control the services provided (Choi, 2014).

A very strong sense of responsibility and obligation (which is strongly influenced by familism) was observed among Korean migrant parents in New Zealand. Accordingly, time management and balancing between parental responsibility and personal care were found to be one of the biggest issues for Korean parents raising children living with disabilities in New Zealand. It was evident that these parents often have no informal support and they also experience a lack of interpersonal relationships and lack a sense of strong relationship within the community (Choi, 2014).

Despite all the difficulties discussed earlier, it was also acknowledged that Korean migrant parents did experience positive aspects while raising their children living with disabilities in New Zealand. It was acknowledged that the societal perception of, and provision of, service for people living with disabilities in New Zealand is much more positive than it is in Korea. These parents often perceived New Zealand disability services as very effective and supportive, and had a belief that the positive societal perception and attitude towards people living with disabilities in New Zealand will bring encouraging outcomes for their children in the future (Choi, 2014).

As discussed throughout the section, culture is a fundamental constituent of a society and plays a vital role in conceptualising understandings of disability and impairment. How disability is understood in a given society may not be reflected in the same way in another. People from different ethnic and cultural backgrounds are likely to perceive, understand, treat and interact with people living with disability differently. For migrants, where they are members of minority community, since the values embodied in the host society's health care system may differ largely from their country of origin, caring and planning for their children's future may be especially difficult. Further, in addition to the migration and resettlement processes, migrant families are faced with a range of challenges, including equality of treatment, service access, and opportunity, and language barriers. Discussion around the impact of migration and the challenges migrant families are faced with were essential for the present study as these all pose potential barriers in future care planning for migrant families. With some



of the essential cultural considerations addressed in this section, the following section of the chapter will provide detailed discussions around provision of care.

## 2.3 Provision of Care

### 2.3.1 Planning for Future Care

As stated earlier, a pervasive concern of parents or family member with children living with disabilities is planning for their future (Bowey & McGaughlin, 2007; Freedman et al., 1997; Heiman, 2002; Lunsky, Balogh, Sullivan, & Jaakkimainen, 2014; Morgan, 2009; Prosser, 1997; Taggart et al., 2012). Although the proportion of people living with disabilities living with family differs across nations, living with family carers seem to be the predominant form of community care. For instance, it has been estimated that 60% of people with intellectual impairments are living with family carers in the United Kingdom (King & Harker, 2000). A similar pattern is evident in the United States. According to a study conducted by Heller and her colleagues (Heller & Caldwell, 2006), nearly three-quarters of people with intellectual impairments live with ageing family caregivers in the United States. A more recent study in the United States also suggested that there is an increasing number of ageing parents who face their retirement age while still holding the responsibility of caring for their adult child living with disabilities. The study indicated that more than one-third of adult children living with disabilities continued to co-reside with their parents until their parents reach their mid-60s (Seltzer, Floyd, Song, Greenberg, & Hong, 2011).

Further, in Korea, 83.6% of people living with intellectual disabilities were being cared by their family members, mainly their mothers (Korea Institute for Health and Social Affairs, 2008). Almost 70% of them were found to be dependent on their parents for their survival even after they reached adulthood, which results in their parents becoming life-long care providers.

However, 93.8% of families have indicated that they have not prepared for the future care provision of their children living with disabilities (Korea Institute for Health and Social Affairs, 2011). Therefore, because services relating to intellectual disabilities in Korea are predominantly focused on children, adults living with disabilities residing with their parents are more vulnerable when their parents get old and become incapable of providing care for their child or when they die (Kim & Chung, 2016).

Families have very deep concerns and anxieties around what might happen to their family member living with disabilities once they cannot continue to provide care (Bowey & McGaughlin, 2007; Dillenburg & McKerr, 2011; Morgan, 2009; Prosser, 1997). Nevertheless, studies (Flynn & Saleem, 1986; Helgeson et al., 2013) revealed that, as well as their parents, people living with disabilities themselves suffer from anxiety about what will happen to them when their family members are no longer available to provide care in the future.

Academics argued that the current and future care provision and needs of people living with disabilities living at home under parental or familial care is an overlooked area, yet one that is critical to address (Bowey & McGaughlin, 2007; Dillenburg & McKerr, 2011; Prosser, 1997; Seltzer et al., 2011; Taggart et al., 2012). This topic is essential to address as it is highly likely that people living with disabilities living at the family home who do not have an alternative support network beyond their family members, will become dependent on some sort of formal care provision of service. Thus, it is argued that, if out-of-home, community-based placement for people living with disabilities currently living in family homes is viewed as a low priority, it is extremely likely that it will pose serious risk to the future security for these people (Prosser, 1997).

Therefore, significant complications can be created with a lack of planning for family members when crisis occurs. It is argued that crisis settlement as a result of ill health or unfortunate circumstances for a primary caregiver is highly likely. This generates vulnerability

for people living with disabilities living at home to sudden, unplanned and possibly traumatic re-location of residence. Crisis resettlement into temporary, emergency (and potentially inappropriate) placements defined by what is available at the time is highly likely to cause unnecessary emotional distress for individuals living with disabilities (Bowey & McGaughlin, 2007; Dillenburger & McKerr, 2011; Freedman et al., 1997; Heller, 2000; Heller & Caldwell, 2006; Kim & Chung, 2016; Morgan, 2009; Prosser, 1997; Taggart et al., 2012). Thus, in order to minimize such circumstances, concrete plans for residential arrangements need to be established *before* the crisis event (Prosser, 1997).

The process and experiences of out-of-home transition not only impacts on their special health care needs, but their psychological development, including ability to build identity, establish adult relationships and achieve independence (Zhou, Roberts, Dhaliwal, & Della, 2016). Yet, the timing of the transition has been the centre of debate for decades. There is an argument (Helgeson et al., 2013) that late transition (individuals older than 18 years old) can lead to poor client outcomes mainly as a result of the late exposure to the care settings and a lack of independence. Others claim that early transition may be associated with increased psychosocial risks (Helgeson et al., 2013). According to the study conducted by Zhou and his research team (2016) aiming to provide a review of the research-based evidence related to the transition process for young adults and adolescents, the ideal timing to transit broadly ranged from the late teens to early 20s, depending on the child's developmental stage and self-management abilities. Hence, as Zhou and his colleagues (2016) note, a structured transition programme is needed to achieve a smooth transition process, and there is a need to accurately and regularly assess children's readiness for transition by applying validated measurement tools (Helgeson et al., 2013).

The issue of future care provision for people living with disabilities has become of increasing interest to researchers (Bowey & McGaughlin, 2007; Prosser, 1997) as cumulative evidence indicates increasing demand for residential provision in the future from such groups, as well as the vulnerable nature of these families (Bowey & McGaughlin, 2007; Kim & Chung, 2016).

Studies argue that one of the greatest needs, yet the most challenging aspect of planning for future care, is around residential care provision (Freedman et al., 1997; Heller & Caldwell, 2006; Prosser, 1997). Freedman et al.'s (1997) study around ageing parents' care plans for their adult children living with disabilities revealed that making decisions where their member of the family with disabilities will eventually live is the most challenging aspect which surfaces the unresolved (or unspoken) anxieties of the caregivers. They noted that families' plans around future residential care are associated with parental desires and hope for their family member with disabilities' future, and the perceived urgency of the immediate circumstance (Bowey & McGaughlin, 2007; Taggart et al., 2012), while parental carers in another study (Prosser, 1997) acknowledged that some alternative provision would be necessary eventually.

Besides, in the study conducted in the United States, co-residence of adult children living with disabilities at home was discovered to have negative impacts on the elderly parents' well-being and their social participation. The study indicated poorer health and mental health were especially evident among co-residing adult children. The study also concluded that parents in their mid-60s caring for adult children living with intellectual and developmental disabilities continued to manifest normative rates of retirement and employment, yet, in terms of social participation patterns, such parents were similar in most respects to the general population during their midlife life course but, by the early stages of their old age, those whose children living with disabilities co-residing at home appeared to make less frequent visits to their family and friends than parents of children living without disabilities (Seltzer et al., 2011).

Despite the concerns and interests around future care, a number of researchers (Bowey & McGaughlin, 2007; Freedman et al., 1997; Heiman, 2002; Heller & Caldwell, 2006; Kim & Chung, 2016; Petriwskyj, Franz, & Adkins, 2016; Prosser, 1997) indicate that many carers have not made concrete plans. Although carers identified residential care as the most needed aspect of future care, Prosser (1997) concluded that plans around the future residential care were only minimal. Only 28% of carers who participated in his study had made any concrete future residential care plans but were more likely to have established financial plans. He stated

that care provided by the family, especially by parents, has been the predominant form of community care for people living with disabilities in the United Kingdom, and a corresponding majority of participants were committed to maintaining long-term home care for their family member with disabilities as long as possible. Nevertheless, the majority of these carers were not expecting to make any sort of formal future care plans.

Another study in the US has also revealed very similar pattern (Freedman et al., 1997). According to the study, 94% of participants believed that their family member with disabilities will still be living at home with them for at least two years. Yet, their study discovered that less than 50% of their 340 participants had made any residential plans for their relative with disabilities, as manifested by having their name on a waiting list for residential provision including apartments or group homes, planning for other family members to take the person with disabilities into their own homes, or planning for siblings to move back into the family home to provide care. It was evident that such low levels of future residential care planning is linked with the substantial reluctance to alter or plan for a change in residential setting. From their follow-up study after three years, 22% of families with short-term residential plans had achieved a placement compared to 14% of carers who had no plans yet wanted a placement.

Planning for the future for a member of a family is a dynamic, complex, and extremely emotional process for any family with relatives who have intellectual disabilities (Bowey & McGaughlin, 2007; Dillenburger & McKerr, 2011; Freedman et al., 1997; Hatton et al., 2010; Heller & Caldwell, 2006; Taggart et al., 2012; Prosser, 1997). Families show tendencies to avoid making any concrete plans as the subject is too painful to broach (Bowey & McGaughlin, 2007; Heller & Caldwell, 2006; Prosser, 1997; Taggart et al., 2012), which also poses questions for carers around their own mortality (Heller, 2000). Freedman et al. (1997) stated that, either in spite of, or because of, concerns, anxiety, and stress about the future, family members often do not make any concrete, long-term plans. In particular, residential planning is recognised as one of the most emotional aspects of future planning (Freedman et al., 1997; Heller & Caldwell, 2006; Prosser, 1997). Yet, planning for the future care is evidenced to have a positive

relationship with adult needs, and family functioning (Brotherson et al., 1988; Heller & Caldwell, 2006). Studies (Bowey & McGaughlin, 2007; Heller & Caldwell, 2006) found that having plans for the future significantly reduced feelings of burden among caregivers. Higher caregiving satisfaction among mothers who are more prepared in terms of permanency planning, hence having fewer worries about future care provision of her children, was evident in a study conducted in Korea to understand the caregiving satisfaction of elderly mothers of adult children living with intellectual disabilities in Korea (Kim & Chung, 2016).

Studies (Bowey & McGaughlin, 2007; Heller & Caldwell, 2006; Prosser, 1997; Taggart et al., 2012) highlight that anxiety around preparing for the future of their member of the family with disabilities is amplified as carers believe that there is a lack of acceptable alternative residential care provision. Heller and Caldwell (2006) found that trusting professionals and service systems, as well as the emotional struggles with the system, pose challenges to carers in planning for future residential care for their family member with disabilities.

In addition to the difficulties discussed above, families from minority ethnic backgrounds are found to be faced with further strains. According to Heller and Caldwell (2006), families from minority ethnic backgrounds are often less tied to the service system, hence they are less likely to have made formal future care plans for their family member with disabilities. They highlighted that families of ethnic minorities are faced with additional challenges around planning for future care provision as a result of lack of information, difficulty affording the financial costs of attorneys, reciprocity of caregiving, availability of appropriate services, and emotional issues concerning their own mortality. These people often encounter high unmet needs for information regarding legal and financial issues, support groups, advocacy, and case management.

To conclude, planning for future care provision is a pervasive concern of parents regardless of where they are situated in the world. Families have very deep concerns and anxieties around

what might happen to their family member living with disabilities when they can no longer provide care themselves, yet many have not made any concrete plans. This topic is essential to address as it is highly likely that people living with disabilities living at the family home will become dependent on some sort of formal care provision. It is evident that one of the major needs, yet the most challenging part of planning, is around residential provision, and this is especially challenging for families from a minority ethnic background. To provide a better understanding of what created the necessity of these parents to consider the matter of future care planning more seriously, the following section provides an overview of the shift in the disability paradigm, with a specific focus on the shift from institution to community living.

### 2.3.2 Shift in Disability Paradigm: Institution to Community Living

The shift in the models of disability and how disability is perceived discussed earlier in the chapter led to changes in care provisions for people living with disabilities. Discussion around such shift is significant for this study as it is the movement that created the need for different care provision services in the community and made it necessary for parents to consider different options of care provision for their children living with disabilities. The section is structured to first explore the reason for the shift, then to provide a discussion around some of the initial reaction of the families regarding the shift. It then aims to provide an overview of the emergence of alternative living arrangements of people living with disabilities and the impact the shift has had on people living with disabilities. Then, the section concludes with a discussion around the issue migrant families are faced with in residential provision. Note that this section of the chapter focuses on providing a general overview of the shift, and an outline of such movement and emergence of alternative care provision in the two countries studied are specified later in the section.

Until the 1980s, influenced by the medical model of disability which emphasises diagnosis, prevention, cure and personal adjustment (Burke, 2008; Swain et al., 2003), people living with

disabilities were often segregated from their families and communities into hospital-style residential facilities. From the 1980s, the social model of disability presented a momentum for deinstitutionalisation of people living with disabilities and a great investment in community alternatives took place (Felce et al., 2008; Morgan, 2009; Kim, Larson, & Lakin, 2001). The movement, which was based on the concept of normalisation (Wolfensberger & Glenn, 1973), allowed people living with disabilities to speak about their rights and placed centrality on community-based living, equal education and employment opportunities (Bonardi, 2009; Race, 2007).

There was also the central issue of human rights. Everyone, living with or without disabilities, has the right to experience life to the fullest, to develop their potential and to actively participate in the community. It was argued that without such opportunities, an individual's development is restricted, the ability to make informed decisions and choices are limited, and also the opportunities for community participation are denied (Cambridge, Hayes, Knapp, Gould, & Fenyo, 1994). Hence, if people living with disabilities are not given such opportunities, the human rights of these people discussed earlier would have been breached.

Such a shift is seen to have generated different reactions among families caring for their family member living with disabilities. There is evidence of overwhelming satisfaction with the institutional services, and evidence of significant opposition to deinstitutionalisation at the time are also found (Tabatabaiana, 2003). Morgan (2009) argues that the questions around future care had become somewhat more complicated in some ways than in past decades. From what he is arguing, in the past people knew that they could not rely on government interventions at the level expected today, hence there were limited alternatives to consider in regard to care provision. Even the closing down of the large institutions makes future care planning more difficult as, although people had never wished for an institutional placement, at least it was there as a backup plan. In other words, from a research synthesis conducted by Larson and Lakin (1991) few studies had shown a high degree of general satisfaction with institutional care provision before deinstitutionalisation. There were parental concerns expressed around



deinstitutionalisation which involved finding and maintaining caring, respectful, safe, and permanent accommodation.

Following the continuing movement towards disbandment of institutional provision of care, there has been increasing international attention paid to the living arrangements of people living with disabilities. Large institutions have been gradually replaced by a range of much smaller community-based residences. Although care provided by the family, especially by parents, has been the predominant form of community care for people living with disabilities across different countries (Heller & Caldwell, 2006; King & Harker, 2000; Prosser, 1997), other forms of residential care arrangements (for example, independent living; group homes; resident campus, etc.) have emerged as alternative living provision to institutional settings.

A number of studies (Beadle-Brown, Mansell, & Kozma, 2007; Chowdhury & Benson, 2011; Emerson, 2004; Emerson et al., 2001; Kim, Larson, & Lakin, 2001; Kozma, Mansell, & Beadle-Brown, 2009; Lemay, 2009; Stancliffe & Keane, 2000) have concluded that the move from institution to community-based living is associated with a range of positive outcomes for people living with disabilities including better lifestyle and quality of life, enhanced community involvement and integration, acceptance by the community, increase in family contact, greater autonomy and choice and greater range of activities both daily and social. Larson and Lakin (1991) also discovered in their studies where they compared and contrasted parents' reactions to deinstitutionalisation before and after the move to community from institutions that parents who were initially opposed to deinstitutionalisation were almost always satisfied after the placement in community (Cooper & Picton, 2000; O'Brien et al., 2001; Spreat & Conroy, 2002; Walsh et al., 2010). There was also evidence of both lower levels of satisfaction with their earlier institution placement and higher levels of satisfaction with community settings.

There is evidence that Asian people living with disabilities may be placed in the most vulnerable position over any other population group in residential provision. Research

(Emerson & Hatton, 1996) conducted to examine the residential provision in England, Wales, and Scotland stated that ethnicity is possibly a powerful predictor of access to residential care. The study highlighted the significant under-utilisation of social and health care services by Asian individuals with intellectual disabilities. The study revealed that young Asian men and women were significantly less likely to be in residential provision than any other ethnic group. Young Asian men were only one-third as likely as their peers from any other ethnic group to have some form of residential care provided. Furthermore, young Asian and Chinese women were half as likely as young women from other ethnic groups to have care provided in terms of residential provision. Utilisation of services other than residential care will be discussed in the following sections.

In the following section, definitions of formal and informal support are provided. This discussion is significant for this study as it provides a general overview of the utilisation of the two primary types of care provision and help-seeking patterns among Korean families, which are likely to have a substantial influence on their future care planning process. Under formal support, a discussion around the difficulty of utilising formal support due to lack of knowledge and cultural barriers, migrant Korean families' experiences and perceptions around differences in the scope and provision of formal support in the host society and homeland, and the cultural impact on the families' help-seeking behaviour are provided. In the subsequent section, informal support, the discussion round the cultural impact on help-seeking behaviour is continued. This section explains the impact of familism on the provision of informal support, how Korean families are doubly trapped between social stigma and the loss of social support; this is followed by a discussion of different experiences around informal support between Korean families living in Korea and Korean migrant families in New Zealand and America.

### 2.3.3 Formal Support

This study endorses the definition of formal support provided by the Office for Disability

Issues and Statistics New Zealand (2013), which states formal support is the assistance with daily activities or living that is provided by organisations or individuals not generally related to the person. Formal support providers are usually paid for their services. This present study also includes all supports that are either publicly funded or privately paid as formal support.

Note that much of the following review of the literature is from the United States rather than New Zealand. This indicates that there is lack of available New Zealand research around the provision of formal support for migrant families caring for children living with disabilities, which raises issues concerning the need for exploration in the New Zealand context. There is a small amount of research which reflects on the implication of provision in Korea, both from studies conducted to compare the experiences of Korean families in the host and home country, and studies conducted within Korea to explore the experiences and perceptions of Korean families caring for children living with disabilities.

Welterlin and LeRue (2007) argue that a shared problem of recent immigrants is a lack of knowledge and understanding around health care and special education systems and procedures, along with the potential benefits and risks involved in using such systems. Such lack of understanding and knowledge can possibly contribute to an inability and a reluctance to seek and accept services that seem complex and unfamiliar. McCallion and his colleagues (1997) study on perception experiences of five different immigrant communities and Native American families with persons with impairment in their family demonstrated that suspicion of formal structures was commonly shared among immigrant groups. All immigrant families expressed concerns around engaging with formal service providers. They were mainly uncertain whether the service would provide services they needed and the quality of the provided care and services. The study suggested that immigrants were having difficulty justifying use of community services that are a modern intervention, and are not part of their own traditional culture. However, some participants, including Korean parents, said such reluctance was an old-fashioned view and in some ways they preferred to be provided services outside their own community (McCallion et al., 1997).

A study conducted using comparisons between South Asian families and American families with individuals with impairments as their family member revealed that South Asian families perceived that service and care was much more organised and better met their needs in the United States than their home country (Raghavan et al., 1999). Similarly, in a study comparing experiences of Korean mothers and Korean American mothers with children living with disabilities unanimously reported that the United States was a better place to raise their children with impairments than Korea, mainly due to differing public attitudes and the availability of social services (Cho et al., 2000).

From the same study (Cho et al., 2000), formal support was reported as one of the major differences between the two participant groups. An inadequate or lack of formal social support made the Korean parents frustrated and caused more difficulty in parenting. For instance, Korean parents disclosed that they had to spend a large amount of their income on early intervention or special education programmes. Higher private educational expenditures were causing significant strain for Korean parents. Such costly education expenses were major indicators of high levels of psychological pressure among Korean parents. Furthermore, these parents had to devote a significant amount of their day to caregiving as schools, for the most part, in Korea did not provide transportation services. On the other hand, free public education, early intervention, school bus services, and case management system became buffers against negative consequences (for example, language barriers) for the American Koreans. Hence, Korean Americans highly valued formal public and social service (Cho et al., 2000). Likewise, Shin's (2002) study revealed that American mothers do rely on professionals more than do Korean mothers of children with impairments. She argues that the higher level of support in all fields of professional support (rated by Korean American mothers) suggest that families and individuals with impairments in the United States were provided with a higher quality of services. Nevertheless, many professionals are far less available in Korea because professional services are still at their early stages of development (Shin, 2002).

Furthermore, another study which sought to enrich cultural understanding of what contributes to adaptation to changed life status and environment after the diagnosis of their children among Korean mothers of children living with disabilities in the context of Korean society suggested that Korean parents are generally hesitant to seek support from social organisations as they are reluctant to expose their children's or family member's disabilities by registering them for eligible services offered the Ministry of Health and Welfare or the Ministry of Education (Park & Chung, 2014). Thus, it is argued that informal support becomes a significantly valuable source of support for Koreans (Park & Chung, 2014).

#### 2.3.4 Informal Support

In this study, the phrase 'informal support' endorses the definition provided by the Department of Human Services (2014) which states "the types of support that people get from family members or other supporters (not from paid carers)" (p. 88). Based on the definition, all voluntary sources of support that can be accessed without direct cost including support from relatives, friends, neighbours and other organisations such as religious organisations will be included.

As discussed earlier regarding the familism culture in Korea, Korean people regard family as the most basic social unit and believe harmony at home is the primary step to achieving harmony in the community and wider society. As is evident in studies (Kim et al., 1999; Westbrook et al., 1993), such communities hold a belief that family members or friends will provide care and support for members living with disabilities within the community. Thus, it is not surprising that family members commonly feel obligated to provide care for old grandparents, young children, or family members who are unwell. Reflecting the values embedded within familism, they feel that it is their mere duty to ensure family members' basic needs are met and to keep up their morale. Similar findings were available in a study involving a number of different ethnic minorities (Raghavan et al., 1999). The study stated that members

of cultural minorities showed a greater reliance on familial piety, greater availability of support from extended family members, and a cultural belief that one should take care of one's own family.

Although little is studied about the impact of informal support on managing children living with disabilities among Asian families, a handful of studies (Cho et al. 2003; Hyun, 2001; Park & Cho, 1995; Shin, 2002) suggest that such support is one of the most significant and beneficial supports within Asian families with disabilities. However, according to a study (Youn, Knight, Jeong, & Benton, 1999) where researchers compared familism values and caregiving outcomes among Korean, Korean American, and White American caregivers, Koreans and American Koreans experienced higher 'burden' levels and emotional distress over White American caregivers while having higher levels of familism. The study initially hypothesised that emotional distress and burden among caregivers may be higher in an American culture emphasising individualism and lower levels of familism. However, the study concluded that burden was higher among Koreans and Korean Americans. They suggested that the greater adherence to the values of familism does not protect Korean caregivers from the caregiving burden, but it may relate more to obligations over perceiving the care provision role positively. Since a contrast was not significant when education, gender, age and health were statistically controlled; the study suggested that familism was a cultural variable that affects caregivers' emotional distress (Youn et al., 1999).

Further, Korean families with a member of the family living with disability are doubly trapped because of negative societal attitudes towards people living with disabilities which prevents them from being open and sharing their experiences with people around them, and the loss of social support associated with the mobility of the society (Park & Chung, 2014; Shin, 2002). Similar to the South Asian parents (Raghavan et al., 1999), Korean parents are perceived to prefer family caregiving and to not disclosing their issues to strangers (Shin, 2002). Korean parents tend to be not very open about their child's impairment with people outside of their family due to negative messages they get from those in their informal networks. Hence, while

being the members of a collectivist society, Korean families caring for family members living with disabilities cannot rely on and enjoy social support as they would normally do in their culture, which results in severe levels of stress.

Studies report that Korean American (Cho et al., 2000; Youn et al., 1999) and Native Americans (Shin, 2002; Youn et al., 1999) receive more informal social support than Korean parents living in Korea. For instance, Shin (2002) reported that mothers of children with mental impairments in Korea received less informal support than American mothers did. According to her study, Korean mothers have a smaller social network and the frequency of contact with their informal support network was significantly lower than the average contact in the United States. Hence, she was not able to conclude that Korean mothers, from a collective society, would rely on informal social support to a greater degree. Youn and her research team (1999) also concluded that Korean caregivers had the smallest levels of both instrumental and emotional support while providing care, with Korean Americans having greater social support than Koreans in Korea but less than White Americans.

Some studies (Chamba, Ahmad, Hirst, Lawton, & Beresford, 1999; Hatton, Akram, Shah, Robertson, & Emerson, 2002) have found that informal support received by Asian families is not sufficient to meet the needs of the person with intellectual disabilities and their families. As studies suggest, migrants, as a result of the migration process, are highly likely to experience a loss of relationship with their family members and friends back in their home country (Problem Gambling Foundation of New Zealand, 2012; Wong, 2000). For example, a study confirmed that South Asian immigrant families missed extended family supports, which can be extremely difficult to be arranged in the host country (Raghavan et al., 1999). Moreover, my previous study provided evidence that Korean parents raising children living with disabilities in New Zealand experience a lack of interpersonal relationships and lacked a sense of strong relationship within the community (Choi, 2014).

Contrarily, in the study conducted by Cho et al. (2003), social support for group members appeared to be a significant value, one which characterises the Korean community. The majority of participants in their study reported receiving informal support at both an emotional and practical level from extended family, spouses, and non-family members. According to Cho et al. (2003), one of the strengths of both Korean parent and Korean American participants was the extensive connections they had with other parents of similar children. However, there was difference in the kind of support from their peers between Korean mothers and Korean American mothers. Korean mothers disclosed that they gained emotional support from other parents with children living with disabilities, whereas Korean American mothers reported more practical support (Cho et al., 2000). Besides, for Korean American parents, their church provided emotional and practical support.

Nevertheless, Kim-Rupnow (2005) argued that, for Korean parents raising children living with disabilities, independence and interdependence can be seen as developmental issues that many parents struggle with. Westbrook et al. (1993) stated “it may be that such [familial] support assists the person’s emotional adjustment but it also tends to impede the goals of rehabilitation programmes as striving to regain independence is not encouraged” (p. 622).

### 2.3.5 Disability Services in Korea

Before 1980, disability facilities in Korea were predominantly asylum-based institutions. It was only in the mid-1980s that the rehabilitation model of services was introduced in Korea. Through 1990 to 2000, welfare services and systems for people living with disabilities have undergone radical changes towards independence and a more inclusive society, under the influence of the social model of disabilities and individuals living with disabilities (Huh, 2016).



Before one can fully understand the overall Korean disability welfare system and how it operates, one must understand the Disability Grading System in Korea. This is a system that can be found nowhere in the world except in Korea and Japan. This is a system where the Welfare Law for Persons with Disabilities 1989 defines a person living with disabilities as a person whose everyday life or social activity is disadvantaged by mental or physical impairment over a long period of time, and classifies disabilities into 15 different types while implying a specific criterion for determining grades in each different type of disability. The types and grades are as in Table 1.

Table 1

*Disability Types and Disability Ratings Specified in the Welfare Law for Persons with Disabilities 1989.*

Types of disability	Disability rating					
	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5	Grade 6
1. Physical disabilities	○	○	○	○	○	○
2. Brain lesion disorder	○	○	○	○	○	○
3. Visual impairment	○	○	○	○	○	○
4. Hearing impairment		○	○	○	○	○
5. Language disabilities			○	○		
6. Intellectual disabilities	○	○	○			
7. Autistic disorder	○	○	○			
8. Mental disabilities	○	○	○			
9. Renal impairment		○			○	
10. Cardiac impairment	○	○	○		○	
11. Respiratory impairment	○	○	○		○	
12. Hepatic impairment	○	○	○		○	
13. Facial disfigurement		○	○	○	○	
14. Intestinal / Urinary fistula		○	○	○	○	
15. Epilepsy disorder		○	○	○	○	
16. Combined determination of multiple disabilities	<p>1. If a person has two or more disabilities of the same grade, adjust the rating to one grade up.</p> <p>2. If a person has two or more disabilities of different grades, a medical specialist may adjust the rating to one grade above that of his/her major disability, with the severity of disability in consideration, pursuant to the decisions of the Minister of Health and Welfare.</p> <p>3. Despite Items 1 and 2 above, disabilities cannot be assessed in combination if:</p> <ol style="list-style-type: none"> <li>1) a person has both a physical disability and a brain lesion disorder;</li> <li>2) a person has an intellectual disability and an autistic disorder; and</li> <li>3) the region or nature of disabilities overlaps and, therefore, determining them together as multiple disabilities is not reasonable according to the decisions of the Minister of Health and Welfare</li> </ol>					

*Note:* Adopted from *Initial Report under the Convention on the Rights of Persons with Disabilities* (p.74), by The Republic of Korea, 2011, Seoul, Korea: Author.

The Korean government determines the degree and types of disabilities according to medical criteria. They then register and manage the grade of a person's disability. The grade ranges from grade 1 to 6, where grade 1 is considered to be 'the most severely disabled'. The programmes in South Korea use both the criteria for rating indicated in the the Welfare Law for Persons with Disabilities 1989 and the definition of disability, and each social programme uses the rating of the beneficiaries as a criterion for eligibility. In other words, the Grading System is designed to determine the types and amount of services available to the person living with disabilities. As an example, the Disability Pension System, a social protection programme designed to target individuals living with 'severe' disabilities, is available for the individuals who are given either grade 1 or 2, or both grade 3 and multiple disabilities. The Disability Benefits System, as another example, targets individuals living with 'moderate (grade 3 to 6)' disabilities. Hence, the persons living with disabilities who are graded between 3 and 6 are eligible to use the services provided under the Disability Benefits System. Such a system is criticised for its denial of human rights in which different disabilities, circumstances, and needs of individuals are not taken into consideration.

In general, current disability services in Korea are organised to support social participation. Service provision in Korea can be categorised into: residential facilities; community rehabilitation centres; occupational rehabilitation centres; developmental rehabilitation centres; and personal assistant services. The use of residential facilities is limited to those who are low-income beneficiaries, and who have no other family members or relatives, yet people who do not fall under the criteria can also be provided with the service if they were to make payments. Short-term respite care and group homes can also be utilised by people living with disabilities regardless of their income level. Community rehabilitation centres are designed to provide supports for people living at home. Developmental rehabilitation centres, personal assistant services and other services where voucher cards can be used to acquire service provision are expanding in terms of both numbers and service options. Yet, some provision of such services is limited to people between grades 1 and 3 (Kim, 2016).

In Korea, although deinstitutionalisation has not become policy yet, it is considered as a direction which the governments are pursuing. Such movement towards deinstitutionalisation by the government can be evident in the Welfare Law for Persons with Disabilities 1989 where a section regarding the independent living of people living with disabilities was included in 2007 (Lee, 2015). A number of changes and efforts were and are being made in Korea to achieve and provide more opportunities for people living with disabilities to participate in communities and independent living instead of being cared for and protected within facilities.

Since 2009, the number of people to be accommodated in a newly established institution has been limited to no more than 30 persons. The government also financially supported the establishment of 90 Independent Living Experience Homes and are also running 65 of such homes across the country where they provide a range of services to train, prepare and assist the independent living of people living with disabilities. Independent Living Experience Homes are considered to be 'transitional residences' where people living with disabilities can experience a range of daily activities independently at home and in the local community while still being provided with some assistance. Centres for independent living are also supported by the Korean government. These are designed to support people living with disabilities to be more independent in their daily lives. The services provided by the Centres provide: peer counselling services; training services to assist people to be more independent in their daily lives; information; and mobility aid services. Further, 170 Welfare Centres for Persons with Disabilities are being served by the central and local governments in the communities. They provide services such as counselling, vocational rehabilitation, and education and rehab treatment to accelerate people living with disabilities' integration into the local community (NHRCK, 2010). Nevertheless, people living with disabilities in Korea are entitled to disability pensions and benefits and receive financial support according to their level of disabilities and needs.

Despite the efforts made, deinstitutionalisation in Korea has faced a number of challenges and governmental involvement in the process is criticised to be at its minimum. Additionally, the

insufficient and significant lack of numbers of residential facilities and community services in place in the local communities (Huh, 2016). From a survey on the Status of Persons with Disabilities (Ministry of Health and Welfare, 2011) lack of appropriate housing supports that meets the needs of people living with disabilities, as well as lack of governmental financial aid for low-income earners who are living with disabilities is evident. For instance, while the survey conducted by the NHRCK in 2012, the desire for ‘housing support’, followed by ‘living expense support’, were identified as the most needed support by people living with disabilities, the research conducted by the Ministry of Health and Welfare (2010) revealed that only 8.9% of all persons living with disabilities had experiences of living in permanent rental houses with only 1.0% having experiences of living in public rental houses. Further, the percentage of people who were supported by the government’s financial benefits for yearly and monthly housing rent for low-income earners were only 0.9% and 3.8% each (NHRCK, 2014).

Also, although the welfare benefits in Korea for people living with disabilities have been expanded through the Pension for Persons with Disabilities in 2010 and in 2007 the Activity Support Services for Persons with Disabilities were introduced to provide more opportunities for participation in local communities and independent living by providing an activity assistant allowance (NHRCK, 2010), institutional residences for people living with disabilities still remain the most dominant form of service provision, especially for people living with developmental disabilities. Further, only people living with disability grades 1 and 2 are allowed to make application for the allowance and different amounts of allowance are granted between the grades for those aged between six and 65 depending on their needs. Thus, this is criticised as denying the rights to apply for such services and the needs of people living with disability grade 3 or below (NHRCK, 2014).

Further, in relations to the family support obligation rules, discussed above as an example of a policy implication of familism, where the family is obliged to provide the service first and foremost over the state, the welfare system in Korea for people living with disabilities is further criticised for the exemption from the basic livelihood allowance for persons with a guardian.

The National Basic Livelihood Act was designed to guarantee a minimum livelihood for people in poverty by granting them subsidies; the beneficiaries to this Act are individuals whose recognised income is below the minimum cost of living. These beneficiaries should have no guardians or have guardians who are incapable of providing for them or from whom they cannot receive financial support. In other words, according to the Act, if the individual living with disabilities has a guardian who has properties or income, the individual is not eligible for the allowance. Hence, since people living with disabilities are likely to be faced with difficulties in engaging in economic activities, they continue to financially depend on their family, making them not being eligible for the basic livelihood allowance under the guardian criterion. Therefore, some individuals living with disabilities who are financially dependent on, and supported by, their family members who are indeed in need of assistance are denied the allowance, and face limitations on exercising their rights to make choices regarding their own lives as their ways of living are decided under the considerable influence of family members (NHRCK, 2014).

In terms of employment, it is evident that the Korean government recognised the importance of people living with disabilities exercising the right to work and its significant impact on social inclusion and independent living. The government makes efforts to support and protect equal work opportunities for the people living with disabilities under the Employment Promotion and Vocational Rehabilitation for Disabled Persons Act 1990. Further, as discussed briefly earlier in the chapter, pursuant to the Act on Welfare of Persons with Disabilities, the Act on Employment Promotion and Vocational Rehabilitation for Disabled Persons, the state, local governments and business owners are obligated to provide education to employees to raise awareness of people living with disabilities. However, the employment system in Korea for people living with disabilities is criticised by the NHRCK for its lack of systematic framework and penalties when such provision is neglected. Nevertheless, the Minimum Wage Act states, upon the approval of the Minister of Employment and Labour, an employer is not required to pay the legal minimum wage to individuals who are living with a mental or physical disability which significantly impedes the undertaking of a job. Again, compared to major OECD countries where they have the ‘Subsidized Employment System’, whereby the government

subsidises wages for people living with severe disabilities so that they are guaranteed the minimum wage, no such system is in place in Korea to ensure that people living with disabilities are not paid less than minimum for reasons of low productivity (NHRCK, 2014).

Further, the Adult Guardianship System was introduced to give a guardian legal power and authority to make decisions around welfare, medical treatment and property management on behalf of the persons living with disabilities and elderly who cannot do so independently. In general, there are two primary types of guardianship: a legal guardian appointed by a court, and a private guardianship which the person appoints voluntarily prior to losing mental functions. Once the application for guardianship is filed by the individual, his/her family, or a prosecutor, the court reviews an evaluation of a medical doctor of the person's physical and mental health and appoints a guardian. Appointed guardians can be family members, relatives, friends, or other professionals, including social workers and lawyers. This is an important system for families when planning for the future care provision of their children living with disabilities as it deals with who will hold legal power and authority to make decisions on behalf of their children when they are no longer able to do so themselves.

Overall, current disability services in Korea are portrayed to be organised to support social participation. The disability welfare system and service provision in Korea are currently operating under the Disability Grading System where the government determines the degree and types of the disabilities according to individuals' medical criteria, which then governs the types and amount of services available to the person living with disabilities. Service provision in Korea can be categorised into: residential facilities; community rehabilitation centres; occupational rehabilitation centres; developmental rehabilitation centres; and personal assistant services. The direction which the Korean government is currently pursuing is deinstitutionalisation, and it is making diverse efforts to achieve their goal, such as limiting the number of people to be accommodated in a newly established institution, providing financial support, as well as operating Independent Living Experience Homes across the country. Yet, despite such efforts, deinstitutionalisation in Korea is faced with a number of challenges and

the governmental involvement in the process is criticised by NHRCK to be at its minimum. Other systems and Acts in place concerning people living with disabilities, include:

- *the Pension for Persons with Disabilities and the Activity Support Services for Persons with Disabilities*: designed to increase opportunities for participation in local communities and independent living by providing activity assistant allowance;
- *the Employment Promotion and Vocational Rehabilitation for Disabled Persons Act 1990*: implemented to support and protect equal work opportunities for the people living with disabilities;
- *the Adult Guardianship System*: granting a guardian a legal power and authority to make decisions around welfare, medical treatment, and property management on behalf of the persons living with disabilities;
- *the National Basic Livelihood Act*: designed to guarantee the minimum livelihood for people in poverty by granting them subsidies
- *the family support obligation rules*: placing responsibility on persons who are the lineal blood relatives between two generations and his/her spouse for providing support for the other family members in need.

These are all questioned and criticised for both effectiveness and operation. These identified criticisms have significant implications for the present study as they have a direct and indirect impact on families, while reflecting the socially experienced reality of caring for children living with disabilities in Korea.

In summary, the Korean welfare service and system for people living with disabilities has undergone and is still going through, radical changes towards independence and an inclusive society. There are a number of systemic challenges and barriers the government and the

families are faced with, and these aspects inevitably impact not only on the current welfare provision of people living with disabilities but also the process of their future care planning.

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### 2.3.6 Disability Services in New Zealand

Over the last few decades, the development of welfare in New Zealand for people living with disabilities has been perceived as revolutionary (Bonardi, 2009). The primary driver for many changes in the country was the vision of achieving a fully inclusive society for every individual in New Zealand. In the history of welfare for people living with disabilities, New Zealand has followed the trends in values embedded within other Western countries including the United Kingdom, the United States, and Australia. In order to provide a general overview of the government and public attitudes towards people living with disabilities, the following paragraphs explore three different time periods (1900-1950; 1951-2000; and 2001-present).

From the late 19th to the early 20th century, responsibilities of supporting people living with disabilities in New Zealand were held solely by the families with minimal government support provision through institutions. A popular movement at the time was the eugenics movement. Motivated by a belief that the ‘feeble-minded’ were people responsible for a diverse range of social ills and hence, for the development of the society, there was a need to control them by preventing fertility of the population through compulsory sterilisation and through limiting contact with the community (Milner, 2008). Such social movements led to people living with disabilities being perceived as undesirables. At the time, the predominant idea within New Zealand was ‘out of sight, out of mind’, as well as the need for governmental intervention for social control over people living with disabilities (Tennant, 1996; Walmsley, 2005). People living with disabilities were restrained and isolated in asylums or hospitals that were placed far



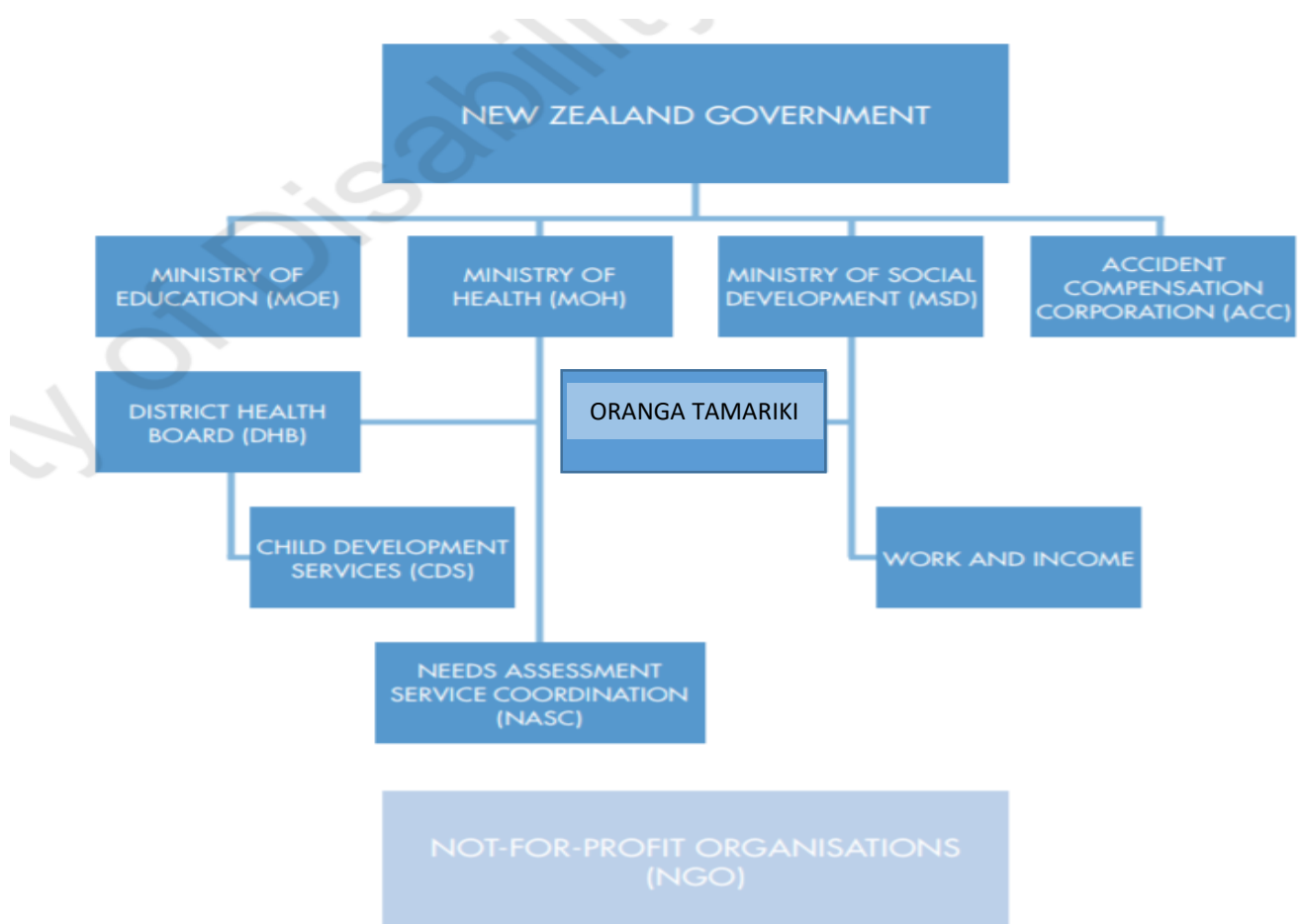
from their families and communities. They were also segregated away from the mainstream systems including education and health care. It was the period when institutions for people living with disabilities were being established and expanded. Institutionalisation of people living with disabilities was to separate and provide care for the population in a collective environment by providing only the very basics for survival including food, shelter, and medical care (Bonardi, 2009). At the time, it was supposed that people living with disabilities were not to anticipate the same rights and privileges as other members of the society who were living without disabilities (Tennant, 1996). In 1935, Crippled Children Society (CCS) was established by Rotary to provide support for children living with polio. CCS is now one of the key disability services in the country that provides support to more than 4000 children, young people and adults living with disabilities every year.

In the 1950s, community support movement was led by the Intellectually Handicapped Children's Parents Association (IHCPA; later known as IHC). The Disabled Persons Community Welfare Act 1975 became a central constituent for the movement towards supporting individuals living with disabilities in the community (Bonardi, 2009; Race, 2007). Since the 1980s, New Zealand has supported the deinstitutionalisation movement, a development which was grounded on the concept of normalisation (Wolfensberger & Glenn, 1973). The institutions discussed above began to be closed. As discussed earlier in the 'Shift in the Disability Paradigm' section, such movement created the need for different care provision services that would replace institutions and provide care in the communities. The movement allowed people living with disabilities to speak about their rights and highlighted the significance of community living, and equal education and employment opportunities. Yet, although such movement provided many people living with disabilities through a positive and empowering model, they still experienced a lack of individual autonomy and choice (Bonardi, 2009; Race, 2007).

From the year 2000, disability services began to reconsider ways to provide structured support and effective funds for people living with disabilities. The central focus shifted to working to

achieve greater flexibility and community participation to meet the needs of individuals living with disabilities. Such a movement went beyond mere community living and led to people living with disabilities enjoying ordinary life just as people who are living without disabilities and fully included in the society. In 2001, the government released the New Zealand Disability Strategy (NZDS) as a long-term plan to make necessary changes to achieve a fully inclusive society. As a result, people living with disabilities are striving to attain meaningful partnerships with communities, the government, and support agencies.

The disability sector in New Zealand is comprised of a number of government-led ministries and non-governmental organisations (NGOs). Figure 1 illustrates the relationship between the government, different ministries, and NGOs.



*Figure 1.* The relationship between the government, ministries, and not-for-profit organisations. Adopted from *Disability Support Guide: An Overview of the Disability Support Services Structure in New Zealand* (p. 8), by Disability Connect, 2016, New Zealand: Disability Connect.

The Ministry of Education (MoE) is the lead advisor on the New Zealand education system which shapes direction for education sector agencies and providers. As all children are entitled to enrol at their local mainstream school, the MoE's role is to provide support for children with special needs. This is achieved through providing and funding services such as: Early Intervention Services; Ongoing Resourcing Scheme (ORS); Resource Teacher of Learning and Behaviour (RTLB); Special Education Grant (SEG); Special Schools; and Special Education Needs Coordinators (SENCOs).

The Ministry of Health (MoH), funds a range of support for people living with disabilities generally up to 65 years of age, to support them to live in their communities. Access to most MoH-funded supports is through the Needs Assessment and Service Co-ordination Agency (NASC). For example, in Auckland, the NASC is Taikura Trust, and any individual living with disabilities in Auckland can be referred to Taikura Trust for free Needs Assessment where the eligibility for Ministry-funded supports is assessed and appropriate services can be co-ordinated for the person living with disabilities. Such referral can be made by a General Practitioner (GP) or paediatrician or anyone under the age of 65 years living with disabilities can self-refer. The MoH-funded disability supports include: equipment and modification services; home and community support; respite and carer support; community residential support; and supported living. They also provide Child Development Services which is intended to support children living with disabilities to maximise their full potential through assessment, intervention and treatment services. The service is mostly available for children aged from 0 to 6, but in some regions, the service is available for children aged 0-16.

Individualised Funding (IF) is also provided by the MoH. IF is a payment option intended to provide the person living with disabilities and their families with greater choice and control over their management of the household and personal care funding by allowing them to directly manage their disability supports. IF can be used to purchase household management, personal care provided by support workers and pay costs relating to the employment of support workers. It can also be used to purchase respite care through support workers or other opportunities (including school holiday programmes or facilities) allowing the full-time carer to have a break.

The Ministry of Social Development (MSD) administers Work and Income to assist with income support and employment services for New Zealand residents. For people living with disabilities, Work and Income administers some of the financial support, including: Supported Living Payment, Child Disability Allowance, Disability Allowance, and Accommodation Supplement.

Accident Compensation Corporation (ACC) provides no-fault personal injury cover for all New Zealanders and administers support for victims of accidental injury/disabilities. They may make a lump sum payment and may fund items depending on individual needs and circumstances. If a child's disability is a result of an accident, care-givers may receive assistance with Personal Care and other supports to help them continue caring for their child at home.

Children or young people living with disabilities may become involved with Ministry for Children Oranga Tamariki if there is a safety concern for the child or their family. The High and Complex Needs Interagency Strategy (HCN) is also available for children or young person with very complex needs, and who are involved with two or more government agencies. It is a joint initiatives strategy of the Ministries of Health, Education, and Social Development through the Ministry for Children Oranga Tamariki. The service is available for short-term intensive intervention for the most challenging children or young people.

NGOs play a role in providing a wealth of information regarding services, support groups, and networking opportunities for family members. There are service provider organisations that are classified as NGOs, such as Disability Connect, IHC, Variety (the Children's Charity of New Zealand). There are also many regional support groups and organisations, as well as support organisations that are not specific to a particular disability, including Disabled Persons' Assembly, Parent to Parent and Carers NZ.

Further, similar to Korea's Guardian System, New Zealand has a 'power of attorney'. A power of attorney is an authority where an individual appoints a person or organisation to act on behalf of the individual. In New Zealand, there are two types of power of attorney: ordinary power of attorney and enduring power of attorney (EPA). An ordinary power of attorney is the authority given by an individual to one or more others to act on behalf of the individual, either on specific issues stated in the power of attorney or in all matters of the individual. An ordinary power of attorney is only valid while the individual has the mental capacity to make decisions as the attorney cannot have more power than the individual. Hence, if the person loses this capacity, the ordinary power of attorney is cancelled. In contrast, an EPA can have effect if the individual is unable to make decision for themselves, or cannot communicate such decisions. An EPA generally only comes into force when an individual has become mentally incapable of managing their affairs for themselves. In other words, appointing someone an EPA is a way of ensuring that someone trusted will make decision for the individual if the individual becomes incapable to make such decisions on their own.

However, many individuals living with disabilities, including children, do not have the capacity to make their own decisions or communicate them. As stated above, in order for an individual to sign a valid EPA, the individual must have sufficient intellectual capability to understand the document they are to sign, yet, where the individual is living with 'severe' disabilities, the person may not be able to sign an EPA due to lack of intellectual capacity. In such cases, the Family Court may get involved regarding appointment of a welfare guardian

and/or a property manager. The Family Court can appoint someone to act on behalf of the person living with disabilities through four different types of order:

- *personal orders*: for personal decision makings, such as residential care facility or medical treatment;
- *welfare guardian orders*: for personal welfare and care decisions involving, for example, where or with whom the individual will live;
- *administer property orders*: for managing finances and property with relatively low values (i.e., assets less than \$5,000 and incomes less than \$20,000 per year);
- *property manager orders*: for assets valued at greater than \$5,000 or incomes of more than \$20,000 per year.

The application can be filed by any person of a number of people including a social worker, a representative of an organisation, a relative, a medical doctor, or the manager of the organisation where the individual is provided with care. This, again, is an important system that is in place for families caring for children living with disabilities to consider when planning for their children's future care provision. The system allows families to plan and appoint someone to act on behalf their children when they are no longer there to provide such support.

To conclude, the development of welfare for people living with disabilities in New Zealand has been perceived to have gone through radical changes over the last few decades. The current disability sector in New Zealand is comprised of a number of government-led ministries, including the Ministry of Education, Ministry of Health, Ministry of Social Development, Ministry for Children Oranga Tamariki, and NGOs. They provide a diverse range of disability funds and services to support children living with disabilities in New Zealand. Provided

identification and discussion around these key services and providers are necessary for the present study as it provides an overview of how disability services operate in New Zealand, how families may utilise these services when planning for future care provision for their children, as well as the impact such services may have on the process of planning.

## 2.4 Conclusion

In conclusion, the discussions in this chapter provide a critical overview of a range of literatures around the proposed research topic. Disability is an evolving concept which makes it difficult to constrain it to one single definition or a model. For this proposed study, disability will reflect physical, attitudinal and/ or societal barriers caused or created by bodily, mentally, or sensory impairments without distinguishing impairment and disability into two different social phenomena. Also, for this study and for lack of a better term, the phrase ‘people living with disabilities’ will be used to refer to people experiencing both bodily, mental, and sensory impairments as well as the social barriers created by their impairments.

It is important to understand the cultural impact of how disability is perceived, understood and treated in a given society. The chapter looked specifically at the Korean cultural context and discussed that there are a number of cultural values and beliefs that influence how disability is perceived and treated in Korea. Traditional Korean culture carries negative attitudes towards people living with disabilities. Further, Korea retains a very strong cultural tradition and repeated affirmation of the practices and values of Confucianism and familism. Sharing Confucianism ethical values and social norms, familism is identified as one of the aspects that represent the traditional values of Korean society, argued to have resulted in Korean society traditionally placing responsibilities for individual welfare on families over any other groups or individuals. Migrant families often have different beliefs and values to native-born people of the country around what constitutes disability based on their own unique cultural and social backgrounds. Consequently, the impact of culture on service utilisation and caregiving is often

changed by immigration, where minority cultures, willingly or unwillingly, give up their own ethnic values, behaviour, and customs for those of the majority. Understanding cultural values and beliefs around disability and the impact of migration is necessary for the research as the proposed cross-national study intends to explore how the different national contexts shape future care plans and possibilities.

In terms of future care planning for children living with disabilities, studies around the current situation conclude that many carers have not made concrete plans, which may result in significant complications when crisis occurs or when carers can no longer provide care for them. This makes it a critical topic to address as it is highly likely that children living with disabilities will become dependent on some sort of care provision. The shift in the paradigm of disability, specifically around the shift from institutional facilities to community-based living is significant as it is this movement that created the changes in care provision and needs for parents to consider different options for care provision for their children living with disabilities. There are a number of different residential care provisions available in the communities and international studies conducted to search for the most appropriate care provision for people living with disabilities. This global scale understanding around different care options and their appropriateness are valuable for the study, especially as there is lack of research available in the local New Zealand and Korean contexts. In terms of disability service system in Korea, it is suggested that, while much effort was made that led changes in regard to people living with disabilities and the treatment of them, there still remain issues that need to be resolved including concerns related to the Disability Grading System, low levels of government involvement, The Guardianship System, and Employment Promotion and Vocational Rehabilitation for Disabled Persons Act 1990. In the case of the New Zealand context, the disability sector in New Zealand is comprised of a number of government-led ministries and NGOs focusing on the quality of life of people living with disabilities and concerned with more control and choices over the support services they receive. Issues of ethnic minorities around resident provision highlight how Asian people living with disabilities may be placed in the most vulnerable position in residential provision. There are also different types of care provision, namely formal and



informal, and one's cultural background can impact on the kind of support one may find more or less valuable.

The discussions of the chapter provide a critical overview of a range of literature around the proposed research topic. With understanding of how culture can impact on experiences and perceptions, the vulnerability of the population intended to be studied and the necessity of planning for children's future care provision, the present research attempts to study how the country contexts shape the plans and possibilities, some of the plans enacted or planned, and the types of care (both formal and informal) caregivers consider as being crucial for their children's future. More specifically, with the support of the existing literature and use of the theoretical and empirical literature discussed above informing the study, the present study aims to answer the following research questions:

What are the plans of Korean parents in Korea and migrant Korean parents in New Zealand for future care provision of their children living with disabilities?

How are plans, perceptions and experiences around future care similar and/or different in the two different countries selected? How do culture and the country contexts shape these plans and possibilities?

How these questions are investigated is discussed in detail in the next chapter.

## **CHAPTER 3 Methodology**

This chapter aims to provide detailed discussions around methodological and ethical considerations. The chapter begins with the research design and provides the rationale for the cross-country comparative work and how that might be located in the research literature, as well as rationales for using a qualitative approach for the purpose of the present cross-national study. Then the sampling process, sample criteria and important key notes that were taken into consideration in terms of the sampling criteria, including some of the terms used, are set out, followed by a discussion around the sample size of 36 (10 professionals and eight parent participants from New Zealand; and nine professionals and nine parent participants from Korea). The process of data collection is then provided in detail. An overview of the data analysis process, including the use of a professional transcriber, and issues around translating are set out. This section also includes discussions around how the collected data were analysed through a conventional analysis method using NVivo™ software throughout the phase to enable organisation and analysis of the data. The chapter then outlines the ethical issues which require special consideration for the proposed study including confidentiality, cultural sensitivity, and minimising harm. Finally, a number of methodological limitations identified in this present study, including lack of power to generalise to a wider population and the locations where the data were collected, are discussed.

### **3.1 Research Design**

As discussed in the previous chapter, national context and the cultural principles embedded within the given society have a significant influence on how individuals living with disabilities are supported and treated. In other words, where the families are located in the world and their cultural backgrounds have a substantial influence on service provision, treatment, processes, and planning for the future for their children living with disabilities. Knowledge and meaning are developed through human practice and are constructed through interactions between individuals and the world around them (Crotty, 1998). Thus, experiences of people from the

same ethnic and cultural backgrounds have potential to differ between people living in the country of origin and migrants due to different social actors (i.e., language, the culture of the society, people they interact with, etc.).

This cross-national research is designed to enable discovery of possible explanation for differences and similarities and to gain a deeper understanding and a greater awareness of socially experienced reality of future care planning in different national contexts. The use of cross-national research was designed to surface taken-for-granted phenomena around ways different countries can impact on families' future care planning for their children living with disabilities. Cross-national research of people from the same cultural background is a rare but a promising methodology for studying the effect of national context and its correlation between disability issues as a comparison can be made between people who migrate and those who remain in the country of origin. Hence, since the primary aim of the study is to explore how the country contexts shape the plans and possibilities for future care provision of Korean parents with children living with disabilities in different country contexts, the use of the cross-country study was particularly suitable for the present study as it allows for between-group comparisons that may be helpful in explaining the ways in which national context affect parental experiences in raising their children living with disabilities (Cho et al., 2000).

The study was conducted by using a qualitative design. Distinct contrasts between qualitative and quantitative research, identified by Bryman (2012), are that a qualitative approach is more appropriate when the researcher is concerned with words than numbers, the point of view of the participants and in gaining rich data rather than hard, statistically reliable data. Hence, since the overarching theme of the study was concerned with gaining rich data from Korean parents on their plans and perspectives around future care provision of their children living with disabilities, rather than gaining factual information from a large number of parents and generalising the findings to a large population, a qualitative approach was considered more appropriate for the study.

Qualitative research is described as an “inquiry process of understanding based on distinct tradition of inquiry that explores a social or human problem. The researcher builds [a] complex, holistic picture, analyses words, reports detailed views of informants and conducts the study in a natural setting” (Cresswell, 2006, cited in Maschi & Youdin, 2012, p. 206). One of the main purposes of such research is to capture the lived experiences of individuals and their social environment that are authentic. Qualitative research tries to do this by conducting research in a natural setting while providing a flexible framework for naturalist inquiry (Maschi & Youdin, 2012).

In contrast to the adoption of a model based on quantitative research, a qualitative approach places more stress on understanding of the social world through examining the interpretations of the world by participants (Bryman, 2001). A qualitative study consults the existing literature and uses the theoretical and empirical literature that already exists to inform and/or frame the study yet, unlike quantitative study that is directed by hypothesis testing, in a qualitative study such information does not dictate the direction of the study (Maschi & Youdin, 2012). The nature of qualitative research emphasises the meanings of people’s points of view and the significance of the ways in which individual members of society interpret their social world. The main purpose of the qualitative method is to gain access to people’s ‘thinking’ and then to interpret their actions and their social world from their point of view (Bryman, 2001).

As discussed earlier, knowledge and meaning develops through human practices, being constructed through interactions between individuals and their world around them, and interpreted through culture and language (Crotty, 1998). Language does not only transmit thoughts and feelings, but makes thought possible through constructing concepts, and hence it structures experience. The concepts people engage in helping them understand the natural and social world are argued to be social products (Crotty, 1998). Therefore, spoken words are not a mere representation of the social world, but are constitutive of the social context in which it occurs (Bryman, 2001). Thus, a qualitative approach using interviews to collect participants’ words, hence constitutive of their social world, allows for developing meaningful

understandings and knowledge. In other words, the data collected through interviews can capture a person's internal world, including thoughts, values, emotion, behaviour, past experiences, subjective perceptions and experiences not readily observed by other people. Such data can provide insight into how a person constructs meanings to his/her experiences (Maschi & Youdin, 2012).

A qualitative approach for this study enabled collection of personal meanings that participants attach to their actions, thoughts, feelings and the world surrounding them (Monette, Sullivan, & DeJong, 2008) and generate meaningful knowledge from the data, as it is believed that the qualitative approach provides a forum for participants to discuss sensitive matters in an open manner, enabling access to participants' feelings and attitudes, and collect richer and more in-depth data (Whittaker, 2009). Such an approach provides opportunities to capture the authentic lived experiences of the participants from the perspective of the participants who lived it and who created meaning from it (Thyer, 2010).

Furthermore, according to Padgett (2008), a qualitative approach is better suited for studies dealing with a topic of "sensitivity and emotional depth" (p. 15). Thyer (2010) also includes in his list of the reasons for using the qualitative research approach: one wishes to pursue a topic or study something that is sensitive and has emotional depth. Therefore, a qualitative approach was appropriate for this study as the primary theme of this study involved participants sharing their plans and thoughts around care provision for their children living with disabilities when they can no longer provide it themselves, making it a topic of great sensitivity and emotional depth.

Furthermore, a qualitative approach is arguably well suited for social work professionals due to our direct contact with the client population and constituents in the field as well as our prolonged engagement in diverse community and practice settings. Further, interviewing itself

is an essential practice task for social work professionals, hence the method is very familiar for many social workers at all levels of practice (Maschi & Youdin, 2012).

## 3.2 Sampling

### 3.2.1 Sampling Approach

Potential participants were identified using a snowball sampling technique in this research project. This snowball sampling was employed to increase not only the number of participants but also the comfort level of the interview participants. In other words, snowball sampling was used to create an environment where participants were able to participate in the study with some level of comfort and trust about both the study and the researcher through being introduced to it by someone they trusted. The participants had to meet the following sampling criteria:

- Nature of disability: children living with physical, intellectual, mental and/or sensory impairments and as a result require ongoing support and care in various aspects of their life including personal care and decision making.
- Parent participants must be looking after their child living with disabilities at home (that is the child should not be living full-time in a residential facility).
- They must be living in Auckland or provinces of South Korea, including Seoul, Gyeonggi, Gangwon, North and South Chungcheong, and North and South Gyeongsang-do, at the time of taking part in the research.
- Professionals: a person who belongs to an organisation or a service provider that provides service to people living with disabilities/ or a person who gets direct funding from the government to provide service to people living with disabilities.

There are a number of important key notes that must be taken into consideration in terms of the sampling criteria:

- ‘Children’ in this present study refers to the relationship between parents and ‘son’ or ‘daughter’, not the age of the person.
- The terms ‘significant disability’ or ‘severe disability’ are avoided in the recruitment process as the terms did not seem appropriate for this study as not only there is no standard definition of the terms but also because the study involves two different national and cultural contexts. As discussed earlier, culture has a significant influence on the construction of the concept of abnormality. What defines ‘severe disability’ in one country context may not necessarily reflect how it is defined in the other. For example, being an amputee with mild mobility impairment in the Korean context is classified as ‘extremely severe physical disability’, whereas in New Zealand it is not considered to be at the same level of severity. Hence, for the purpose of this present study in terms of the nature of the disability, instead of ‘significant disability’ or ‘severe disability’, the criterion is that the child must require ongoing care including personal care and decision making as a result of any type of disability.
- Depending on the child’s and parents’ age, their involvement, experience, and perception in planning may differ as the level of necessity of planning for their children living with disabilities for when they can no longer provide care may differ. Hence, the researcher started by focusing on care for children who had left school and then extended that focus to children who are in their last few years of school to ensure there were enough participants. The age distribution of the children ranged from 17 to 38 years.

The researcher contacted ‘key informants’ (non-participants), identified from researcher’s personal and professional networks within the Korean community (churches, and formal and informal gatherings), who were willing to identify potential participants through their

professional or personal networks. According to Suh, Kagan, and Strumpf (2009), using key informants to introduce the researcher to the participants was a useful strategy for conducting successful interviews within the Asian community. These key informants in the present study played a significant role in bridging the researcher to the participant. Once the participants were introduced to the researcher by an individual they trusted and they learned about the study, they willingly built a trusting relationship with the researcher. Suh and her colleagues (2009) argue that this is a typical cultural attribute of collective communities, including Korea.

As discussed in detail earlier, the research was conducted by ‘an insider researcher’ within the disability and migrant communities. This definitely had a great and positive influence throughout the sampling process, especially around gaining access to potential participant groups, building trusting relationships and rapport with the participants. Though the participants of the study and the researcher may hold different thoughts and beliefs, and our experiences may differ largely, at a certain level we were able to share, understand and make connections with each other through shared experiences within the migrant and disability communities.

The researcher then provided the key informants with the information about the research for him/her to pass on to potential participants who could then express their interest and contact the researcher. Once a potential participant expressed an interest in the study, they were provided with verbal and written information about the research project via letter, email or telephone. Then, after each interview was conducted with individual participants, they were asked if they knew other parents in a similar situation which then snowballed from there. Information regarding the study and researcher was left with the participant to pass on or sometimes, where appropriate, the researcher sought their agreement to contact a person directly to ask about their possible participation. Similarly, professionals were able to tell me the names of other professionals whom the researcher could approach through a snowball method. For the interviews, up to 18 participants (nine parents and nine professionals) from Auckland and 18 participants from various regions of South Korea, including Seoul, Gyeonggi,



Gangwon, North and South Chungcheong, and North and South Gyeongsang-do were interviewed.

One parent was to be representative of one family unit yet, if both parents wished to participate in the study, they were regarded as a single unit and were interviewed together. Professionals from both cities were recruited through snowball sampling to provide professional views around how well Korean parents are prepared for care provision, what kind of services are being identified as valuable by the parents, and the perceived challenges and difficulties in terms of future care planning for Korean parents. They were recruited to provide a different perspective and knowledge which informs approaches and experiences of future care planning of Korean parents in Korea and in New Zealand caring for their child living with disabilities. Contradictory and differing perceptions and opinions were often communicated between the professional and parent participants, within and between the national contexts, during data collection and such differences are evident throughout the thesis. Discussion around how the different knowledges were managed is set out later in the chapter, under Data Analysis.

### 3.2.2 The Sample

The proposed sample size of up to 36 participants for this study was considered appropriate as it is anticipated to be large enough to allow for ‘saturation’ to be achieved. The concept of ‘saturation’ or the point where no new themes or information are observed in the data is argued (Guest, Bunce, & Johnson, 2006) to have become the gold standard by which the size of purposive sample is determined. The concept was first defined by Glaser and Strauss (1967, cited in Guest et al., 2006) as the point at which “no additional data are being found whereby the (researcher) can develop properties of the category. As he sees similar instances over and over again, the researcher becomes empirically confident that a category is saturated” (p. 65).

When designing the study, it was perceived that there is no consensus around an ideal sample size. For instance, David and Sutton (2004) suggest the sample size should be a minimum of 30, whereas, Gerson and Horowitz (2002, p. 223, cited in Bryman, 2012, p. 425) argue that “fewer than 60 interviews cannot support convincing conclusions and more than 150 produce too much material to analyse effectively and expeditiously.” Bryman (2012), however, suggests that if researcher feels that ‘theoretical saturation’ has been achieved (that is, no more relevant or new data seem to be emerging regarding a theme), a smaller sample can also be justified. In other words, the sample size that supports convincing conclusion can vary from one situation to the other (Bryman, 2012). The final sample size of the study was concluded to be 36 participants (10 professionals and eight parent participants from New Zealand; and nine professionals and nine parent participants from Korea). Theoretical saturation was believed to be achieved at the point where there were no more new insights communicated by the participants. Hence, the participant number of 36 was concluded to be sufficient for the purposes of the present study.

There was difficulty in differentiating the professional and parent participants who live in Korea as there were a number of parents in professional roles – this is discussed in detail in the next chapter. There was one participant from the New Zealand group who was identified as both parent and professional, whereas there were six participants in Korea who were identified as falling under both parent and professional sample criteria. Participants who fell under both sample categories were asked if they had a preference in how they would like to be identified; if not, these participants were classified according to statements they made during the interview (that is, if the statements they made during the interview were predominantly from a professional viewpoint they were considered as professionals, and vice versa). This did not affect the numbers of participants as they were categorised into appropriate groups during the data-collection process and the researcher carefully balanced the numbers in each group throughout the collection process. The differentiation of participants’ roles was to enable management of different knowledge through categorising them into four main groups: Korean parents in Korea; Korean professionals in Korea; Korean parents in New Zealand; and professionals in New Zealand (nine Korean and one non-Korean) working with Korean

families caring for children living with disabilities, and also to ensure balance in sample size for each group. The researcher had thought about creating a new group and grouping participants who fell around both sample categories into a new separate category, yet this was not possible as there was an imbalance in participant numbers who could fall under the new group in New Zealand and Korea. As a cross-national study, balance in participant numbers was important in order to ensure a similar range of data from both countries were collected. The researcher has categorised them on the basis of their primary status, however there are occasions when the categories come together and this is acknowledged in the writing of the results.

Participants were from a variety of backgrounds and profile. Table 2 presents the demographic profile of the participants of both countries.

Table 2.

*Demographic Profile*

<b>Demographic Profile</b>	<b>New Zealand</b>		<b>Korea</b>	
	<b>Parents</b>	<b>Professionals</b>	<b>Parents</b>	<b>Professionals</b>
<i>Number of Interviews</i>	8	10	9	9
<b>Gender</b>				
- Female	6	5	8	6
- Male	2	5	1	3
<b>Age-group</b>				
- 20-29				2
- 30-39	2	2	3	4
- 40-49	3	7	4	2
- 50-59	2	1	2	1
- 60-69	1			
<b>Age of child/ children</b>				
- 10-19	4		6	

- 20-29	2		2	
- 30 and over	2		1	
<b><i>Years stayed in New Zealand</i></b>				
- 1-9	1	1		
- 10-19	5	5		
- 20 and over	2	4		
<b><i>Years in Practice (in the field of Disability)</i></b>				
- 1-9		6		3
- 10-19		4		3
- 20 and over				3

### 3.3 Data Collection

Data were collected through face-to-face, semi-structured interviews. Semi-structured interviews are known to be one of the most popular methods of social work research. As Whittaker (2009) states, for social workers whose main skill (that they use in everyday practice) is interviewing, the method highly likely feels instinctively familiar. Hence, compared to other research methods, researchers from the profession are more likely to have transferable skills and experiences, and feel more confident in utilising this method. Further, interviews are the most appropriate tool for gathering the sensitive and personal data the research is interested in.

As mentioned above, interviews were conducted with 36 participants (10 professionals and eight parent participants from New Zealand; and nine professionals and nine parent participants from Korea). Initially, two thirds of the New Zealand data were collected within the first five months of data collection. Then all data from Korea were collected in the following six months. Once data collection was completed in Korea, the researcher came back to New Zealand to complete the remaining data collection in New Zealand. The data were collected in this way to

allow validation of collected data during the process as well as allowing for refining purposes. In other words, the first two thirds of the data collected in New Zealand were used to validate and refine the data-collection process in Korea, and the initial New Zealand data together with data collected in Korea were used to support and polish the final New Zealand data collection. In this way, the researcher was able to compare and contrast some of the findings in the two countries, refine questions in respect to issues raised in previous interviews, and review findings with some of the key participants later in the process, which may not have been possible if the researcher had completed the all data collection in one country then moved on to the other. For example, one of the major issues raised among participants in Korea was the financial burden related to care provision and planning. Yet, this was not raised in the New Zealand context in the first set of interviews. When the researcher returned to New Zealand after all the interviews were completed in Korea, when appropriate, the researcher asked the remaining participants in New Zealand about the impact of financial circumstances of the parents on care. Splitting the data collection in such way has added to the validity of collected data and strengthened the research through enabling the researcher to refine the research questions throughout the process of data collection, allowing more focused questions concerning the research topic to be asked and answered. To give another example, when asked questions related to the state or government involvement in the care provision, the researcher noticed Koreans living in Korea using a scale to answer the questions. Hence, to make comparison between the two countries clearer, the researcher refined the questions around the topic to a '0 to 10' rating question for the remaining interviews.

Interviews were semi-structured, using an interview guide (see attached Appendix 13). The researcher had a list of questions as an interview schedule, developed with guidance from knowledge and understanding gained from writing the literature review chapter, with some degree of flexibility. According to Whittaker (2009), such a form of interview allows the researcher to have sufficient structure while having some degree of flexibility to explore responses of participants in depth. According to Monette et al. (2008), interviews can provide deeper and more insightful data. It allows deep and rich understanding of people's lives that are beyond public perceptions and presents behind-the-scene aspects of their behaviour. Thus,

further, as the focus of the study is to gain deeper and greater understanding around Korean parents' plans and subjective experiences and perceptions, a semi-structured interview was appropriate. This enabled collection of personal meanings that people attach to their thoughts, feelings, actions, and the world surrounding them, which would be difficult through other methods such as questionnaires which involve more structure (Monette et al., 2008; Whittaker, 2009).

Two different interview schedules were necessary as the specific questions which needed to be asked of parents and professionals differed slightly within the boundaries of the three major questions. This form of interview allowed sufficient structure while having the flexibility to explore the responses of participants in depth (Whittaker, 2009).

Each interview lasted approximately about 60 minutes. The date, time and venue for one-on-one interviews were arranged by mutual agreement based on participants' convenience and availability. Interviews were conducted in the participants' native language (Korean and English). Some interviews with New Zealand participants were conducted both in English and Korean. Conducting interviews in Korean sometimes posed difficulties for the researcher as an interviewer. The researcher came to New Zealand when aged 11. Though the researcher can speak and understand general everyday conversations in Korean fluently, when participants used complex vocabulary or sentence, language became a barrier. The researcher acknowledged this issue at the very beginning of the interviews, and when faced with difficulties understanding clearly what the participants were communicating, the researcher then politely asked the participants to clarify what they were meaning. The participants also had the right to review and edit their interview transcript to verify its accuracy or completeness.

As the study involved participants from a comparatively small community, especially for Auckland participants, anonymity was an issue. In both countries, although the researcher tried to ensure anonymity, some participants already knew some of other parents or professionals

who were participating in the study. Hence, a discussion around the seriousness and importance of confidentiality and anonymity was held at the very beginning of each interview and participants had to agree that all discussion in the interview remain within the interview confidentially. Further, in the writing of the findings and discussion, extra attention was paid so that the participants cannot be identified by the way they are described. In the findings chapters, pseudonyms are used to preserve anonymity.

A few participants from both New Zealand and Korea asked if the interview could be conducted as a group interview or if they could be provided with a questionnaire to save time. The researcher explained that, for the nature and purpose of the study, one-on-one, face-to-face interview was most appropriate and it would be much appreciated if they could participate as individuals rather than a group. It was explained to the participants that as the study is concerned with individual perception and experiences around future care provision of Korean parents raising children living with disabilities, such a method was necessary.

Nevertheless, communication patterns among Asians was a critical aspect to consider and understand as it has a significant impact on interactions with Asian participants. Given the cultural orientation of Koreans, where they value group customs and collective perspectives, there was a risk of participants presenting ‘desirable’ opinions, rather than personal views in a group setting. According to Suh and her research team (2009), in most of the Asian countries, including Korea, individuals have the tendency to reflect the thoughts of the elderly or the majority. Loyalty to the group and normative values take primacy over personal thoughts and are considered essential to cultural discipline. In favour of group solidarity, individual opinion or uniqueness is minimised. Individual belief is less important than group harmony (Suh et al., 2009). Hence, in a group interview situation, there was a potential that the participants would reflect what the other people in the group perceive and communicate. It was possible that the participants would give responses that are what Strumpf, Glicksman, Goldberg-Glen, Fox, and Logue (2001) refer to as ‘simple and alike’.

Yet, despite all explanation given to the participants, two group interviews were conducted as it was strongly requested by the participants. One group consisted of three mothers and one married couple. A strong desire to have a support person during the interview was especially expressed by the married couple. This case of the married couple directly reflected familism and the values attached to it. As discussed earlier in the literature chapter, family values in Korean society, where interconnectedness among family members is exceptionally strong and family-centred thinking is predominantly emphasised in all social relations (Yang, 2002), were clearly evident in the case of this married couple. It was also evident during the interview that familism had great influence on other aspects of their lives such as the meanings attached to the values, and ideologies they construct and hold. On the other hand, the three mothers requested to be interviewed together due to issues around making time for the interview as they were extremely busy and preoccupied with providing care for their children living with disabilities.

As mentioned earlier in ‘sampling techniques’, the married couple interviewed together were regarded as a single unit as they shared the same views regarding their child’s future care provision when they can no longer provide it themselves. On the other hand, the three mothers, although they were interviewed together, were considered as three separate individuals and interviews. This was because, although we met as a group, the interview was conducted to gather individual experiences. Each participant was asked all scheduled and necessary follow-up questions equally. Hence, the researcher was able to capture each individual’s experiences and perceptions around future care provision planning. The experience and perceptions shared by each participant were distinct and unique reflecting their own circumstances and socially experienced reality regarding the provision of current and future care for their children living with disabilities.

Despite all the concerns discussed above, both group interviews turned out to be a great success. Participants were sharing their personal insights, experiences and ideas freely and they were gaining knowledge from each other. After the interviews were concluded, participants



from the group interviews, especially the three mothers, expressed their gratitude to the researcher for providing an opportunity and a forum for them to discuss such sensitive matters in a comforting and open manner. They shared that, although they gather and network together most of their days of the week, they never had a chance or ‘dared’ to talk about such sensitive topic with each other. They acknowledge that such conversation needs to happen more frequently and in greater depth among parents. They also made plans to have regular meetings to discuss ‘the sensitive topics’ and to involve other parents who are willing. Such successful group interviews may have been possible because participants may have felt more comfortable discussing experiences with similar others. Thus, a more open and honest discussion was able to take place (Suh et al., 2009). In other words, it is likely that the group interviews had created an atmosphere where participants felt connected with each other through shared experiences which enabled them to provide more in-depth and insightful data that may not have been available in individual interviews (Park & Chung, 2014). It also provided an opportunity for participants to share ideas around their future care plans and learn and grow new insights from one another. However, in order to minimise the risk of encountering collective perception among future participants at the time, no further group interviews were conducted as the primary aim of the research is concerned with individual perception and experiences around future care provision of Korean parents raising children living with disabilities.

All interviews were recorded by a digital voice recorder. This allowed the researcher to concentrate and focus on the interviews. Recordings also produced an accurate and detailed record of the interview. It enabled the researcher to listen to the conversation over and over, allowing ideas to merge and be picked up which may have been missed or did not seem important when the interview was still in process (Valentine, 1997). Recording also enabled the use of accurate direct quotes from the interviews, which allowed the voices of the participants to be heard (Butler, 2001).

As in the sampling process, being an ‘insider researcher’ is believed to have had great positive impact on building trusting relationship and rapport with the participants. As Chavez (2008)

note, as an insider researcher, I was able to present an “understand[ing of] the cognitive, emotional, and/or psychological precepts of participants as well as possess a more profound knowledge of the historical and practical happenings of the field” (p. 481). As a result, successful interviews were achievable through enabling the participants to share their authentic lived experience and insights.

However, being an ‘insider researcher’ has also posed some challenges in the data-collection process. Although the researcher is an ‘insider’ of both the Korean and the disability community, greater sensitivity in approaching potential participants was perceived to be necessary at times. One of the challenges was that many participants assumed that the researcher already knows what they know. This was evident through the statements some of the participants made, such as “She must be the expert. I don’t know if I can be of any help” or “You [the researcher] probably know better” or “You know, right?”. Hence, efforts to reduce such assumptions were made by the researcher for successful interviews. For example, a process of assuring that they are the experts and I was there to gain understanding of their experiences and perceptions around the topic was often required at the initial stage of participant recruitment to minimise participants making assumptions during data collection.

The potential for being too subjective was also a challenge that the researcher had to be alert to during data collection, as well as throughout the analysis process of the collected data. Being too familiar about the research context has the potential to limit analysis of cultural and social structures and patterns, and to become normalised to a degree that threatens to impede analysis. In other words, greater familiarity may lead to a loss of ‘objectivity’ and hence increase the risk of the researcher making assumptions based on their prior experiences and knowledge. Further, by being too close to the culture that is studied, insider researchers are often accused of being inherently biased (Greene, 2014). There is a danger of overreliance upon researcher’s previous insider experience as a bias for a certain perspective (Hodkinson, 2005). The researcher’s personal experiences, values and beliefs have possibilities to influence the methodology, design, and/or findings of the study (Greene, 2014).

Therefore, efforts had to be made to become aware of possible biases and alleviate the negative effects of such bias when concerned. There was the need to keep some distance. The researcher had to learn ways to separate her own experiences and beliefs from those of study participants. Learning to utilise personal experiences selectively, instead of being confined to them, and to increase the ability to have a more distanced and analytic perspective were crucial aspects in respect of the interpretation of the data and the research agenda (Hodkinson, 2005). Hence, practice of reflexivity was vital throughout the study which involved establishing and maintaining and appropriate levels of emotional and social distance as an important element of this process.

My supervisors were available to support the researcher in the process of debriefing. The researcher was able to share the findings of the research with the supervisors, which allowed a space for critical thinking about the research and acknowledge feelings that could have affected judgment. Rooney (2005) notes that enlisting the help of an academic advisor is an effective practical step to minimise the impact of biases. Also, to minimise personal biases throughout the collection of data and analysis, the researcher kept field notes and a personal reflection log. The researcher was able to reflect on these logs and notes throughout the collection and analysis process of the data, which allowed the researcher to identify and minimise any potential personal biases that may have affected the findings of the collected data. Further, the researcher kept paper, as well as electronic, copies of all material related to the study, including raw data, reports and findings, methodological process notes, and personal notes to develop and maintain an audit trail.

### 3.4 Data Analysis

All recordings of individual interviews were transcribed by a professional transcriber. The initial plan was that transcribing would be carried out by the researcher. However, after a thoughtful process, it seemed that having a professional transcriber to transcribe the recorded interviews was more appropriate. This change around the transcribing had been made as transcribing was an issue for the researcher during her master's programme. It was much more time consuming than expected because of the researcher's disabilities. As the researcher only has one hand to type, it would take much longer for her to transcribe and one recording would take approximately two days to complete. Hence, hiring a professional transcriber seemed appropriate. A request for change of Ethics Approval in regards to the assistance of a third party to transcribe audio recording had been made and approval was granted for the amendments on 24th of February 2016. However, although transcribing is a very time-consuming process, as the researcher understood the value of it, she carried out some of the transcribing herself in order to gain deeper and thorough insight of the collected data and analyse the data carefully and thoughtfully.

There were difficulties and challenges associated with translation and its accuracy as the meaning of words can change at times when applied in different cultural and linguistic contexts. The identified concepts and related passages from transcripts were written in both languages in a balanced and harmonious manner. Considerable efforts were made to achieve the best translation between the two languages throughout the process of data analysis. In cross-cultural research, translating has the potential to generate inaccurate data. In other words, translation has a potentially huge impact on the validity of findings from interviews. As Esposito (2001) stated, it is the researcher's role to ensure accurate representation of participants' words, behaviours, and beliefs in the process of translation. In order to minimise errors in translation, support from a professional translator was sought when necessary.

As stated above, the collected data were categorised into four groups: Korean parents in Korea; Korean professionals in Korea; Korean parents in New Zealand; and professionals in New Zealand (eight Korean and one non-Korean) working with Korean families caring for children living with disabilities. There was a process of working out how best to group them. Since the present cross-national study is concerned with difference and similarities across the two countries selected, the researcher initially thought about managing the data in two groups (Korea and New Zealand). However, such categorising could not capture some of the contradictory and differing perceptions and opinions communicated between the professional and parent participants, both within and between the national contexts. Hence, the collected data were grouped into four major categories and were treated as separate sets of data in order to capture and reflect all major issues raised from each group.

The data collected from interviews were analysed through a conventional analysis method where coding categories are derived directly from the text data. Conventional analysis is acknowledged as a useful approach for studies designed to describe a phenomenon. According to Hsieh and Shannon (2005), researchers using a conventional analysis method immerse themselves in the data in order to let new insights emerge instead of using fixed categories and provide an explanation of the topic which is minimally influenced by preconceived ideas. As discussed above in research design, spoken words are constitutive of our social world. It is a mere representation of the social world but is constitutive of the social context in which it occurs. Hence, qualitative conventional analysis plays a crucial role in developing an understanding of the social world of participants; just as discourse analysis does in relation to the social construction of meaning and events in televisions or newspapers (Bryman, 2001).

As the focus of this study is generating knowledge from obtaining subjective aspects of social phenomena such as opinions or values that are current in a population rather than testing of theory, allowing themes to emerge out of the data and understanding the meaning in the context makes it an appropriate method of analysis for this proposed study as it aims to develop knowledge around the perceptions and experiences of the participants (Bryman, 2001). Also,

this method was particularly suitable for this study as the method is suggested to be appropriate when existing literature, theory or research on a phenomenon is limited (Hsieh & Shannon, 2005). As discussed earlier, although a pervasive concern of ageing parents or family member with adult children living with disabilities is planning for their future, the current and future care provision and needs of people living with disabilities living at home under parental or familial care is an overlooked area. The issue of future care provision for people living with disabilities has become of increasing interest of researchers, however still lack in existing literature, theory or research on this phenomenon. Hence, for the present study, a conventional analysis method was employed to analyse and generate empirical findings from the ground using collected data.

As Monette et al. (2008) noted, analysis of qualitative data collected for the purpose of the present study shared similar characteristics with social work practice in that both practices in the fields and research are concerned with making sense of the rich and complex situation or data we encounter. In the process of analysing such rich and complex data a systematic process described by Elo and Kyngas (2008) was followed which is divided into three phases: preparation, organisation, and reporting.

### **Preparation:**

This phase began with a selection of texts to be analysed. For this proposed study, each interview was regarded as a single text. The next step of preparation phase was becoming familiar with the text through multiple readings.

### **Organisation:**

This phase focused on organising the data and extracting themes from the text were of interest to this study. This phase was divided into three steps including open-coding, creating categories and abstraction (see Table 2). NVivo™ software was used throughout the phase to enable

organisation and analysis of the data. During the open-coding process, with the transcribed data, initial codes, heading and identified features that were of interest to this study were generated according to subjects that were frequently visited by participants. After initial codes were generated through open-coding, headings with similar subjects were grouped under a generic category. This was to create a more detailed description in relation to the research aim. Finally, the abstraction process involved grouping of generic categories and creating main themes (see Table 3 for an example of how this process relates to the use of NVivo™). Each main theme was given a heading that reflects the content of each group and made new information on the research aims available.

Table 3

*Stages of the Organization Process*

<b>Open-Coding</b>	⇒	<b>Creating Categories</b>	⇒	<b>Abstraction</b>
Generate initial codes and heading		Group headings with similar subjects under a generic category		Create main themes through grouping generic categories
<i>Example</i>				
Initial Nodes:		Grouping the Nodes:		Final Theme:
<ul style="list-style-type: none"> <li>- No plan</li> <li>- Considering different options without a concrete plan</li> <li>- Concrete plan/ no initiation</li> <li>- Teaching/training life skills at home</li> <li>- Attending services to learn how to live independently</li> <li>- Having them at home</li> <li>- Asking other members of the family</li> <li>- Creating employment opportunity</li> </ul>		<ul style="list-style-type: none"> <li>- No or Vague Plan</li> <li>- Preparing Progressively</li> <li>- Familial Care</li> <li>- Establishing a Care Centre</li> </ul>		<p>Options for Future Care Provision</p>

- 
- |                            |  |  |
|----------------------------|--|--|
| - Establishing group homes |  |  |
|----------------------------|--|--|

The process outlined allowed some themes to emerge during the analysis that are not directly the answers to the questions asked of the participants during the interviews. For instance, although the questions around the needs of the families were not explicitly asked during the interviews, during the analysis process it was evident that discussions around the needs for community involvement, education and culturally appropriate services, and the need to plan were some of the major subjects recurrently visited. Hence, these major subjects were grouped into and introduced as a theme ‘Needs’. Likewise, the theme ‘Self-Service’ was also one of the most significant themes and emerged through the analysis.

## **Reporting**

The reporting of the results was the final stage of analysis (Elo & Kyngas, 2008). Themes identified through analysis were used to facilitate presenting findings and to answer the research questions.

### 3.5 Ethical Considerations

All the core principles of conducting research with human participants were considered as prescribed by the Human Ethics Committee (University of Auckland, 2013), and ethical approval was given (see attached Appendix 1). All the participants were provided a Participant Information Sheet and an Informed Consent Form (see attached Appendices 2 to 11) to sign which clearly addressed the ethical principles related to the protection of participants’ privacy and confidentiality, and informed consent. Participants were informed that participation was completely voluntary, which means they were not under any obligation to participate in this



project and have the right to withdraw participation in the study within two weeks after they receive their interview transcripts, without having to give any reasons. In order to ensure safe storage, security, destruction, and retention of the information, collected data in all forms were kept in safe custody accessible only by the researcher and supervisors. Ethical issues which require special consideration for the proposed study include confidentiality, cultural sensitivity, and minimising harm.

### 3.5.1 Confidentiality

The names of participants are to be only known to the researcher who conducted all the processes of data collection. The information collected was kept confidential at all times. Participants were guaranteed confidentiality through use of pseudonyms and will remain anonymity in all reporting. Only the researcher and supervisors have access to the data that may identify the participants and their information.

A professional transcriber transcribed the recorded interviews and the researcher read through the transcripts of interviews to check their accuracy. The transcriber signed the Transcriber Confidentiality Form (see attached Appendix 12). The transcriber was bound by a confidentiality agreement as a condition of engagement. To avoid the possibility of the participants being identified to the transcriber who prepared interview transcripts, their names were not given to the transcriber.

### 3.5.2 Cultural Sensitivity

Since the study was undertaken in two countries that are culturally very different to each other, the participants had to be approached with great respect and sensitivity towards their own

culture. The researcher is of Korean ethnicity. Although the researchers had some difficulties around language on occasions (how the researcher dealt with this is outlined earlier), the researcher is a fluent speaker of the Korean language and is well aware of general Korean culture and customs. Similarly, the researcher has been living in New Zealand for the last 12 years and is well acquainted with the 'Kiwi' way of life, as well as being a 1.5 generation migrant. However, the researcher understands that, within each culture, people have individual values and beliefs; hence the researcher was very careful in conducting the research without using any presumptions and was guided by the participants in following appropriate cultural protocols when approaching individual families. Cultural sensitivity in the Korean context was an essential component for conducting successful interviews with Korean participants of the present study. For instance, Korean people use honorifics depending on a number of social factors such as age, profession, socioeconomic status, and so on (Strauss & Eun, 2005). Hence, to show respect, when interviewing with Korean participants, the researcher used honorifics. As discussed earlier, the use of key informants whom the participants trusted, the use of language, and having some degree of flexibility in interview setting played essential roles in building trusting relationships, showing respect, and empowering participants from a collectivist cultural background.

### 3.5.3 Minimising Harm

Since the qualitative element of research question deals with parental concerns and plans around their children's future when they are no longer able to provide care, it was possible to trigger some emotional responses. This was to be managed by either giving the participants enough time to recover from their emotions before continuing the interview, or stopping the interview completely on the day and giving the participants an opportunity to meet again at a future date. In fact, there was one case where parents in a group interview were extremely emotionally charged which resulted in parents being unable to continue the interview process. They asked for and were given time to recover. The interview and recording were stopped during the recovery process. The interview was resumed after about 30 minutes when they gave a sign that they were ready to continue. The participants were also offered contact details of

local professionals/services offering counselling support if necessary, yet no participant needed such support in the present study.

### 3.6 Methodological Limitations

The study involved one participant from New Zealand group who was identified as both a parent and professional, and six participants in Korea who were identified as falling under both parent and professional sample criteria. This posed some challenges around categorising participants into different groups. Further, although it was not often, these participants occasionally jumped from one role to the other during the interviews, which was observed to be a natural aspect of participants with dual identities. When necessary, the researcher tried to assist participants to remain within the role they wanted to be identified as, and/or tried to re-ask the questions so that the collected data encompasses both sides of their identities during the interviews. Despite these efforts made, the researcher acknowledges that this may have had some impact on the data, but this is not considered to be significant. A further study capturing the experiences and lives of participants who are both parent and professional would certainly complement the findings of this study.

The introduction of group data was also something that was unintended and unexpected. Yet, as discussed in detail earlier, both group interviews were conducted to encounter and capture each individual's experiences and perceptions of the participants in the group interviews. Hence, although the group interviews may have shaped the data gathered, it was not significant.

Furthermore, New Zealand participants were recruited only from Auckland. The experiences, perceptions, and expectations around processes of planning for future care provision of parents outside of Auckland were not included in this present study; had this been the case it may have resulted in different findings and discussion. This may also have an impact on the balance of

data collected from the two countries studied, as data collected from Korea was collected from not only one city but a number of cities in Korea. However, according to the 2013 Census Quick Stats about culture and identity (Statistics New Zealand, 2014), of the 30,171 Koreans in New Zealand, 21,981 are residing in Auckland (this makes up around 73% of the total Korean population in New Zealand), followed by 3336 in Canterbury. Although the specific number of Koreans living with disabilities in New Zealand is unknown, it can be assumed that Auckland has one of the biggest Korean disability communities in New Zealand. Accessing potential participants out of Auckland was not only difficult, but there were also issues related to representability of the migrant population. Hence, the study focused on the experiences of Korean migrant families caring for children living with disabilities in the region with the most significant Korean population. Further, although the participants in Korea were recruited from almost all provinces of Korea, including Seoul, Gyeonggi, Gangwon, North and South Chungcheong, and North and South Gyeongsang-do, the experiences and perceptions of parents living in Jeju Island, and North and South Chōlla are not included in the study due to difficulty gaining information and access to the population group in the area. Therefore, the present study provides a basic understanding of how separate country contexts shape the plans and possibilities for future care provision of Korean parents with children living with disabilities in Auckland and six major provinces of Korea.

### 3.7 Conclusion

In conclusion, as the study aims to explore how the country contexts shape the plans and possibilities for future care provision of Korean parents with children living with disabilities in New Zealand and Korea, a qualitative approach was employed to collect rich and lived information from participants. This was the most appropriate and useful approach for gathering the sensitive and personal data the present study is concerned with. Using purposive and snowball sampling, 36 participants were recruited among Korean parents of children living with disabilities and professionals working with them (10 professionals and eight parent participants from New Zealand; and nine professionals and nine parent participants from

Korea). The names and contacts of potential participants were obtained through the researcher's networks within the communities (churches and informal gatherings). Once ethical approval was obtained from the Auckland University Human Participants Ethics committee, participants from both New Zealand and Korea were interviewed to share their plans and perspectives around future care provision of their children living with disabilities. All interviews were recorded by a digital voice recorder. Once transcribing was completed by a professional transcriber and the researcher, the collected data were analysed through a conventional content analysis method where coding categories were derived directly from the text data. A number of methodological limitations identified in this present study, including a lack of power to generalise to a wider population, and the locations where the data were collected. The following chapter presents in-depth discussions of the findings and their meanings in the analysed data.

## **CHAPTER 4 Findings (Part 1)**

This and the following chapters are organised to discuss the findings and their meanings of what shapes and influences the future care plans for parents in Korea and New Zealand caring for their children living with disabilities. Participants from Korea and New Zealand have shared their experiences, understandings, knowledge, perceptions, and expectations of planning for future care provision for their children living with disabilities. Through the thorough, systematic analysis process of the collected data outlined in the previous chapter, this chapter is divided into three major sections: options for future care provision, reasons for lack of planning, and systemic issues. Under each heading, a number of sub-themes are identified. To make it easier for the readers to follow, sub-themes that are identified as similarities and are commonly discussed by participants from both countries are structured to be discussed in the beginning under each heading, followed by country-context-exclusive aspects. While there are three sections in the chapter, there are some overlaps between the sections here and the next chapter; the sections are not clear and distinct but the discussion is developed in this way to assist presentation and facilitate the discussion. Verbatim quotations from the interviews are used to illustrate the main points of each theme.

### **4.1 Options for Future Care Provision**

Most participants in the study have noted that parents in both countries recognised the need for future care planning and expressed their concerns regarding the issue, yet lacked concrete plans and practicality. Most had either no, or very vague, plans only, and few were identified to be progressively preparing for the future by training skills that are necessary for out-of-home care provision. While the details differed slightly between the two countries, one of the most frequently shared future care provision plans and options among participants was having them under their familial care. Further, although the option was perceived to be only available for financially wealthy parents for both countries, establishing a private living facility, or owning

and running a small-scale business were identified to be some of the possible future care provision options for children living with disabilities.

#### 4.1.1 No or Vague Plans

A pervasive concern and anxiety related to planning for their children's future care were evident in both countries. Most participants in the study have stated that parents in both countries recognised the need for, and showed great interest towards, future care planning and expressed their persistent concerns regarding the issue, yet they lacked concrete plans.

Professional participants from New Zealand have stated:

*They are not prepared at all (Go).*

*I don't think there are many parents who actually have a plan itself around what to do about their child living with disabilities when they are no longer around (Park).*

*Although parents do know the limits of their child, it's ambiguous.... They don't have a definite plan (Jo).*

A professional shared a case where he showed evidence of the recognition of the importance of, and the need for, planning by a father, yet lacked concrete plans:

*I was talking about a few things with a father of a student with autism. I told him "there are these kinds of workshops available. It might be good for you to consider them". And the father said that he believes that it is an important matter. He was thinking about who*

*will be responsible for the child if he passes away first, and how is he going to use his house that he owns for his son. So I asked him “so do you have any plans or some thoughts?” and he said “no, nothing yet”... So I gave him information around different workshops available (Lee).*

Another participant in New Zealand also commented how parents have great level of interest in future care planning, yet planning for the future care provision for children living with disabilities is a rather new concept for the Korean parent. Further, it was articulated that immigrant parents were too preoccupied with settlement processes while caring for their children living with disabilities to actually have time and space to consider and be involved in future care planning.

*This is a very new idea for Korean parents, right? They thought the best they could do is to look after their child well right in this moment, but people are already thinking about and preparing for who will care for my child when I am no longer around. But, what we felt was, initially it wasn't really accepted by the parents. Because it was about [the] far future and too ideal. They were preoccupied with making ends meet and to settle after migration. They were using all their capacity to look after their kid, and to additionally think about future seemed, to most parents, a little too early, or too much... Although, the whole idea of future care planning seems too far ahead of future, they have a great interest and do feel the need. But, for them, it just seems too early to plan yet (Lim).*

Such lack of planning was also evidenced by professional participants in Korea:

*In my view, they are not prepared at all. Yeah... they are not prepared at all and there is no alternative plan after school age (Lee).*



*It still seems insufficient. Such issue[s], when you watch television interviews, many parents talk about living just one day longer than their child. In reality, plans for when parents get older are still very insufficient (Cho).*

Parent participants in Korea have also shared similar reflection around future care planning:

*To be very honest, when I am gone, my child will be left hanging in the air (Lee).*

During the interviews with parent participants in Korea, when they were asked to rate how prepared they think they are in terms of future care provision on a scale of 1 to 10, almost every participant rated this less than five. However, it was clearly evident that they do see the need for planning and are constantly thinking about future care provision for their child.

*I do think about it a lot. I think it's my homework until I die. I am thinking about 3. I think it's a big problem. There is no answer to it (Lim).*

*I do think about it in my head. I still can't trust my neighbours, community, or church organizations. It's a sad story. My child is turning 29 and I should plan. I am thinking about it. There is nothing concrete yet if I try to jot down the plans... I am currently just worrying whether my child's life will be sustainable once his mother is gone (Choi).*

Feelings of having no concrete plan and having no other choice have made some parents think about rather extreme alternatives:

*I even said let's die together. Should we all die together? (Jang).*

#### 4.1.2 Preparing Progressively

Drawing on data collected, it was evident that future care planning is still ‘in process’ in both country contexts. A small number of parents from both countries stated that, although they do not have a concrete plan for the future yet, they are constantly training skills necessary for out-of-home life. Such skills included daily self-care skills required for upholding basic personal hygiene and basic standards of living, and other skills necessary for independent living and social adaptation.

A parent participant from Korea noted:

*What I am doing now to prepare him for the future is practicing him to eat and clean after himself. I am only doing that. I am not thinking about institution, and I am teaching him skills he can do himself, such as going to the bank and stuff...When my child turns 40, it's not too far away actually, we need to practice if he can live alone. When I am still healthy... we need to practice and see if he can manage. Get him into an apartment and live next to him, and see if he can do things on his own. Have a support worker and guardian next to him (Go).*

A few parent participants from New Zealand also shared the process of progressive preparing for their child’s out-of-home future care provision.

*We are always training him life skills. We are preparing for it [the future]. Although he may not be able to do everything himself once he moves to a residential care or a group*

*home, he must be able to do at least a few things himself to make it easier for the carers. So I am teaching him life skills at home, such as showering by himself, checking fees when going somewhere and preparing money to pay. And when cooking, I ask him to help and do things he can do (Park).*

Such skills were not limited to daily activities, but also embraced thinking about others and learning to consider others.

*He only knew about himself, because everyone took care of him. So, I thought this shouldn't be the way. That is part of life skill[s] too. So, I tell him what is his brother's, and to do things for his brother first. I felt that he was too spoilt. So, I think these kinds of life skills are important in the future. Parents need to teach them well, so that when parents are no longer there, they should at least be able to follow what people tell them to do. So I think that what I am doing in terms of preparing for my child's future (Park).*

Another parent participant in New Zealand shared how she is progressively trying to set up a support circle for her child as a process of planning for his future care provision. She was inviting people who showed interest in her son and other close family friends to her place on a regular basis, in an effort to let them get to know her son. She also stated that she openly discussed her son's conditions with people around her and people at the church, and actively participates in the community. She is hoping that such efforts will create support networks for her child and they will become sources of support when she is no longer available to provide care for her son.

*I think this kind of things will be helpful for my child's living in the future. Because I really value community.... Also even if I don't have close relationships, if I belong to a community and actively participate, it will form relationships quite naturally. And I think*

*it is good for my child to keep showing his face and build relationships. I think that is part of planning (Kwak).*

Professional participants in New Zealand shared some cases of progressive preparation they encountered while working with children living with disabilities and their families.

*The care provision can only be different when they leave familial care. So, as one of the practices before leaving home, a lot of practice happens around eating. Because at home their mothers always provided hot rice and stew, always. So, when they are out-of-home, they don't eat packed lunch. Even if they do, they want it heated up. But is that possible? So, they are trying to lessen these thing[s]. At the end of the day mothers do it as practicing to leave home. Practice showering alone, brushing teeth and things like that. They don't leave home suddenly, so slowly step-by-step (Han).*

*There was an example where the parent prepared a lot. What it means is that the child was well prepared in terms of brushing his teeth alone, going to bathroom alone, and showering alone and et cetera. His parents prepared him a lot and well as he was even able to count and use simple words to express himself (Hyun).*

*Practice, some start practicing sleeping at others' place[s]. They start this process when the children turn 17? 18? (Jo).*

Further, a small number of professional participants from the same group expressed how they actually perceive planning as a gradual process, rather than a product of a sudden arrangement.

*Who will be able to do that [planning] in a blink of an eye? I think that [practicing and training at home] is a plan in itself. To have a plan around what I will do and is just too ideal, and not realistic. Plan doesn't have to be a bombastic plan, but it is actually about*

*giving as many opportunities as possible to expose the child into the community in the process of the child's development. So, should I say "it's rather a process than a plan?" should be the concept that we approach planning, I think (Do).*

*It doesn't and can't happen in a logical manner where parents have a detailed plan around what services to use the day after they die, like having a will before you die. If the worst of worst happens, and parent dies suddenly and they were living at home together with their child living with disabilities, "in that case I want things to be done this way and do this after that" ...it doesn't happen that way just because the parents want it that way. It's not like you can ask for specific organization to do so... They may think like this, but it's not possible to have concrete plan (Lim).*

#### 4.1.3 Under Their Care – Familial Care

One of the most frequently shared future care provision plans and options among participants from both countries studied was having them under their familial care for as long as possible. However, there were slight differences in the details of such option between the two countries.

For participants in New Zealand, the idea of 'having them under familial care' meant having them under their care for as long as they can provide care, and then placing them under the care provided by welfare services as a last resort. Parents also often expressed their desire to spend more time with their child and the positive impact the children have on the parents as some of the reasons for having them under their care.

*There are still a lot of things I would like to do together with my child. So I want to delay putting her under residential service for as long as we can, unless there is no space for*

*her later... I think it's better for my child to be cared for a bit longer, and I haven't decided around putting her under the care service yet. So, does that mean I will live with her until I die? I haven't thought about those days yet. But, for now, I am going to have her under my care until my body allows (Ga).*

*Because they remain pure and innocent, it seems that they purify parents. So it's my greediness as a parent to live with her for as long as I can, but I need to help her settle. But I am less worried as she settles well no matter where she is. So I consider that it might be okay for her to leave [familial care] later (Jo).*

A professional participant in New Zealand also evidenced parents' desire and plans to have them under familial care for as long as they can provide care.

*I feel a lot of parents are holding on to their children, within themselves. For whatever reasons, I sense that they feel that it is their responsibility. And, on the other hand, maybe it is because they think that the care they are providing is better than what their children will get provided under welfare services. I am not too sure, but I feel that the parents are trying to hold on to them to the end (Baek).*

The severity of children's disabilities was also identified as having an influence on parents' choice to have them under their care.

*Firstly, for children who are considered a bit more independent, parents are not planning to send them away to group-homes, unless necessary. It's because they are able to do things in the household as a contributing members of the family. The reason they have them under their care is because they feel that they can care for them, they are still alive, and healthy (Gi).*

On the other hand, for participants residing in Korea, the option ‘having them under familial care’ was communicated as an option that involves other family members, in their nuclear and extended family, in the actual care provision when the parents are no longer available to provide care for their child living with disabilities.

*Mostly, family and extended family member support them. I don't think that parents think that the state will do something for them. So family members and extended family members come in as the first option. I think (Shim).*

*Because the family need to take responsibility, when they are planning for the care provision of their child after they are gone, where do you think the responsibility to move to? If they have siblings, they are asked to provide care (Koo).*

Parents staying healthy and well, then placing them under the care of other family members when they are no longer available to provide care were often noted to be a feasible option among parents living in Korea. A mother caring for her child living with disabilities noted:

*I am trying to stay healthy, exercise and live as long as I can. Otherwise, if I can't trust my younger child, we have nieces. My son says the nephews are nice, but I think girls are better. My nieces are in their late 30s and when I look at them, I feel like I could ask her to take care of my son. We gather together a lot, and I think I can ask her for the care of my son. So I am considering that as an option (Ha).*

A professional participant who is also a father of a child living with disabilities also stated:

*Planning for the future.... It's the same. One option is for the mother to live a long life, and then the next would be relying on siblings? (Um).*

In short, for New Zealand participants, the option 'having their children under familial care' referred to having them under familial care for as long as they can provide care then placing them under formal services as a last resort, while Korea-based participants communicated it as an option that implicates direct long-term involvement of family members in the actual care provision. Such difference between the two countries may be a result of limitation of availability of extended family members for families living in New Zealand. This possibility will be revisited and discussed further later in the discussion chapter of the thesis.

Some parent participants also argued that parents do want their children to leave home and live independently, but because they lack trust in the system and services, they feel that having them under their care is the only option available:

*When you hear the mothers talk, they do want their children to leave, but they feel that their safety won't be ensured and they won't be supported well enough. So they say they will take all the responsibility and go with it. But if the support system was good enough... (Hong).*

*Mother are human beings too. They say "I want to let them go, but there is no guarantee...." There are stories of inhumane treatment in institutions... Instead of seeing them over-drugging my child so that they are just lying in bed doing nothing, I will have my child under my care (Kang).*

A number of professional participants, from both Korea and New Zealand, have highlighted some of the problems associated with this option. Some have argued that the tendency of



'holding-back', evident among Korean parents, may eventually result in more difficult situations for the children around adaptation to a changed environment, which will be discussed in detail later in the chapter.

*There are cases where parents couldn't educate and train their children to live out of familial care. But the child grows. There is nothing much we can do in terms of care when the child comes under our care after teenage (Jang).*

*Some parents say that they will take the responsibility to the end. But because of such idea, the children get less educated. Although there are some differences in the level of disabilities, but some children are absolutely not ready at all (Han).*

Some concerns for the siblings and other family members who are expected to care for the child living with disabilities in the future were also expressed by professional participants from both country contexts. For instance, a professional participant in Korea expressed his concerns around the responsibility and the level of stress the siblings have to bear regarding future care provision of their brothers or sisters who are living with disabilities. For such reasons, he noted how in his practice, he advises parents not to place responsibility for care provision on the siblings.

*I tell my clients not to [place responsibility of care on the siblings], because it's [making] the siblings [sick]. They get the most stress (Um).*

A professional participant from New Zealand also stated:

*Korean parent thinks I will sacrifice everything for you. It even extends to sibling,*

*“because you are bother/sister, please sacrifice yourself”. So another victim is the siblings. They don’t get the attention, so when they grow up, they end up saying “I had to suffer because of you”, definitely. Consciously or not, they get hurt a lot (Lim).*

#### 4.1.4 Establishing a Care Centre

One of the future care provision options for their children living with disabilities that parents identified was establishing a private living facility, or owning and running a small-scale business. Only a very few New Zealand participants discussed this option, yet it was predominantly discussed among Korean participants living in Korea. This option is closely linked with ‘Having No Choice’, ‘Economic Capacity’ of both the child and parents and ‘Self-Service’ which is discussed in depth later in the chapter.

Few parents, from both countries studied, expressed that they were thinking about opening living facilities, such as group homes, with a few other parents who share similar thoughts, as one of the possible care provision options. A parent participant in Korea shared:

*To be honest, even though I participate in the campaigns, the direction for my child’s future has no choice but to be different from the campaigns I take parts. I am actually personally thinking about other place[s] that my child would go in the future. It’s a religious organization but there is no other option. It because the nation had omitted its responsibilities, so individuals are privately collecting some money, establishing an institution and entrust it to professionals. There are no choices. I am also thinking about this option... about 10 mothers? They make payments to the construction of the building, and once that’s complete, then we place our children under their care. But there aren’t many teams doing this. Because it costs million dollars (Go).*

A professional participant in Korea also noted:

*I actually thought about mothers coming together to open a centre to care for our children. It would be nice to open one for children to stay together. But this is only possible for parents who [have] the financial means. Otherwise mothers have no choice but to have their child under their care at home (Jo).*

Such a plan was also shared as an option among Korean parents living in New Zealand. A professional participant shared:

*Plans vary. If the mother is financially well-off, they personally have purchased a house. And gather people who can get along well with their child to move in together. And say “I’ll buy the house and you just pay for the living cost” or something like that. There are parents who are thoroughly prepared like that (Kim).*

A small number of parents in Korea were directly involved in creating job opportunities for their child to enable and secure the child’s income activity in the future. Purchasing a small shopping arcade in the community or initiating a small-scale business were some of the examples of such direct initiatives. However, this is again an option only for financially wealthy parents.

*There is no choice. So, because we have no choice, the best way to care for the child when I get old is to own a little arcade. I could rent it out or run a small business there, or let the child clean the building for at least half an hour every day. So the parents have to create[d] a space for the child to make living. Parents have to provide the environment.... Although there are group-homes, but they can’t be just placed there*

*doing nothing but eat and play. They need to work. But who is going to employ them? Nowhere. So I am going to buy an arcade and I have some land here... There are no other options. That's the only alternative I have (Jang).*

*Our children can't do things independently, so we should start first. For people to come together, open work and education facilities.... This centre is to provide people living with disabilities a place to rest and work... we made our own brand and named it as well. We grow ginseng and sell. It is to help people living with disabilities. So the important part is the market. The business is run by parents of children living with disabilities. So they come together when needed and have discussions, research how to run the business and market and things (Hong).*

#### 4.2 Reasons for Lack of Planning

Participants in both countries have unanimously identified lack of information, living everyday life, and emotional distress as some of the key reasons behind the low level of future care planning. Public perception was identified as one of the key reasons for lack of planning among participants in Koreans, and it was identified that parents in both New Zealand and Korea are exposed to negative public perceptions while planning for future care provision for their children living with disabilities. Further, while professional participants in Korea have identified having no choice and the economic capacity of the parents as major reasons behind the lack of planning, professional participants in New Zealand have articulated cultural barriers as one of the most significant reasons for such lack of involvement in the planning processes.

This section is structured to firstly provide a detailed discussion around the commonly shared reasons behind a lack of planning among Korean parents regardless of the country context, namely lack of information, living everyday life and emotional distress. Public perception, having no choice and economic capacity identified exclusively by participants in Korea as

reasons for lack of planning are then explored, followed by an in-depth discussion around cultural barriers which were indicated as significant reasons behind lack of planning in the New Zealand context among Korean parents caring for children living with disabilities.

#### 4.2.1 Lack of Information

Professional participants from both countries have stated that planning process for future care provision is significantly influenced by lack of information. Professional participants in New Zealand have noted:

*Surprisingly, there are a lot of parents who don't have much information, surprisingly (Park).*

*I feel that they don't know where to start and what to prepare, and what is available where (Jung).*

*The biggest challenge for parents in the planning process is that they don't have information around what is available and where they can find [it] (Kim).*

These participants approached this issue from a public education perspective and emphasised the importance of informing parents about the need and the available supports.

*Although I have lived here (New Zealand) for a long period of time, it is right to question "such things did exist?" around the aspects I haven't encountered. So, even though it will take time, such small efforts should be talked about, and I think it will be helpful to use mediums to consistently inform people (Lim).*

*It may be that parents are not planning as they do not know anything about such thing[s], so education, public relations is very important (Kim).*

On the other hand, Korean professional participants have criticised a lack of public support and systems as the main causes resulting in a lack of information among parents.

*It's very ambiguous and daunting for parents as actually there is no service system providing information or guidelines around the process (Lee).*

*Well, to begin with, there is no information. As discussed, there is no information around what public system is there to support my child and ways to plan (Cho).*

Such lack of public support and system around information provision is further criticised and it leaves the planning process as a personal and familial problem, which then leads to a 'self-reliant' process.

*They have to do everything personally. They have to gather information themselves. Mothers' ability to gather information is critical.... It's solely about the mothers' ability to gather information (Kim).*

According to the participants in the study, such a lack of information becomes even more problematic once the child enters adulthood or completes school years without being connected to any service providers as it cuts off channels for possible information exchange. From a number of examples participants shared, this then led to parents experiencing future care planning process as an individual problem which needed to be resolved on a very personal level. Professional participants from both New Zealand and Korea have emphasised parental

education and peer networking as ways to tackle the issues around lack of information. Such issues regarding post-school age planning process and need for parental education and peer networking are further discussed in detail later in the chapter.

#### 4.2.2 Living Everyday Life

As mentioned previously, participants from both countries commonly expressed that parents are settled for and accustomed to the status quo, hence do not perceive future care planning as a serious and critical matter. As parents in both countries are perceived to be relatively used to living everyday life with their children living with disabilities, unless there is challenging behaviour or difficulty living with the child, they are committed to be living a day-to-day life without making any definite, concrete plans for the future care provision of their child living with disabilities.

A professional participant in New Zealand has noted that unless the child's level of disability is exceptionally severe to the level that other family members cannot carry out their daily activities, parents tend to be used to living day-to-day life with their children living with disabilities at home without having concrete plans for the future.

*I think parents are just very used to it [living with their child]. It just becomes a part of their life... they are just living their life. So they don't have any definite plans around what to do when it becomes too hard to care for their child... They don't have any special plan. They just live their day-to-day life instead of making a special plan. So the parents are just very used to the daily life (Kim).*

Similar reason for lack of planning was also evident in the Korean population. According to

a professional participant in Korea:

*I also wonder about what plans parents have. I can't guarantee but what parents are doing is that when asked about future care planning, they think as they go. If the child's disability is severe, they leave the familial care earlier... It's about up to what level the parents can have them under their care (Cho).*

Parents in Korea have also made connections between living daily life, settling for the status quo, and lack of planning:

*Participant 1: Plan is having no plan. When I ask other parents "what are you going to do?" they just say they are living everyday life. It's a concept of a mayfly<sup>2</sup> ... from their point of view, that may be the plan, because for now...*

*Participant 2: Current situation is too difficult that although they want to make plans, they just can't. They have no choice but to live like that.*

*Participant 1: It is hard enough making ends meet right now. Their plan is [a] very inferior plan.*

#### 4.2.3 Emotional Distress

Experiencing emotional distress was another significant reason participants in both countries avoided future care planning. This included parental responsibility, self-blame, guilt, and other

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<sup>2</sup> An insect known for their extremely short life span. Often used in Korea to refer to people living day-to-day lives



complex emotional aspects. Participants in the study have expressed that these complex emotional distresses have a substantial impact on future care planning for their child living with disabilities.

A professional participant in Korea has emphasised the guilt and parental responsibility the mothers bear. He noted that mothers in Korea not only feel guilty for giving birth to a child living with disabilities, but they also feel sorry for the other members of the family, such as their in-laws and husband. He also stated, such negative feelings of guilt and immense pressure from the responsibilities they carry, mothers eventually burn out.

*In Korea, when mothers give birth to a disabled child, mothers feel guilty. Firstly, they feel sorry for giving birth to a disabled child. They don't know the cause of it. It could be inherited or medical malpractice, and it is more likely that it is not the mother's fault actually. But the mothers take all the responsibility. The psychological responsibility... And they burn-out at the end (Jang).*

New Zealand professional participants have also articulated the parents' emotional distress and the significant level of parental responsibility, and discussed its impact on the low level of future care provision planning.

*There are a number of parents who say "My biggest wish is to die at least one minute later than my child". What that means is that they will take responsibility for the child until the end, and a lot of guilt. That's the base of it, which they may be conscious or not. Koreans...their love towards their children is somewhat... should I say self-giving? (Go).*

*So parents have this thing, consciously or not, of feeling sorry towards their child. So they have this mind-set to care for them till the end, until the end of life. And I am only assuming that this is may actually be impacting negatively by not educating them (Kwak).*

Such parental responsibility, parental role and its relations to future care planning was evident in New Zealand parent participants as well as professionals.

*We are always living in the limits of time, right? Within the time. There is a limit, that's why I need to use more time for the child, so that my child can spend more time with mum and a lot of time with the family. We need to empathize and take part, as once I am no longer here, she has no choice but to go [to a residential care] (Jung).*

There are also emotional distresses that are linked with public perception which have substantial influence on parents' level of future care provision planning. This is discussed in depth in the following section.

#### 4.2.4 Public Perception

The findings suggest that, while much has changed in Korea regarding people living with disabilities, throughout history and the treatment towards them has changed substantially, some traditional perceptions regarding people living with disabilities still remain in how they are perceived and treated by others in contemporary society.

From what was shared by the participants in Korea, it is evident that there is a lack of positive perceptions among the general public towards people living with disabilities. Both parents and

professional participants from Korea have indicated that people living with disabilities are still regarded negatively in Korea.

*Participant1: System is important, as well as people's perception.*

*Participant3: Perception is important. System is one thing but...*

*Participant1: if you just think about it, although we think there are a lot of nice people and we are living in a better society, in fact there are a lot of discrimination.*

*Public perception must be changed. Korea's perception around disability is lack in huge degree. See, when I go out in the public with my child, although it is much better now than the time when my child was small but still...I want some improvements on how people living with disabilities are perceived (Jo).*

As stated in the beginning of this section, although it is argued that much has changed in Korea regarding how people living with disabilities are perceived and treated, participants in the present study argued that it is still not at a satisfactory level, and changes are only starting to happen recently.

*Although it's argued that the public perception has improved, it's not satisfactory for parents of children living with disabilities. So, it's difficult as it seems that our society does not have the conditions to be inclusive with these children (Kim).*

*People living with physical disabilities were able to make conscious judgments on the situation and started to make voices on what they needed in early stages. So the welfare is somewhat serving their needs right. But parents with developmental disabilities were too focused on raising their child. So there was no conversation happening in developmental disabilities community. We never raised our voice. We are only just*

*starting now. We were neglected by the society and it was seen as the parents' responsibilities, and until now we raised our child believing that it was our fault (Kim).*

A number of Korean participants linked such negative public perception with the population being ignorant:

*I think people just don't know. That's why they feel repulsion and look down on those living with disabilities. They see it as problem behaviour when the child is only trying to express themselves. So, simple little things become a big matter. This happens even within schools, so I worry how open and understanding our society will be for a big grown adult (Noh).*

*I think people are just indifferent. We are making developments in making money, but perception-wise I don't think we are at the level of developed country (Jang).*

On the other hand, when discussing issues around public perceptions towards people living with disabilities, comparison with Korean society was frequently made among New Zealand participants. They indicated that their experiences in New Zealand were much more positive than in Korea in terms of public perception and treatment towards people living with disabilities.

*I would have been more worried if I was living in Korea but this country (New Zealand) protects [people living with disabilities] (Lee).*

*Recently, I thought about how unhappy I would have been if I lived in Korea. How well I could have raised my child in such a complex and competitive society. But this county [New Zealand], they perceive my child with comfort (Kim).*

*People say Korea is still the same, public perception and things, so a lot of people inquire from Korea. But here [New Zealand] it seems that the child is treated adequately whether the child is docile or not (Park).*

However, professional participants from both Korea and New Zealand have stated that parents are exposed to negative public perceptions around child living with disabilities leaving the family home. Such negative perceptions include neglecting their duties as parents and dumping their child living with disabilities. These negative public perceptions around children leaving family households were argued to have a great impact on the process of future care planning for parents in both countries.

*They feel like they are dumping their child. And they feel that people will criticize when people ask “where is your child?” and they say “I sent them away” (Jo).*

*They are very sensitive about others knowing about their situation. So they don't openly discuss, and I get the feeling that they are not as open as Kiwis [New Zealanders] around sending and having them under organizational care. And comparatively [to New Zealanders], when planning and preparing, Koreans often give an impression that they are holding on to them (Noh).*

#### 4.2.5 Having No Choice

One of the most significant reasons for the lack of planning for parents living in Korea is that they do not have any choices and options to consider. (Note that this theme will be revisited in the ‘Systems’ section, where some comparisons are made between the two countries studied). These issues around having no choices are also very closely linked with the economic capacity of the parents, which is analysed further in greater detail in the following section.

A professional participant who is also a father of children living with disabilities in Korea expressed:

*Mothers in Korea, when I do counselling, education and lectures, most of them say “I should die 5 minute later than my child”. There is no other way. If someone asked me “what should I do?”, even as professional I can’t comment and suggest ways at all. That’s how it is now, from a professional point of view. There are no ways (Jang).*

Other parents have revealed how there are no service providers they can entrust with the care for the child living with disability, and concerns around lack of service options to consider. A mother shared a case in her community where a church provides special programmes for children living with disabilities. She noted a lack of quality and diversity in the programmes offered. She stated:

*If you hear how they are spending their days at the programs, they just go there and eat and come home... When I look at these things there is nowhere I want send my child to. The centre where I want to send them are not available. It’s just too hard. (Noh).*

*There is a social worker that I know. She said that in our country [Korea], there is no place where I can entrust girls yet. There are a lot of sexual issues, domestic violence and things. So if something was to happen to me and I can no longer provide care for my child, I think she will have to go to day-care centre during the day and stay there, and come home over the weekend. There seems to be no other way. Otherwise she will have to stay home all alone after day program or something like that (Na).*

As discussed earlier, establishing a residential facility can be an option for some parents.

However, a mother who is thinking about opening a living facility with a few other parents noted that if the parents do not have the financial means to secure future care provision for their child, they are left with no other option than to have them under their care.

*Mothers have no choice but to have their child under their care at home. Even if we protest, they are planning to establish three life-learning centre[s] a year. If they open one in each district and they facilitate 30 people, but there are 28,000 people living with disabilities just within Seoul. It's difficult for such centres to facilitate all (Jo).*

#### 4.2.6 Economic Capacity

Another significant reason behind lack of planning among parents living in Korea was identified to be the economic capacity of the parents. Both parent and professional participants residing in Korea have articulated the economic capacity of the parents as one of the major reasons for lack of future care planning. Parent's economic capacity not only determines the range of service providers, but the possibility of thinking about the actual plan itself is also determined by the parent's economic capacity.

*It is hard enough to just make a living. The aspect that I hear the most is about financial side. To think about when parents have passed away or too old to provide care, if the parents are not financially stable, they cannot make any progress further with the plan, right? One of the biggest obstacle[s] can be finance... (Ham).*

*Making living for the moment is hard enough. Parents are thinking about planning when it is need and living as it is for now. The plans are very inadequate (Noh).*

A number of professional participants in Korea have stated that economic capacity of the parents is the ultimate standard or determinant of parents' ability and involvement in future care planning:

*The most difficult aspect for parents in planning is economic capacity. That's the standard for everything. If they have money to spare, the mother doesn't have to work and focus a bit more on the child, otherwise children can't be cared for (Hyun).*

*At the end of the day, parents try to make more money. They need money to send their child to a residential care. So they try really hard to make money. Because we are living in a capitalist society, capital becomes the criterion for everything. Rationality, ethics and morals are way below, holding up the capital (Jang).*

*The basic requirements need to be met in order to ensure basic standard of living including food, clothing, and shelter. But if the parents [do not] meet the financial requirement, this children can't even make friends, and although there are support worker services available, it is very [tight] these days (Jeong).*

Some of the choices and options regarding future care provision in Korea were perceived to be only available to families that are wealthy enough to have money and time to dedicate to caregiving activities for their children living with disabilities. For example, as we discussed before, parents who do not have the financial means to plan and provide secure future care provision had no choice but to have them under their care. The option of opening and/or placing their children in private residential care facilities were again an option only for financially wealthy parents. Further, from the data collected from Korea, it was evident that there are cases where the children were placed in institutions without having any other choice as the parents had to continue with their income activities to make a living and were not able to provide care for their children living with disabilities.



*Planning, I think the reference point will be economic capacity. The carer's economic capacity. So, parents with some financial means can look for diverse options, and look for institutions, more education, rehabilitation centres, independent living and search in various ways but people who do not have such economic powers, they have no choice but place their child in [institutions]. And once they are admitted, what they want from the service providers is to stay healthy in the institution. That's what they ask for (Im).*

Such cases are predominantly among middle-class families in Korea. On the spectrum of poor and wealthy, people who are considered to be on the poorer side are entitled to and can somewhat rely on government financial support. People on the other end of the spectrum, as discussed above, tend to have more time, space, resources and choices to consider when planning for their child's future care provision. However, for people who fall in between, middle-class parents with low income levels, this matter is especially concerning. In other words, as they have to be abidingly engaged in income activities to make a living, economic reality does not allow the time or space, never mind the planning, for their children's future care. Indeed, even providing adequate care in the present, leaves them with no or very limited alternatives to consider.

*People who are in the upper class, in other words who are not experiencing difficulties around finance, are already thinking a lot about the adult guardian system and inheritance. And parents who are beneficiaries, as the nation support them a lot under the system, they are getting a lot of support from those.... But the biggest problem is the middle-class. It is hard for parents in the middle-class to get supports from the system, and because they are also experiencing financial difficulties, I think parents in this class are most problematic. Most of them are focused on getting their children employed, and actually can't think a lot about the children's future or plans after their death or what they need to do when they get older (Bae).*

Another professional participant based in Korea who is also a parent of a child living with disabilities shared his experiences around losing contact with parents after the child is placed under the care of institution. He identified the main reason behind such a disconnect with the parents to be financial hardship.

*There are a lot of cases where the service loses contacts from the parents. The biggest reason behind it is finance, I think. Because families like mine who are caring for children living with disabilities and [are] middle-class, both parents need to be engaged in income activities. But one person can't make income because they need to look after the child. Then it becomes very hard for middle-class parents to make [a] living (Jang).*

He also stated that he knew of a number of cases where such hardship led to break-ups of families, leaving no alternative for the children but to be placed in institutions.

*It often leads to cases of divorce. Someone needs to care for the child after the divorce, and that person can't carry out income activities. Then what happens to the child? They end up coming to institutions. There are many cases where the relationship between the parents and the children get cut off as the parents do not have economic capacity (Woo).*

Further, parents in Korea argue that economic capacity also has a significant impact on their ability to participate in the community, and engage in activities organised by parent societies or associations for people living with disabilities. For instance, when a mother was asked a follow-up question regarding whether the participating parent members of the parents society had some level of economic power, she stated:

*Yes, they have it basically. That's why they are willing to participate. There are mothers who need to make money, right? Of course, there are mothers who are professionals and they don't want to waste their ability, but there are mothers who really want to participate but they need to make money to make living for the family. The mothers actively participating in our parent society are mothers from a family where, at least, women don't have to work to make living. When we try to do some activities, it's unfortunate to see mothers who can't participate because they need to fit their time into their income activities. There actually aren't many cases like mine...there are many cases where mothers have to make living. It's a bit unfortunate because there are too many families like that (You).*

Although the emphasis on this issue was significantly weaker and was much less frequently mentioned, issues around the economic capacity of the parents were also raised in New Zealand. For instance, when asked to identify some of the difficulties Korean parents are faced with in New Zealand in the process of future care planning, a professional participant in New Zealand stated:

*Money. The financial aspects. I think the children's basic needs can be met even if their parents don't have enough money, but they need extra money to actually enjoy life. For example, you can't get your teeth fixed with the financial aid you get from the state. So, there are people living with disabilities in our service without front teeth in their 50s. there are a lot of clients in our service who have missing [teeth], but to get it fixed it cost about 8000NZD. Even though New Zealand welfare is good enough, they can't meet those needs. They are only supported to make living and education maybe. They go to school, and go out have a cup of tea or coffee and go for a walk on Sunday. That's about it (Kim).*

Another professional participant also commented:

*If you want to go into a residential service but it's full, you need to buy a house next to it. Parents need to pay for this. So in terms of care provision, just like in Korea, if you want to put your child into better service with better care provision, this country is no different. So, even though it's perceived that the state takes the responsibility 100%, mothers need to have money to provide better service for their children (Jung).*

Yet, despite these comments, in contrast to the Korea-based participants where they express their concerns around the economic capacity of the parents, the main economic concern for New Zealand based participants appeared to be around access to funding, which directly or indirectly reflects Korean parents' expectations around state-level financial support in the provision of care for their children living with disabilities in New Zealand. Korean parents residing in New Zealand commented:

*At the end of the day, it's all about money when you talk about your child leaving home. So you need to get the approval for funding (Lee).*

*The first thing for my child's care provision at the moment is funding. Money is a big issue so we need to get the funding (Park).*

Nevertheless, compared to Korea-based participants, participants in New Zealand more often made references to the financial status of the nation and the government in relation to service provision in New Zealand, rather than to individual or familial financial status.

*The problem at the moment is that New Zealand government doesn't have enough money. So you apply for a service and wait for one to three years, just like that (Cho).*

*Although people say New Zealand's disability welfare service is well structured and organized, they lack in detail in regards to service provision. And this is because they don't have enough money (Kang).*

*New Zealand has run out of pension. So they are saying that they will not give all the money people are entitled to when they get old. What they are doing is reducing the financial support (Do).*

The hardship experienced in Korea in regard to economic capacity of the parents, and perceived higher level of national level financial support available in New Zealand was identified as a significant 'push' factor for Korean parents to migrate to New Zealand. For instance, a parent participant who migrated to New Zealand to obtain a better welfare environment for her daughter, identified financial burdens experienced in Korea as one of the 'push' factors that impacted on the family's decision to migrate to New Zealand. She noted while making comparison between his financial input in Korea and New Zealand:

*We migrated when my daughter was about to enter primary school in Korea. We had a lot of concerns. We didn't feel confident about sending her to a primary school in Korea. Although it seems that it has improved now but special schools had a lot of problem[s] back then. Also, I spent a lot of money back then in Korea. Because my son needed a lot of individualized special education. So it was very costly. But, since I came here [to New Zealand], the services that my son is getting is much more beneficial even though I don't spend as much money as when I was in Korea (Go).*

#### 4.2.7 Cultural Barriers

One of the most significant differences between Korean parents in Korea and in New Zealand was revealed to be around whether they experienced cultural barriers in the process of future care planning or not. In the New Zealand context, the socially experienced reality of future care

planning among Korean parents was seen to be impacted by cultural barriers; this was not evident among Korean-based participants. Professional participants in New Zealand have articulated some of the issues which may rise from cultural differences. Most of professional participants from New Zealand have argued cultural barriers as one of the most significant reasons for lack of planning among Korean parents in New Zealand. Lack of culturally appropriate services for Koreans, New Zealand 'style' provision of services, coercion of independent living, food, lack of understanding around social community, and language are some of the cultural differences repeatedly identified by the participants.

Professional participants in New Zealand stated:

*The background of the programs designs is very Western, Western culture. The aim is independent living and supporting them to live independently and to find a job... So if the parents do not have an understanding about it, they can't benefit from it. (Noh)*

*For example, even if children can get into residence care or respite care, the biggest problem is that the system is completely "Kiwi style". So the way they treat children...it's more about "yes or no". It's about disciplining the child in this country [New Zealand], whereas in Korea children living with disabilities are treated with greater sincerity. So it's doesn't seem suitable for Koreans. Another thing is that the food is not suitable. Food provided by the services are not adequate for Korean children as they have been only eating Korean food at home (Lee).*

*To begin with, I was providing care for Korean children with a New Zealand service provider at the same time. But, as that provider reflected Caucasian sentiment, New Zealand sentiment.... So in that aspect, a big part, from communication to food, and to emotional touches for individuals, there [were] a lot of limitations (Koo).*

Cultural differences in general care giving and child rearing were also revealed to have a level of impact on parents' involvement in future care planning.

*A lot of physical affection is involved when Korean parents raise their child. They sleep next to them, piggyback them and all that. But in Western culture, babies have their own rooms. Their culture is not one that involves a lot of physical affection. But Koreans are completely skin-ship culture. So the bond between parents and children are significant. It's like "you are me" and "I am you". But in Western culture, there is this thing about "I am me" and "you are you" (Kim).*

The unavoidable cultural difference of language was also articulated by a number of both parent and professional participants living in New Zealand.

*Language barrier is also very significant (Park).*

Language was communicated, once again, to create barriers around information circulation, which may ultimately perpetuate a lack of systemic understanding, limit information gathering and use of available services, and reduce the level of involvement in communities.

*I think language creates significant barriers. Korean parents tend to meet within the Korean society, and within that community, parents who have some level of English ask from other service providers, "come and run a session for our Korean parent". If they can, they do that and we get interpreters and get information together. It would be nice to see that happen more often, and a lot (Lee).*

*Especially with English, when you search for meaning for one single word, they come up with eight different meanings in the dictionary. What is described by the dictionary is not what they mean in Korean in the given situation... so it's very hard to find what is available where, and you don't know who to ask for help... So I think not now where information is and language barrier[s] have significant impact on the planning process (Cho).*

Difficulties around adapting to the host country as migrants, no matter how long they have lived here, were articulated by the participants in New Zealand as one of the significant reasons impacting on planning for future care provision for their child living with disabilities.

*Even if they came to New Zealand at [a] young age, if they are raised under the care of Korean parents experiencing Korean culture, when the parents are no longer around, children will be faced with problems with food, culture, language. Some parents may think and say "my child is okay". But I don't agree with them (Noh).*

*Some parents think "my child went to school in this country and has no problem adapting to this society". But they definitely do not live like that at home. Do they use fork and speak English at home? Definitely not. They believe that their child has adapted well to Kiwi society when they are actually not living like that [Kiwi style of life]. Such problem[s], if not recognized by the parents and society, will be left as a latent problem (Jeon).*

A participant also articulated her concerns around such cultural barriers experienced by children being expressed in unexpected or problem behaviour.



*When people migrate to New Zealand, despite adapting through living here for a while, there are limitations. Because there are cultural limitations. In addition to [those] limitations, although children living with disabilities can't express themselves, it is likely that they feel even bigger limits. And such limitation[s] they experience may be expressed in unexpected behaviour or problem behaviour. So this can become a significant problem later on (Suh).*

Further, in addition to the connections between lack of planning and cultural barriers and a perceived lack of appropriate cultural services, this participant group has also commented on aspects of general Korean culture that impede the process of planning for future care provision among Korean parents living in New Zealand.

A professional participant has noted how the Korean community is rather exclusive and passive. He also noted that such passive attitudes in the New Zealand Korean community pose challenges among Korean parents in taking parts in the mainstream community and pushing their own boundaries.

*Korean community in comparison [with the New Zealand mainstream community] is a very exclusive community. They are very tightly linked within their own community but in terms of outer boundary? They are very passive in pushing their boundary and taking a part in other new community or mainstream community. So parents lack in understanding communities in the country and this is in fact the biggest challenge (Choi).*

Another participant from the group has also commented on the introverted aspects of the Korean community and how it makes it very difficult to invite them to share information and to involve them in community activities.

*We sent out invitations. But it's very hard to distribute information all round in the first place, because, within [the] Korean community, people don't voluntarily step out and say they have a family member living with disabilities. If possible, parents don't want others to know about it. And they have this very Korean idea of "our problem can only be solved by us". So we had difficulty inviting them (Moon).*

### 4.3 Systemic Issues

The findings from the study show that there are systemic differences and similarities regarding future care planning among Koreans in different national contexts. Participants in both New Zealand and Korea have identified a number of systemic problems, such as segmentation and discontinuation of information, services and systems, quality of education, lack of functionality of the systems, lack of flexibility in service use, and lack of systemic support following the changes in the welfare system. Although the nature of insufficient database material differed in the two countries studied, findings show that both New Zealand and Korean parents were experiencing difficulties around lack of a database. However, the two countries studied showed rather significant differences in trust towards the overall disability system and services, as well as the perceived choices and options parents have regarding future care provision for their children living with disabilities. In contrast to New Zealand where service coordinators and referral services in a wide range of disability organisations are available, participants in Korea criticised the absence of medium bridging service providers and users.

#### 4.3.1 Systemic Problems

Although the details differed depending on the country context, participants from both countries have identified a number of systemic problems and issues they faced and experienced

while caring and planning future care provision for their children living with disabilities. It was evident that participants in both Korea and New Zealand experienced segmentation and discontinuation of information, services and systems. The overall quality of education provided for the children was an issue identified exclusively by New Zealand participant groups as a major systemic problem, while in Korea, participants were mainly concerned with lack of functionality of the system, lack of flexibility in service use, and lack of systemic support following the changes in the welfare system.

As mentioned above, participants from both country contexts studied stated their experiences around segmentation and discontinuation of overall service and system. While talking about circulation of information shared by service providers, a participant in New Zealand commented:

*There are quite a lot of loopholes in New Zealand, in terms of system. When you get to a certain point there is a complete disconnection (Jo).*

Similar systemic problem around discontinuation of information, service and system was also evident in Korea:

*From the parents' shoes, it's depressing and indefinable because there is no information provided or supports available. It's all very instant. Although our support system starts when the child is young but all of it gets cut off in a very instant manner. When they are at school they get special education but when they are out in the society there is no connection after that. Even if they go to school or other centres, it doesn't guarantee employment. So everything gets cut off, which makes it difficult for parents to think ahead and plan (Go).*

Participants in New Zealand identified the overall quality of education provided for the children as a major systemic issue the disability community is faced with. Both parent and professional participants in New Zealand criticised that the education provided in New Zealand is overly focused on the happiness of the children while somewhat neglecting children's full potential to learn. In other words, participants in New Zealand are concerned that some children living with disabilities in New Zealand are not given proper chances to be educated and pushed to test their limits and reach their full potential.

According to a professional participant:

*New Zealand system is not detailed enough to need treatment recreation professionals. Even in my workplace, when the person is said to be living with disabilities, there is absolutely no thoughts around looking into his/her life and think about how to improve their lives. They just ask "what do you want to do?" and only simply assess what to do, but nobody looks deeply into their lives.... Nobody analyses the child's life... That's the limit of New Zealand. The facilities are well organized but they lack in detail because they don't have the budget (Tae).*

A parent participant made a comparison between the education system in the United States and New Zealand and commented:

*I heard that in America, children get educated according to their characteristics, according to the child's abilities. But in New Zealand, at the school that my child goes to, there is even a blind child [laughter]. They do not belong to that school. I think that's just nonsense. So because it's not detailed enough, although the government fund people*

*living with disabilities and all, in terms of education, they are zero out of 100, zero [laughter]! It's about being "happy" rather than education. Their drive is happiness. Whether the child is happy or not is the most important. That's not wrong. But for the child to live, be able to read, write in English makes a huge difference (Kim).*

A professional participant also noted the importance and the significance of early education for children living with disabilities and criticised the lack of availability of such services in New Zealand.

*Someone said, there [are] no [recreation] clinics in New Zealand. I think it's strange too. When children are young, it's actually much helpful, because of the rapid development and things, they can benefit the most when they are young, so it's good to do a lot of things when they are young. That's called early education. In Korea it [is] well developed so you can just send children to centres and clinics. There are a lot of them... But in New Zealand, even if you want to do something for the child and educate them, but there is nowhere that provides such services (Jang).*

On the same note, a professional participant in Korea revealed a rather contrasting perception. She argued that the socially experienced reality of children in Korea is that they have no choice but to be educated and improve as they have no other support available.

*People say that Korean children living outside Korea improve less in terms of skills and things than children living in Korea. But they [children living in Korea] have to improve because it is the reality. Because the government doesn't provide anything, we have to try our best to make sure they can do things on their own and we can't say that children improve depending on their happiness. I think that's what is making such difference (Kwak).*

While participants in New Zealand expressed their concerns around the quality of education, participants in Korea communicated their apprehensions around present Korean law and policies around disabilities. Many participants have criticised the grading system in Korea. They argued that this system limits the use of services by people who are in need.

*In terms of disability allowance, there are people who are actually in need but can't get it. Because they only fund people living with disabilities who are at least grade 3 (Lim).*

*They shouldn't be graded from 1 to 5, but get services according to their needs, not according to their grades (Oem).*

Nevertheless, it is argued that such a system also creates dilemmas for individuals around further personal development and growth.

*Since they are young, after we try really hard and train them to talk, train them to eat and help them rehabilitate, and improve their cognition, so they can start to read a little and communicate what they need, their grades get better. And they get assessed by the grade. That gets me so angry sometimes. They are not meats at the butchery where you grade them. I wonder "are they doing this to them when they are only funding the minimum?" (Min).*

*To be honest, I often really wonder whether I should help them get better. Because even if we train them, disability allowance is only entitled to 2-3 graded people. People under that, can't get it. And because they can't even get support workers, so for the sake of the child, it might be better to just train them so they are at grade 2 so that they can get the allowance. I wonder if we really have to do it. If the system is no longer there in 10 years' time, then we will have to work hard (Joo).*

Participants in Korea also argue that the system is not functioning to support independence, rather it is discouraging independence and encouraging the population to be dependent on the welfare system. A parent participant who identified herself as a beneficiary shared her situation where she feels that the system is making her stay dependent on the welfare system. According to her statements, she is only making KRW100,000 (NZD125) more for working full time as a nurse's aide than just receiving an allowance without working. She noted that the welfare system in Korea is demotivating and discouraging people to be independent of benefits.

*Our welfare policy is not one that supports people to be out of welfare service, but one that makes beneficiaries... If in my case, people won't work just to make 100,000won (NZD125) ... So you settle like that. I'll just get little and live with little. I will just live with what's given. The policy doesn't allow people to have hopes and dreams. People will have the motivation if there is a "plus" side of it. You need to see positive changes to continue doing things but people won't work just to make 100,000won (NZD125) (Han).*

Another participant also criticised the welfare system in Korea:

*If you are poor and entitled to benefits, you would have been getting some funding and things. So if the parents die, the children may get things too. Because even if I die, I have no assets so my child would be entitled to what I was receiving. So people choose to be poor (You).*

Korea participants also identified lack of flexibility in service use as one of the critical systemic errors in Korea.

*They are making the available services to run like businesses. I don't think this is the right way to go. It's weird for it to be like business, it should be individualized services so that we can use the vouchers like gift vouchers. So that it could be used for any kind of cultural and leisure activities (Ga).*

Another mother also expressed her desire for individualised funding so that she can use the funds to best serve her child's needs. She also expressed her dissatisfaction around the system limiting the use of services only to the designated centres. She argued:

*I think this is a form of discrimination. Why do children living with disabilities have to only go to the centres? It should be given directly to me so that I can use it to help my child do things she wants. People's desires are diverse, right? (Soo).*

A professional made a comparison between the services and supports that were available in the past and criticised how the welfare system in Korea is retrogressing rather than progressing.

*I think Korean disability welfare is going backwards rather than improving and widening service system. We see the need for improvements but the budget for welfare is decreasing for people living with disabilities. There were a lot of different supports available before but it's all disappearing. I think it's getting less and the populations is getting out of sight.... Our country is well advanced financially but public perception and all are not at a developed country level (Lee).*



Participants in Korea argue that disability law and policies in Korea are at the highest level of development on paper, yet they lack in functionality. In particular, a number of participants criticised the lack of systemic support following the changes to ensure that such changes are actually taking effect and operating as intended.

*Our country is characterized to be impetuous. They tend to make things [policy and law] first in a hurry (Ham).*

*Development Disabilities Act was passed and the enforcement ordinance came into effect last year. Yet, there is no movement in the government and local government (Lim).*

Such a lack of systemic support and follow-up are also evident in the process of recent movements towards independent living. It is argued that children living in institutions are forced to move out of institutions into communities without any other sufficient alternative residential care provision in place.

*They are telling the institutions to cut down the numbers without any alternatives. And [when] parents search for residential facilities they say there is no room. Of course they will because they are told to not get any more people. They are asked to down the numbers to 30. But they have not prepared any other alternatives in the community either. It's funny that way. That's why parent shave their own heads<sup>3</sup> and ask what they need to do for their child and all (Kim).*

Participants argued that, as result of such a lack of follow-up and preparation of alternatives, parents are reluctant to move their children out of institutions to try an independent living

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<sup>3</sup> a symbolic gesture often used among demonstrators in Korea to show their strong resolution to attain their goals.

option as they fear that there is no alternative or a back-up plan if they fail to live independently. They fear that their children will have nowhere to go if the attempt to live independently fails; they experience a lack of support and eventually end up coming back to familial care.

*Parents don't move them out of institutions because they feel that their child may not be able to come back to institution once they leave, especially in the situation where the parents get sick and unable to care for the child. Institutions are making group homes these days, down scaling the size, but it's really hard to convince parents as if they want to try group home setting, they have to be discharged from institution[s]. Parents hate discharging their children from institutions. In case they can't come back... if the child fails to adapt, they might have to take them back home. They fear that their child will be asked to live independently and leave the service. At the end of the day, after they get discharged, the institutions only hold follow-up responsibilities (Min).*

A professional participant related that the Seoul Welfare Foundation is now supporting independent living and running trial homes. However, the foundation does not hold supervisory responsibility for the children and institutions are asked to take the role. Yet, she argued that there are limitations in the supports they can provide to the children as they are all discharged already to go into the trial homes. This then elevates the level of anxiety among parents as they lose a sense of belongingness, and fear for the loss of state-level support and governmental responsibility. According to the participant:

*The foundation's responsibility ends after allocating a support worker for the individual. But if a child gets involved in legal issues or medical issues, support workers can't solve the problem. And parents are fearful as they know that the institutions will not take responsibility. They want their child to live independently but they hate it. So, in 70-80% [of] case[s], even if the children living with disabilities want to leave and live independently, they can't because the carers don't want it (Hyun).*

Further, such concerns around lack of systemic support are articulated again in the enactment of the guardianship system.

*If I apply for a guardian at the Family Court, you get assigned a guardian. It could be a family member or, in many cases these days, it's the institution that the child stays in. Even in that case, it's not the person you know well who get[s] assigned but just any supporter at the institution. It's rather ironic. The person who is managing the money become[s] your guardian. You can't tell whether the child really wants something because they can't communicate. But in Korea, there is no managerial organization managing the guardians. And it surely needs to be there. It's only been 2-3 years since this system came in, so we need a managerial organization. And if this works well and become widely used, there must be an organization managing it (Joo).*

*In my case, although I will set up a guardian, I don't know who can actually look after the asset that my child will get from me. I can't trust the country so I will have to trust the guardian or my family. But there is nothing controlling or managing the guardian in Korea (Hwang).*

Such lack of systemic support around following up and operation are pushing parents to the frontline. As evident in the discussions throughout the chapter, parents are directly involved in many aspects of children's care and welfare. Following up the process of functionalization and ensuring the operation of law and policies concerning their child was evidently one of the most significant parts of such involvement among parents caring for children living with disabilities. This is further discussed in much greater detail later in the chapter, under 'Self-Service' section.

#### 4.3.2 Lack of a Database

The findings of the study show that New Zealand- and Korean-based parents were both experiencing difficulties around the lack of a database. However, the details around the types of database lacking differed in the two countries studied. It was evident through the interviews that parents from Korea were experiencing a lack of an overarching database of organisations which provide services for people living with disabilities, whereas New Zealand parents were experiencing a lack of databases around case studies to provide guidelines on how to support and raise children living with disabilities. Although the types of insufficient database differed, in both countries, it was reported that the lack of database was a significant influence on the future care provision plans for the parents caring for their children living with disabilities, as well as the general use of support services.

As discussed above, for parents living in New Zealand, having a lack of database material meant that they do not have enough cases to use as reference to provide guidelines around how care should be provided to the children living with disabilities, and what they need to do in the future care planning process. A participant also commented how the population size is too small in New Zealand to provide cases to make reference to. Others also reported:

*There is a lack of case studies. Yeah, because there are no such cases. So what kind of education can the school provide? They should be able to think “there is this type of children, so he or she should be approached this way, how could we educate such child?”, Right?... but then again we can only understand that because the population in New Zealand is so small. So there is no experience or cases, so they have nowhere to go and just end up going to whatever institution/organization [is] available (Kim).*

*There is no role model... I think it is very important to have [a] reference book, a source to refer to (Baek).*

Meanwhile, parents in Korea were experiencing significant difficulty and inconvenience due to the lack of a database when planning for children's future care provision. In Korea, experiences of lack of a database were mostly related to the lack of an overarching database of service providers. This meant that parents have to personally search for and contact each possible service provider for availability.

*There is nothing there. So people living with disabilities have to gather information from their personal relationship[s] and go to [the] labour market for the disabled. The problem is that, when you encounter a person with disabilities, there should be a system assessing what this person living with disabilities is capable of and find [a] doable job and type of job within the city. It may not be a control tower, but something.... There is something like this for people without disabilities, but there is no overarching database for people living with disabilities (Cho).*

This was also very closely linked with having no options to choose from.

*There is no "one-stop-service". We should be able to ask just one place and it should open and provide all services and supports available for the child, so that they can make choices. But this isn't happening now (Lee).*

*Once the person living with disability can longer be cared for at home using day-care centres or community welfare centres, all data around living options should be opened, and it should inform which living facility is most suitable for the child considering the child's level of disability, community she/he is based in, age and kind of disability (Choi).*

Another participant also commented:

*There should be a data[base] for people to have a look at and make choices to ensure and support the lives the person living with disabilities and their family members... they don't even know what is available for them. And so there are many cases where benefits they are entitled to just slip away. They have to search service by service. The closest information provider is the Community Centre (Park).*

However, although the Community Centre was mentioned to be the key information provider by a number of participants, an interviewee from one of the centres in Korea argued:

*There are too many institutions and too much information, so we can't make contacts to every single one of them. We just send an official document to the ward office and I heard that they find out and reply whether there is an opening or available space. If they get the reply they can get into a living facility otherwise they just have to wait (Lim).*

Such significant lack and absence of medium bridging service providers and users, and its impact on the future care planning for parents caring for children living with disabilities in Korea is discussed in much greater detail in the following section.

#### 4.3.3 Trust

As opposed to all the similarities discussed above between the two countries, there were significant differences in trust towards the overall disability system and services in different national contexts.

Parent participants from New Zealand expressed their trust in the overall welfare system and services.

*Although there are other countries where welfare for people living with disabilities is great, but the father of my child said New Zealand's welfare is good. You don't need to worry from birth to death. It's comforting... I think it's really comforting for parents to know that the government is at the back support[ing] you (Jang).*

Some parent participants expressed their trust towards New Zealand and its system while making comparisons with how life could have been more difficult if they stayed in Korea:

*I trust the system of this country a lot and I benefited a lot from it. These days, I imagine how miserable it would be if I lived in Korea. How well I would have raised my child in such a competitive and complex society. But this country, the way my child is perceived is with comfort and they have willingness to help (So).*

*If my child was in Korea, I would have been more worried about mistreatments, but this country protects my child. So, if I was to die before my child, no, it is the fact that I will die first. But if I was to die in an accident or something, I have no fear. I have a trust and understand what they mean by "from birth to death" (Hyun).*

Such trust towards the welfare system and services were also evident in regards to future care provision for their children living with disabilities.

*I trust this country. Trust... If I was to die right now as a result of an accident, I don't think my child would be neglected or anything. The system here, and the service*

*providers that my son belongs to, if some unfortunate thing was to happen suddenly, I trust that they will take actions (Lee).*

Further, a substantial number of participants in New Zealand have expressed their overwhelming satisfaction around the general and overall disability welfare system and services provided in New Zealand that are not necessarily linked with future care provision and the process around planning such provision. For instance, a parent participant from New Zealand expressed her overall satisfaction around the system and the availability of professionals. She noted:

*Being able to make good use of the service system in this country, and also that I was able to have many discussions with professionals... (Hong).*

Another parent participant expressed her satisfaction around availability and diversity of services that are funded, while making a comparison with services provided in Korea.

*Not having to pay to send my child to programs at least. It's still unimaginable in Korea. Still, the only thing that's starting to be available is the programs organized by community centres, and sending caregivers, even that's not guaranteed. So, if you just look at the level of welfare system here in New Zealand, it's heaven. That's one of the drives why I decided to come to this country (Kwan).*

A professional participant also complimented the quality of services provided in New Zealand, particularly around the person-centred provision of services.



*The service users of our organization are not merely being fed and living, but they all have their own personal plans. This includes aspiration, dreams, and gets quality review. The biggest focus of our organization is personal plans. This is unimaginably systematic and well organized system... it is incredible... the service system in New Zealand is operating very well (Go).*

Further, a high level of satisfaction towards the education, workshop and training opportunities were also identified by a number of New Zealand professional participants.

*I think "Disability Connect" is playing a big role, in my experience. They are running most of seminars, and it seems that they are thinking a lot about the cultural aspects as well (Koo).*

*Also, one of the things that strike me was, as you know well, there are many workshops available, right? For the parents, and if you have a family member living with disabilities, you can come and share your thoughts, and express and communicate your needs and wants to the service providers and things. What I felt through looking at these was that the services are organized very well (Soo).*

Although many of the comments made by the participants were not directly linked with future care planning, it was apparent that such overall satisfaction is an essential component of the strong trust towards the general system and services in New Zealand discussed earlier. In other words, the overall satisfaction with the general welfare system and service, together with the sense of having choices, and other positive experiences around public perception and treatment while caring for their child living with disabilities was evident to have created the fundamental platform for the strong trust towards the welfare system and services among the parents living in New Zealand.

A significant contrast was evident between the two countries studied in relation to satisfaction and trust towards the service system. While a considerable number of participants from New Zealand, both parents and professionals, expressed their satisfaction towards the quality of general system and service provision, and shared pleasing experiences parents had with the service providers, such satisfaction and experiences were not identified by the groups in Korea. In contrast to participants based in New Zealand, participants in Korea pervasively expressed to have no expectations nor trust in the system and services provided. There were also rather negative views regarding the situation from a number of participants.

*If I was to rate it out of 100, it [trust towards the system and the government] would be less than 20% (Lee).*

*It might be an overstatement to say we have no trust, but we almost have no trust. How could we have trust? It's receiving monthly pension under a system and that's about it.... Don't we regard our nation as a nation that takes away what we have, rather than expecting the nation to provide something for us? (Lee).*

Some participants made links between the low level of trust felt between the public and the system with economic capacity.

*I think the trust towards system, government will be around two out of 10. Because, if the parent passes away, the child has no source of income, unless they have other assets. These days, people who are really poor would have been continuously getting benefits from the government, but for people who have a bit of assets, they can't even get the very minimum financial support. They don't get to use what they have and die. So I don't trust this country, because this country provides nothing (Kim).*

The concept of 'Self-Service', which is discussed in great detail later in the section, was also apparent when having a discussion around trust towards the system and the nation.

*I don't think I have much trust. I need to somehow... I feel that I need to somehow make sure my child has ways to make living before I die (Jung).*

#### 4.3.4 Making a Choice Versus Having No Choice

As briefly mentioned in several different sections of the chapter, one of the most significant differences evident in the data between the two countries studied is around the perceived choices and options parents have regarding future care provision for their children living with disabilities.

From the data collected in New Zealand, a sense of 'having a choice' were evident around how their children's future care provision will be arranged.

*In this country, parents make the choices, whether they want to place them under a service providers' care or have them under their care at home. And changes can be made along the way. If I get sick and feel that she needs to go into a service she can, and we can also bring them back to our care. This provides freedom and I think it's great. I think this country is good in that respect (Lim).*

*While I am still alive and healthy, what people usually seem to do is to have them under a service during the week and bring them home over the weekend to have some family time. If that makes my children happy, I am going to choose to do the same, but if my*

*child seems happier staying at the residential service, I will let them stay there and maybe take days off when [I] wanted to go on holidays and so on (Jo).*

However, although the wider choice was perceived to be generally available, of those very few parent participants of the study and parents identified by professional participants as preparing and progressively planning for their child's future, only a small number of parents were seen to be actively involved in searching for the best care provision options for their children living with disabilities. Yet, although the number is small, these parents were identified to be actively comparing the living options of Community residential care (that is, group homes), Supported Living, and Choice in Community Living to select the most suitable option for their child. They were attending seminars and workshops regarding living options and making visits to the actual service sites to see if the service would be appropriate for their child:

*It's about what provider you get. There are three major providers in this country, Idea, Spectrum Care and one in west that I can't remember the name of. And there are small providers. The small providers are similar to Korea's sliver town, or rest home. I have been there to see how it is already (Kim).*

Such a sense of having choices was also evident through the comments professionals in New Zealand made around what parents should do when planning for their children's future care provision. These professionals often made statements about the need for parents to actively search and engage with different service providers to be able to select the most appropriate care provider for their child, which shows how parents living in New Zealand have a range of different service providers they can make choices from.

*It's not easy to find a service provider that fits the children's needs. It is hard to say what is an ideal model of service. So they must try everything according to their needs. I think this is the most practical way (Joen).*

*It's hard to say which provider is good or bad, because every individual's level, medical conditions are different. Every child's personality, condition and family environment are all different. So I hope they make choices from them. If they want to try IF (Individualized Funding), and use that to go to classes, they need to know what to do and who to meet. Try the classes and if it doesn't fit, try using different services. Parents need to discuss with case workers or other[s] to find the optimum environment, I think that should be the way to go about. Because everyone's situation is different (Shim).*

*To make visits to the sites, and find out what is available. Then visits [to] another site and visit different day programs. Keep visiting different services. Go check for yourself. See how it is run with your own eyes. Meet the staff (Kwon).*

On the other hand, as evident in the other sections throughout the chapter, Korea-based participants often communicated 'having no choice', which was often linked very closely with the economic capacity of the parents and low levels of planning. A sense of powerlessness and a lack of an alternative leading to unfortunate situations were frequently evident among participants in Korea regarding planning for future care provision for their children living with disabilities.

*There has to be some kind of system for parents to make a choice and prepare.... In fact, parents' preparation is about having a number of services and choosing one that best services their situation and then preparing.... But there is only a limited range of choices here. So when talking about what parents must consider, it's just hopeless (Han).*

*There is absolutely no place where I can entrust my child with comfort. But then I can't do anything about it (Shim).*

Further, as discussed previously, some children whose parents could not provide care as they had to continue with their economic activities to make a living, were placed in institutions as they did not have any alternatives. Nevertheless, some professional participants shared very extreme cases where their clients were thinking about family members committing suicide together as an alternative.

#### 4.3.5 Lack of Professionals

One of the principal differences in service systems between the two countries was the bridging role between service users and providers, as well as between the society and the population group. The data collected in Korea revealed an absence of medium bridging service providers and users. In contrast, service coordinators and referral services between a wide range of disability organisations are available in New Zealand to support direct contact with possible service providers. Also, as discussed earlier, the organisations in New Zealand are also observed to be more actively involved in providing education and training for parents. For instance, a professional participant in New Zealand noted:

*Things need to start from transition services. Usually, in the last year of schooling, transition coordination begins. From my understanding, it is supported by the Ministry of Social Development. From then, for a year the transition coordinator provides and supports the child for smooth transition. The school [refers] them and the child gets referral to a transition coordinator and they get funded for a year. The schools have such programme for the child's transition. The school provides the service for community integration. For example, they support the child to go to the community library, to go to a café and order food, get on the bus and so on. Some schools have contracted coordinators at the school, some get contracted by support organizations. They support*

*the parents, have meetings and coordinate and support the child's employment, housing and things that needs to be in place for independent living (Pyo).*

The experiences of participants in Korea regarding the absence of medium bridging service providers and users are very closely linked with the concept of 'Self-Service', which is discussed in further detail in the following section. As there is absence of organisations or service providers to enable direct contact between the service users and providers, when planning for children's future care provision, parents experience significant difficulty and inconvenience as they have to personally search and contact each possible service provider. Participants in the study noted:

*The most difficult thing for the parents when planning for future care provision is that they have to do everything personally. They have to search for information themselves (Koo).*

*One by one... for example, if someone says respite care is good, and they think they should look into it. Then they make calls to all respite centres in the country that [are] nearby to check for availability. I want there to be a caseworker who can assess their family environment after making visits, assess the level of disability and connect services, find out what supports are available and what might be the most appropriate support for them. There needs to be people who are doing this. But there is no such system (Do).*

It was evident that this lack of bridging had a negative impact on how professionals are perceived in Korea:

*People working at the community welfare centres only have as much information as I have. You can find enough information on [the] internet. But if you are working at a*

*community Welfare centre and your role is liaising service users with appropriate services, you should have much more information. But that's not the case. Also, the community service centre, there is no professional there. There is nothing organized or arranged (Kwan).*

*When parents make calls to the community service centres or the ward office, the social work departments there lack in professionalism. Because the rotation of their role circulates too fast. So they lack in professionalism, and mothers often find it frustrating. So, because they find working with social workers at the community service centre frustrating, they start doing it themselves, directly making calls here and there (Kuem).*

However, a comment made by a social work professional participant from the present study who is working at the community service centre was not much different from the experiences noted by other participants, but rather supported the argument of lack of bridging:

*If they submit the application, we send it off to [the] ward office and they sort it from there. You can apply here [community service centre]. But there are too many institutions that we can't make contacts to every single one (So).*

Social workers' professionalism is not only questioned for its lack of involvement as agents for bridging between service users and providers, but also for absences in the role linking the society and the population group. Social workers in Korea at this stage are further criticised as being overly focused in day-to-day support work. Professional participants of this study argued that social workers must lead social and system changes as social activists together with service users.



*When people living with disabilities protest on wheelchairs, it's always only them [people living with disabilities on wheelchairs]. People who have to be involved and working together are social workers. Social workers should be involved in the protest activities as well... Although social workers are working for the nation and getting paid by the country, social workers have their role in the middle. But they back out from these roles. Social workers should be working as a bridge, but we are languished in a care role. We don't try to get involved in system changes (Lee).*

*We often talk about professionalism in social work. But it seems that social workers lack in perceiving themselves as professionals as social experts, or having expertise around empowerment or human rights or social justice (Jin).*

On the other hand, social workers in the field have expressed that there are a lot of difficulties in carrying out their roles as a social work professionals in Korea due to staffing issues, diversity of service needs, and the nature of organisations.

*There are issues around staffing. [They] diverse support needs, but we have only one person working in disabilities department in this community service centre. From my knowledge we have around 600-700 people living with disabilities in our community. For one person to care and manage all these people, when I was working in the department I was busy enough dealing with people who walk in to the office. There is no room for me to search for people in possible needs in my hand (So).*

*Social workers working in institutions are in the position where they are to do whatever is asked by the district office (Jo).*

Other field workers have suggested parents' active involvement in systemic changes to overcome such limitations:

*Parents shouldn't be timid just because they are parents of children living with disabilities. They must speak out loud. As social workers in an organization, we can only do what we are told to do. Parents should get involved and make their voices heard to make changes in the conditions of institution and things. If parents can't prepare for their children's future care provision, the society will have no choice but to take responsibility. So in order for the country to make such [an] environment, I think the parents and the children are in the position to talk about it (Han).*

This is a contradictory point made from previously discussed professionals who argued that social workers should stop taking the role of day-to-day support workers and must lead social and system changes as social activists together with service users. Such contradiction then leaves questions around where social work as a profession stands in Korean society.

Nevertheless, a small number of parents are, in fact, actively involved in activism to countermeasure the lack of bridging and lack of professionals. In fact, parents in Korea are reported to be actively involved in making proposals to change policies and system, networking with people involved to enforce such changes, and protesting to ensure welfare security for their children living with disabilities.

#### 4.4 Conclusion

To conclude, participants have communicated that many parents from both countries recognise the need for future care planning, and expressed their persistent concerns regarding the issue, yet lacked concrete plans and substantive practice. Most had either no, or only very vague, plans, and few were identified to be progressively preparing for the future at home.

Having them under familial care and establishing a private living facility, or owning and running a small-scale business were some of the alternative plans and options shared by other participants.

Participants in both countries have unanimously identified lack of information, settling for the status quo and emotional distress as some of the key reasons behind the low level of future care planning. Public perception, having no choice and the economic capacity of the parents were identified as some of the other key reasons for lack of planning among participants in Korea, whereas cultural and language barriers were evident to be one of the most significant reasons for such lack of involvement in the planning processes among parents living in New Zealand.

There were a number of systemic differences and similarities regarding future care planning among Koreans in different national contexts. Participants in both New Zealand and Korea have identified a number of systemic problems and were evident to be experiencing difficulties around lack of a database. However, participants in the two countries studied showed significant differences in trust towards overall disability system and services, as well as the perceived choices and options parents have regarding future care provision for their children living with disabilities. Participants in Korea criticised the absence of medium bridging service providers and users, as well as bridging between the society and the population group.

It was also discovered that disability service systems in Korea are experienced as a 'self-service'. In other words, participants of the study living in Korea perceived the Korean welfare system for children living with disabilities as a system where parents have to actively and directly seek and secure service provision for their children living with disabilities. In contrast, a number of participants from New Zealand have expressed their satisfaction with the general system and service provision, yet, were clearly faced with difficulties around understanding

the service systems of the host country, as well as lack of culturally appropriate services and provision of information for Koreans living in New Zealand.

## **CHAPTER 5 Findings (Part 2)**

The discussion moves now to the findings around aspects to consider when planning for future care provision, needs, and self-service. The theme ‘Self-Service’ was one of the most significant themes to emerge through the analysis and is discussed throughout this and the previous chapter, rather than being treated as a separate category. This theme is, however, revisited under a separate major section here, gathering all the relevant data, to highlight its significance and implications on future care planning process among Korea based parents caring for children living with disabilities. As in the previous chapter, a number of sub-themes are identified and there are some overlaps between the sections and the previous chapter. Verbatim quotations are used to illustrate the main points.

### **5.1 Aspects to Consider When Planning for Future Care Provision**

There were a number of identified aspects parents take into consideration when planning for future care provision for their children living with disabilities, which often reflected the socially experienced reality of future care planning in the countries studied. Note that the issues identified here are linked with those discussed in the previous section and that there is a comparatively strong crossover between the two. However, while this section may seem rather similar to the section discussing the identified reasons behind lack of planning, what makes this section distinct from the previous section is that, while the previous section discusses the factors that are impeding the actual planning process itself, this section identifies the needs of the parents, and the worries and the desires these parents have for their children’s future welfare, and the services that must be in place for future care planning to take its place as an anticipated part of the caring process.

The findings show that there are both differences and similarities in the aspects they consider depending on the country they are based in. Parent participants from both countries studied have disclosed that they are seriously concerned about the child's ability to live independently and their social adaptation. They also expressed security over the basic standard of living as one of the aspects they consider the most when planning for the future care provision. Parents who had formerly experienced and gone through a similar journey, often referred as 'senior parents' by the participants of the study, were often identified as one of the most valuable and helpful supporters and resources, therefore the experiences and advice from the senior parents were considered significantly, regardless of their country context. Furthermore, one of the biggest concerns for parents in both countries appeared to be on post-school-age care provision. If country-exclusive aspects are taken into consideration, economic capacity has been emphasised by Korean participants once again, while participants in New Zealand repeatedly emphasised cultural barriers as one of the most predominant aspects to consider when planning for future care.

#### 5.1.1 Child's Ability to Live Independently and Social Adaptation

While the reasons behind a lack of planning had greater focus on service provision and availability, the principal emphasis of the discussion around the major aspects parents consider in the planning process was placed on the child. Participants from both countries have commonly articulated the child's ability to live independently and social adaptation as the most important aspects to consider in the process of planning for future care provision. However, there was a clear difference between the parent and professional groups around the specific areas they placed emphasis on concerning the adaptation of the children. Parent participants, from both Korea and New Zealand, were found to have a great level of apprehension around the details of adaptation related to separation, unexpected behaviours that might occur in the process of adapting to a new care environment after leaving familial care, as well as the ability to adapt to a communal living environment. On the other hand, professionals, again both from Korea and New Zealand, articulated the correlations between the starting time of the adaptation process and its effectiveness.

According to parent participants based in Korea:

*My child likes his mum too much still. So in the separation process, I am concerned if my child can adapt well, and get along with others without looking for his mother (Lim).*

*Adaptation. Adaptation to society is one of the aspect[s] I consider the most. I think my daughter can manage it once she acquires some practical skills (Kim).*

Parent participants from New Zealand also shared their concerns around independent living and social adaptation. Some perceived adaptation and leaving familial care as a gradual process which requires some level of responsibility, support and care from the parents in the process. Such perception was particularly articulated by a very small number of parents who identified themselves to be progressively preparing for the future of their child by training skills that are necessary for out-of-home life, including skills needed for independent living and social adaptation.

A mother shared her experiences around the process and expressed her concerns about her daughter leaving familial care as her daughter feels discomfort around staying away from the family home. Her daughter had never experienced spending a night somewhere other than familial home and the mother had never left her sight. However, she stated that she sees the need to train her daughter and is gradually exposing her daughter to the idea of living out of mum's care. She noted:

*I thought we must train her in that first. Even I need to prepare my mind-set, and she needs it too. So I talk a lot about independent living with my child these days. I tell her "when mum is not around, you have to stay alone". Because they have intellectual*

*disability, it's not easy for them to accept that. So they get anxious when we talk about it repeatedly, so it's very difficult. It's about adaptation. We lived in a big family, so staying alone for her seems very hard... I don't think it's the best option but we are just giving it [residential care] a go. Because she needs independence. Then, if she can't adapt, she can come back home (Go).*

Another mother who is included in the very small pool of parents who are identified to be progressively planning and preparing for the future care provision of their children stated:

*My son, squirms. Every child reacts differently, and some just adapt. But my son squirms and struggles. So I am going to take it slow. To help him adapt (Ji).*

Professional participants in New Zealand have also emphasised that the process of adaptation has to start in the early stages of the children's lives.

*If you look at things from the children living with disabilities side, if you go into residential care when you are old aged, they themselves have difficulty adapting and feel distanced at first, because they have not lived in communal settings for a long period of time. If you go into residential care when you are younger the adaptation process is a bit faster, but the older you get, there are cases where it is a bit more slower and difficult (Cho).*

*If you are considering independent living when the child turns an adult, it's too late. It is challenging for both [the child and carer]. You have to engage them in different group setting when they are young (Kang).*



*For these children, the longer you keep them under your care, the harder it gets. So in our centre, we go on camps and things for 2 to 3 nights. This seems to be training them, consciously or not, if they keep doing it from young age (Lee).*

The same emphases were made in the professional participant group from Korea:

*Once they become an adult, if they were raised where the parents pamper them, they can't leave that behind. They ask for and whines for everything. But people who have started living in institutions earlier, they [have] experienced communal living. So they know they need to live together with others, so they don't just make argument from their point. They are less stubborn. So if they can't live under the family house and get familial care, they should be, even if it's not an institution, able to live a communal life before they become an adult (Shim).*

#### 5.1.2 Safety and Standard of Care Provision

Safety and the standard of provided care were aspects identified by participants from all groups as the most significant aspects to consider when planning future care provision for their children living with disabilities.

*I think the biggest consideration for parents when planning for future care provision is safety of their children (Do).*

*The first request parents have when putting their kid under residential care is that they want their child to be healthy and stay well. That's number one (Oh).*

Such concerns around basic standard of living do not only include food, clothing, and housing, but also include health care and medical treatment.

*There is nothing else. Taking my child to a hospital when he is ill, quickly. So that he is not in pain (Kang).*

*I think it is possible for our kids to not get medically treated at [the] appropriate time because they can't express their pain. And I thought, people living without disabilities get annual medical check-up provided by the government, I want that kind of services to be available for our children. To be able to get medical services... (You).*

#### 5.1.2.1 Daily Activities/Quality of Life/Happiness

Quality of life, continuation of daily activities and children's happiness were identified to be some of the major considerations parents take into account while planning for children's future care provision among participants from both New Zealand and Korea. However, it was much more frequently discussed among the participants from New Zealand, and only a very few participants residing in Korea discussed it as an important matter to consider when planning for future care provision for their children living with disabilities.

Ability to continue regular everyday-life routine was also highlighted frequently by the participants from both Korea and New Zealand. These participants noted that parents have expressed that they have immense concerns about the availability of continual leisure activities and activities related to the child's hobbies when planning for future care provision.

Participants in New Zealand expressed:

*They need exercise. But if he goes into a residential care, he won't be able to go for walks, because one support worker can't care for five people by her/himself. So they can't make to most of what he can do or his hobbies. He can't meet people he knows or his friends. This just can't happen. Although New Zealand is operating residential homes, there are a lot of problems with the policy. So there were a lot of voices around the need for children to live as an individual, and need to help them to do "independent living" (Jo).*

*It seems that parents want their children to go out for walks, go swimming and enjoy these things in their lives, instead of just staying home (Lee).*

A parent participant in Korea also stated:

*The most important thing about independent living is daytime activities. Instead of doing it as a group... To be honest, people living without disabilities, they spend their time learning, meeting friends, watch movies and stuff right? It would be nice for people living with disabilities to learn and have opportunities for self-development, spend their spare time, stay home and rest... instead of going to centres all the time, do thing[s] individualistically according to their personal traits... (Woo).*

Further, it was evident that significant consideration around children's happiness was taken into account in future care planning process among Korean parents in New Zealand.

*I am not fussy. I just want my child to be happy. It's about being happy, because if he is not happy that means he's not being allowed to do things he wants to (Jin).*

*Important things to consider are... I think all mothers are similar. We want them [children] to be happy (Park).*

*The most important thing for my child is to live happily, until the last day of her life (Baek).*

A mother also commented and shared her desires for her child's continuous involvement in a specific activity related to the child's happiness.

*For my children to be able to show his art works to other people once a year or to have an exhibition at least every 3 years to make him happy. I should put that as an option (Kim).*

One mother from Korea, while highlighting the importance of her child's happiness, expressed her hopes for her child to live as a contributing member of society, and for the child's dignity to be upheld and advocated for.

*If I just look at my child, I hope there is an organization that will uphold and advocate for my child's dignity. The aim of our life is to be happy every day. This happiness should be blocked once they leave the care of their mothers. I want my child to live happily, with plans, while being accepted as a member of a society who is needed (Ham).*

On the other hand, there was a professional participant from Korea who shared a sceptical opinion regarding happiness being one of the major aspects to be taken into consideration when planning for future care. She noted:

*There is really nothing I can say. You talk about the future, but it's about where they can live that comes first, and I don't think we can discuss ... their happiness. If I was to say, if they were to go into institutions maybe you can talk about whether they would be happy, but if it's about leaving the care to live independently, happiness is one thing, but you need to consider safety and so many others things, and because of it, the things you should be cautious of increases (Kwan).*

For New Zealand participants, selecting a service provider that will enrich children's quality of life was discussed as an important aspect to consider.

*The care of the service my child is using at the moment is very good. Although I have to spend a bit of money, around \$20. They come out of the community, go to gyms to exercise, go grocery shopping once a week and cook together, and go bowling and things. This is fun, right? So, it would be nice for her to go to a group-home where they provide such service (Kwak).*

### 5.1.3 Experiences and Advice from Peer and Senior Parents

Many participants, regardless of their country context, identified other senior parents who have experienced similar journeys as one of the most valuable and helpful supporters and resources. Hence, the experiences and advice from the senior parents were considered significant, both in general caregiving, as well as in future care provision planning.

A number of parents identified senior parents as their guides, reference books or role models.

*Senior, especially. You don't need to listen to any other people. Seniors who have done it already. They are the best role model. And say, if I have 2-3 year[s] left till I need to make [a] choice, then parents who are about 2-3 year[s] ahead of me, who are preparing now. If you chose them as a model, that you will get the best sources (Ga).*

*I know what to prepare, because I have a source. I have a reference book. I think that is really important. You need to be sensible to look around and find parents who had done it before me. And don't hesitate to ask (Jo).*

Others also indicated that the senior parents' advice and support were meaningfully valuable and had a huge influence on their journey of caring for children living with disabilities.

*Parents' ability to gather information... [advice] from parents who have already raised their child living with disabilities is significant. What the senior parents tell me has a significant impact on me. The kinds of advice senior can provide. Senior parents have a lot. Senior parents are the biggest treasures at this moment (Jin).*

*Senior parents helped us to think about difficulties we may encounter, and what we might need and think about. They were really helpful (Han).*

Moreover, some were identified to be motivated by senior parents. For instance, a mother of a child living with developmental disabilities noted:

*We get motivated by other parents' stories. And then it followed and got motivated from what we heard from the senior parents. Why? Because we haven't experienced it before. We thought it was easy to get a job, we didn't know. But the senior parents have [previous experience] (Kang).*

Such support from seniors was also evident amongst children living with disabilities themselves. A professional participant shared an example she knew of where a child living with disabilities was relying on another senior person living with disabilities. It also appeared that when children go into communities for independent living, professionals try to pair them up with their senior members who are considered to be doing well in the community, to create a reference point for them.

*We try really hard to match them up with seniors who are living well after going into the community. I tend to introduce them to the ones who are doing well (Park).*

Other parents have identified peer-parents as one of the most significant source of support and resources:

*The most helpful people are obviously us, mothers. The information we share among mothers are really good. Mothers' information. What I am referring to now is unofficial information. The information we get from unofficial routes (Hwang).*

Professionals also appeared to have observed such connections and networks between parents where information gets circulated amongst parents in the community. A professional participant from a community service centre shared:

*When parents make complaints I sense that there is some kind of network amongst just the mothers. I think there is an exchange between the mothers. Because when they come to apply for a service, like I said before the diversity of services available is huge, there are services that I have never processed before. But they seem to know it all and say that they heard it from the other mothers. There are cases where I then search for it and check with the ward office. I think there is some kind of network between the mothers (Jeong).*

#### 5.1.4 After School Age

One of the biggest concerns for parents, living in both Korea and New Zealand, caring for children living with disabilities appeared to be around post-school-age care provision.

As discussed earlier, the issues related to lack of information are revealed to become even more problematic once the child enters adulthood or completes their school years. For both country contexts, it was indicated to be highly likely that channels for possible information exchange get cut off once the child graduates from school and no longer falls under the responsibility of school system. From a number of examples participants shared, this then led to parents experiencing the future care planning process as an individual problem which needed to be resolved on a very personal level.

A parent participant from New Zealand stated:



*Once my child graduated from school, she [had] no point of contact. So it was hard to get information. Especially when you are still at school, information continues to flow, but once school end[s] and if you are in my situation, unless I go searching and get involved, it doesn't happen for my child. Unless the parents diligently get involved in searching and [try] to listen, it's is hard to get information, and there are a lot of limits (Go).*

Professional participants from Korea also commented on the lack of opportunities for information exchange and collective initiatives to make changes.

*Among parents of school aged children or parents who belongs to the parents' society, they form a solidarity and information gets exchanged really quickly. And if there is an issue, parents get together and do something about it. But after school age, once the child enter[s] adulthood, it is hard for parents to rally around, hence there is no information exchange or anything in particular, and they lose [a] sense of unity (Ham).*

He continued and expressed his concerns around caring and planning becoming an individual problem after school years, as well as lack of appropriate opportunities for parents to network with others:

*So they worry about things on their own at the moment. Although the community centres and parents within certain communities do things like seminars and get together to discuss how to do things, but that that's only [a] minority who [get] that service. Overall, there are no special alternative[s] (Ham).*

Another participant stated that it would be beneficial for parents to start planning for their child's future care provision while the child is still at school as parents have more informational strength and financial means to undertake the process while their children are still under the care of the school system. He stated:

*If they get educated when the children are still under school, I think it would be much more helpful to plan for the future. After school years, parents become individuals, and it gets harder to gather information, so they have more opportunities to get together and focus before they finish school. So I think it would be better to start planning while the child is still at school (Kang).*

Participants from both New Zealand and Korea emphasised parental education and peer networking as ways to tackle this issue, which is discussed in further detail later in the chapter.

*Although, the focus is on school age in terms of education at the moment, parents need such education. So, in conclusion of what I am saying is that it would be good for parents of school aged children to get education about life-long issues (Ham).*

Professional and parent participants from both countries expressed their immense concerns around support and service quality and availability for children living with disabilities once they enter adulthood or graduate from school.

According to a parent participant in Korea:

*At least for now, my child belongs to her school. The special education teacher at her school is very passionate. She tries to get children employed and gives [advice] so that they can do things they can. So that once school finished, they don't just stay home and get cared for, but go out and work. She takes them to different working places. But this won't be available once school age is over. That's when things get precipitous. I think this year, while my child is still in the school, is the time to prepare as much and all that (Im).*

A parent participant from New Zealand expressed her concerns around availability of professionals once the children reach adulthood:

*In terms of having meetings with paediatricians, until the child is 18 years of age I can meet them several times a year according to my needs. And it is mandatory to meet them at least once a year, but once they become an "adult", it become way too hard to meet them when I make a choice. Once your child becomes an adult, there aren't many psychiatrists here. I can't meet them unless there is an issue (Kim).*

Professional participants in Korea also expressed their concerns around service availability after the school years' end. They often criticised the lack of available services for children living with disabilities after school age.

*Most of [the] children with developmental disabilities, after they graduate they go to several community welfare centres for years, and that's it. Even the centres don't have the system[s] to connect them along the way to individual living support. So they spend [two] years in one centre, the next two in the other centre, and kill time like that. And once they have nowhere else to go, they just end up going home... the more I talk the more depressing it gets. It really seems that there isn't anything (Hyun).*

*There is no other way. At least when [a] child goes to school, high school, school age, you can send them to school or special school or places like this, but once school age is over, except for the 1% who can get employed, 99% have nowhere to go. That's what parents struggle with the most. There are cases where children get admitted to institutions, but in Korea that's only 5-7%. So in the end 94% have nowhere to go. So there is nothing to prepare (Jang).*

*So, in terms of education programs and things, there is nothing available after school, in fact. It's just blank because there is nothing happening after that. I was surprised too... There is lack of life-long programs including simple education, vocational education or other [education] (Joen).*

A professional participant in Korea also criticised that once the children graduate from school, everything becomes dependent on the child and their family's ability to support themselves and gather information.

*The system is such that it only supports them up to school age then it all depends on the individual's ability, parents' ability to gather information and economic capacity. There is nothing supporting it at the back (Han).*

The desire and need for continuation of education and training for children after their school age was also expressed by a mother living in New Zealand. She stated that the senior curriculum provided at the school, in preparation for living under residential care setting, helped her child become more independent. However, once her child graduated from school and started staying home, she observed a loss of independence in her child. She also stated that realistically it is hard to provide such training at home, and expressed her desire for it to be extended and to be continuously provided for children beyond their school age.

Professionals in both Korea and New Zealand expressed their concerns around the panic and shock that are often experienced by the parents at the out-of-home transition stage, especially because most Korean parents, in general, do not transit their children to residential care services from familial care straight after they graduate from schools. This may be because, in contrast to many Western countries where when children turn 18 years of age they are seen as adults and it is common for them to leave the family home. In Korea, most people living with or without disabilities do not leave the familial home until they get married and form a family themselves.

*Sometime[s] parents try to place their children under residential care after having their child under their care for a while. And they make application and they don't meet the criteria. They get shocked. There is no funding so they just continually have them under their care. They only find out when they apply. These cases are evident time to time these days. They don't really think about residential care straight after their child graduate[s] (Byun).*

*At this stage, parents in Korea are starting to think about what they really need to do after school age. They panic. And they stay in the thought of "it would be nice to at least have a place they can go everyday". Because it's too difficult to think about the future for these children living with disabilities (Na).*

She continued and articulated the need for parents to engage in the transition process while they are still under the care of school system.

*During school age, that's when parents at least have some [drive] and motivation to get together and do something. So if they start then, maybe the transition process can happen in a connected manner from graduation to adulthood. Otherwise, if they try to do it once they are already in adulthood, parents are already too exhausted (Na).*

### 5.1.5 Economic Capacity

Among the Korea-based participants, economic capacity was articulated again to be an aspect where most consideration is required in the planning process. However, in contrast to reasons behind the lack of planning where economic capacity of parents was argued to be significant, economic capacity and the ability to carry out financial activities for children living with disabilities were communicated as having a substantial impact on the process of planning. In other words, a significant amount of consideration is made around whether their child living with disabilities can generate income or not, and whether they can participate in financial activities or not when the parents are no longer available to provide care.

When asked about aspects parents consider the most when they think about future care provision for their child living with disabilities, parent participants in Korea stated:

*Everything is indefinite. To be honest, although under [the] Korea Employment Promotion Agency for the Disabled policy, [they] are pushing companies to employ people living with disabilities, it doesn't really apply to intellectual disabilities. I guess it's because there are risks.... If my child was to get employment under the policy, he could make very minimum wage. Living is training for him, so if I was to be next to him for just few years, maybe even when I am gone, he may be able to [carry on]. I think about these but there is nothing I can actually educate in detail or do anything (Na).*

*I think children should at least be able to make minimum wage. Whether it be parents preparing for it, or they get employed, or get benefits from the government, or have a wealthy grandfather. Otherwise everything is too difficult. Or you have to be very poor so that you get the very minimum support from the government (Kwak).*

She also articulated the importance of continuing income activity, as it is not only a means to make a living, but also one of the avenues for social participation:

*Maybe the aim is different, but the main significance is in participating in the society, despite how much you are earning, is the important thing (Kwak).*

The economic capacity of the child was also articulated by professional participants in Korea as an aspect a significant amount of consideration is required in the planning process.

*The aspect they have to consider would be around finance. A person must be economically independent whether they are living with disabilities or not. If they are not economically independent, in reality there is nothing we can do, including things like quality of life (Ham).*

*If the disability is mild, it's okay. But if it's severe, it is difficult for them to carry out income activities... even if you are eligible for disability allowance, it's not a lot. The maximum you can get is around W200,000 (equivalent to approx. NZD250). But, honestly, you can't make living out of it... So it could be around income (Jin).*

Another professional also noted:

*In Korea, there is [a] Family Support Obligation Rule, so it's hard to be beneficiaries, and it's hard for people living with disabilities to get a job. And even if they get a job,*

*the wage is very small. So it's not really income activity or employment, but rather a place to spend their daytime, so the financial burden is huge (You).*

Further, as discussed previously, a small number of parents were directly involved in creating job opportunities for their child living with disabilities to enable and secure the child's income activity in the future. Initiating a small-scale business with other parents or purchasing a small shopping arcade in the community were some of the examples shared among participants in Korea. However, this was only an option for financially wealthy families.

On the other hand, the economic capacity of the children did not appear to be a great concern among parents caring for children living with disabilities in New Zealand. Rather, it was evident that the parents in New Zealand were provided with and expected a degree of state-level financial support in the care provision for their children living with disabilities. For instance, a New Zealand-based Korean mother stated:

*In terms of money, the state agency called Work and Income New Zealand is providing some financial aid for my son. Also, my son is funded with the Sickness benefit. He receives about NZD209 under the Sickness benefit category. It does not go up or down. So, even if I am no longer here to provide care for him, I think he can live his own life (Ham).*

A Korean professional participant in New Zealand also commented:

*In New Zealand, there [is] certain financial funding available depending on the level of the child's needs. You know the systems, right? So they get pocket money and all, which is enough for the children make [a] living (Suh).*



## 5.2 Needs

There were a number of needs identified by the participants in the present study. Regardless of the country participants were based in, they articulated the need for the carers' openness and active involvement in the communities. The need for education, training and workshops were also mentioned by participants regardless of country context. Nevertheless, the importance of, and the need for, parents' recognition of the significance of future planning, as well as the need for culturally appropriate services were argued exclusively by the participants in New Zealand.

### 5.2.1 Community Involvement

Participants, regardless of country context, have articulated the need for parents caring for children living with disabilities to be more open about sharing their experiences and to be actively engaged in communities. The need for such involvement and engagement was often interconnected with increases in information exchange and possibilities of better service provision and support, as well as providing opportunities for their child to live inclusively within the community.

Parent participants in New Zealand shared their experiences and highlighted the need for parents to actively network with people in the community, to communicate, and to be open about their experiences and situation.

*In the process you should not hide yourself and, in fact, things people need come to people who are proactive. I really want to let people know of this. This is an important*

*point. I did it because I needed to survive in New Zealand while thinking about financial issues, caring and all, I had no choice but to be open at the end. I needed to be open so that people ... can help. And if I didn't know things, I asked a lot of questions. If I don't know something, I went to the school. Asked for help. And there are people who are willing to help... I networked with teachers. So if I needed, under consent, they contacted others as a bridging role. I think this is what is really needed (Lee).*

*When I try to solve a problem, I open my thoughts to others and share [them]. Then it actually becomes a training for me. So, if you try to listen a lot [to] other older children, senior parents, and try to understand the system [from when] the child is young, if something unexpected happens like it did to us, we have [the] strength to embrace it. It would have been much more difficult otherwise (Hong).*

Another parent participant in New Zealand also shared that she is making efforts to encourage other parents to be actively involved in building networks with relevant people in the community.

*I tend to find support workers quite easily, but there are parents who are struggling every day. Then I tell them "go out and meet some people". But mothers tend to avoid it, meeting people (Go).*

Professional participants in New Zealand also stated that for parents to be more informed, they need to be engaged in communities.

*Family members tend to unite together tightly, but then they won't have enough information. So, because they do not have enough information, they face limits around education, and it becomes a vicious circle... So we need to try to loosen that connection,*

*and really pay attention to help them to be engaged in community much more in comparison. Because, within the community there are service and information, right? especially in the mainstream Kiwi community (Im).*

Further, as discussed briefly earlier, many participants identified other senior parents who had experience similar paths as some of the most valuable and helpful supporters. Hence, forming and strengthening peer-support and networks were other significant reasons for supporting community involvement.

Parent participants from both countries noted:

*My child still goes to school and Korean community support and service for children living with disabilities provides a lot of opportunities for us to meet other mothers, so I tend to have a lot of information. But for people who are like us, families supporting each other becomes a huge strength. You can hear about other people's stories, and get information. So I think, even in [the] Kiwi community, people who are believed to be more informed, parents meet up and things. It's very significant. From my knowledge, there are many peer-support groups in Korea. That helps a lot (Noh).*

*What parents really want is a support-circle. Not one layer, but two, three layers of support. To provide support in layers. I decided, this time, I should not only do it amongst us, but also revitalize the surroundings (Do).*

A professional participant in Korea articulated the limits professionals have in understanding parents and highlighted the value of peer-support and networking between the parents.

*Even if we try to understand parents from [a] professional perspective, we cannot fully 100% understand them. It's not something that had happened to us. We try to understand, and sometimes I pretend like I do even when I didn't but, to be honest, mothers are different. They feel the pain and that's why they become seniors to the others, and I think the conversations they have amongst themselves are the best, and needed the most (Choi).*

Another professional participant in Korea, while criticising the lack of systemic involvement in such a process, also articulated the need for parents to create opportunities to gather, share and support each other.

*There are systemic problems, but I want to still make a claim that parents need to continuously be involved in education and also they need to create a space for them to get together and talk about what needs to happen and make changes. But always it's only a few people who come together. That's a pity (Hwang).*

Moreover, the importance of engaging and exposing children living with disabilities to communities in the early stages of their lives was highlighted by a professional participant in New Zealand.

*From the time when the child is small, they need to be engaged in community programs or school programs. They need to continuously expose the child to the community from early stage. That's how it becomes natural, and parents need to bear the unfair treatments or pain the child may face. And make them gradually get used to community, and then independent living may happen one day (Jo).*

Participants from both countries have also argued that there is a need for the parent and the

child's active involvement in the communities in order to overcome stigma, negative public perceptions, and to work towards a more inclusive society for their children to live in.

According to a professional participant in New Zealand:

*Even within [the] Korean community in New Zealand, the barriers and stigma around disabilities [need] to be reduced a lot. There needs to be a continuous movement and I want there to be autonomous support within our community to do so (You).*

Parent participants in Korea also commented:

*The most important thing that needs to happen is change[s] in perception. Yes, vocational training is good, education is also good, but changes in perception [need] to happen so that our kids can live in the same space with people living without disabilities without being discriminated against. So, the most important thing for parents to do to change the perception of people around us, instead of avoiding it, is to go to small markets with them, take them on buses, what I mean is keep going out into the community. We need to continue doing such activities to broaden recognition and understanding among people around us (Um).*

Another mother also noted that people living without disabilities may be scared and fearful of people living with disabilities as a result of people's ignorance around disabilities. She noted that people may be unsure of what do to and how to treat people living with disabilities, which may then lead to avoidance. She noted:

*When meeting with people living with severe disabilities, even I, as a mother of a child living with developmental disabilities, was scared at first. But after meeting him several times it felt like nothing and I think it will be similar for people living without disabilities. If they keep encountering children living with disabilities, they will understand the way how these children behave. The opportunities to meet... people living without disabilities don't really exist. So we have no choice but to keep taking them out into the community (Tae).*

Despite the efforts made by the parents, a participant criticised the lack of systemic involvement in creating opportunities for individuals living with disabilities to participate in the community, as well as the actual lack of services available in the community for the population.

*Well, to start with I want the service system to be developed to be suitable for developmentally disabled, in terms of finance, budget, and environment. One of the most difficult aspects around when the child becomes an adult is that there are limited services available in the community for people living with disabilities. When they were young they can go to community services, but when they get older, there are no service providers accepting them. And even if they are willing to pay and buy the service, there are limitations, the range of services available [is] limited (Ham).*

Nevertheless, some participants from Korea have shared their positive experiences of community involvement, in the process of overcoming issues discussed above, and further articulated the need for community involvement.

*The acts to support people living with disabilities are actually demanded by parents of individuals. It would be good for such acts to be continuously developed. There were a*

*lot of process[es] involved until the act came [to] be established, although it would have been nice to have more detail and forcibleness, but even if they lack, we can rearrange things later, but we need to place the significance on that fact that it was developed. I think the value is in the fact that parents and people living with disabilities got together and work together (Ham).*

*Although the Disability Discrimination Act was passed, that was passed because people living with physical disabilities were lying on railway[s] and things. So I think we need to do it stronger [laughter]. Get together and lead the way [laughter] (Kwak).*

### 5.2.2 Education and Training

The need for education, training and workshops where parents are provided with general information regarding raising children living with disabilities, available supports and providers, and processes of future care planning were identified by participants regardless of country contexts.

Although some level of satisfaction around the education, workshop and training opportunities were evident among New Zealand participants, desires and the need for further parental education were also mentioned by a participant living in New Zealand:

*There seems to be a lot of parental education going on in this country. And, within such forums, I hope conversations to continue happening (Woo).*

*[For parents to realize the importance of future care planning] people like you need to raise voices. Run a seminar for Koreans around the transition process and things, like*

*an expo-seminar. Have interpreters, and have brochures in Korean, and advertise it more. So that we can make a system where parents are well informed and [are] ready to make plans (Jeon).*

Desires for continuous training opportunities for the children were also expressed by participants living in New Zealand.

*Independence education. I think it's unfortunate. Before the children go to residential care, after school curriculum, in the senior curriculum they carry out independence training at school. They learn how to cook and things at special schools. So my child was more independent at that stage. But now she is done with school and she started to stay home. I want such [training] to get extended. There are difficulties training at home. And they realize how comfortable home is, right? So they continuously do things that are comfortable rather than being independent, they seem to [lose] independence (Bae).*

While similar comments were made among participants in Korea regarding the need for education and training opportunities, in contrast to participants from New Zealand who were seeing the need for *continuous* and *further* opportunities, Korea-based participants expressed that there is an absence of any actual tangible and appropriate education and training available for the parents at this stage in Korea.

Parent participants in Korea expressed the need and their desire for parental education around what to expect, the developmental expectations, as well as available service and programme options. For instance, a parent participant caring for her child with autism stated:



*Education for the children is a good idea, but I want there to be basic education for parents as well. So that we know the problem we may be faced with according to the children's age, and what kind of programs are available, what organization are out there, so take this path kind of thing. Like a roadmap. It may at least give us an opportunity to prepare systematically, because at the moment there is no information available for us (Do).*

The importance of, and the need for, parental education from the early stages of diagnosis was further developed through a comment a mother made as she shared her experience around the diagnosis and her initial fears of not knowing what to expect from her child.

*When I found out that my child is a bit different and that the child will be living with disabilities, I felt fearful. Because I don't know what to expect [in] the future, the process of my child's growth and what the future will look like. There is no modelling. For children living without disabilities, I can predict his/her life, what it may look like. But what does a person with developmental disabilities look like when they become adults? I had no idea and that got me really frustrated (Choi).*

A professional participant in Korea made comments on the parental education sessions and workshops provided by community service centres, and criticised the fact that it is provided merely for evaluation purposes. According to the professional:

*For community welfare centres and institution[s] we are asked a lot to run education and workshop[s]. For facility evaluation purposes we run parental education, future care planning session, or parents of children living with disabilities come in to give a lecture or something. But it's done merely for courtesy. Because we need the evaluation.*

*Even in Community Centre[s] they do it because it is a courtesy to do it periodically (Han).*

### 5.2.3 The Need to Plan

Professional participants in New Zealand have argued that parents' perception regarding the issue of planning for future care provision has a huge influence on planning processes and outcome. Hence, it is vital for parents to realise the importance of planning. The child's ability to adapt to a sudden change in the care environment and to live independently as a result of unexpected absence of parental care was one of the main reasons supporting the importance of parents' recognition of the significance of planning.

*The thing the parents must consider is the fact that parents can't always be around. I might get into an accident and could die or get ill and die suddenly. They could also not have the capabilities to care for the child. There are many unexpected situations that could occur. It is not possible to keep holding on to them, so they must think about how their child could live independently. To help them live independently. Although they are unable to live 100% independently, they must seriously think about how their child can live independently with minimum support. Because the parents have always backed them up, their children are very dependent on the parents (Ahn).*

Professionals also claimed that parents must recognise the importance of future care planning in order to be fully and actively involved in the planning process, ensure available supports are in place, and to maximise the development of the skills children require to live independently, while they are still able to provide support.

*It is significantly important. Once they reach the age of 21 and have to leave school, their funding gets cut suddenly. So it is important how to prepare and plan for their life after that. It is important for Korean parents to know...to support them in transition to help them live independently...and to be fully involved actively when they can, to support the capabilities the child has, and to help them develop what they can do within the given situation. It is important to work on everything they can do to ensure that support is available for the child even when the parents are not available to provide care and support for them (Lee).*

Further, quality of life of parents and other family members were also identified as one of the major reasons supporting the need for parents to recognise the significance of planning.

*Say I am now 50 years old and I had my child when I was 20. I want parents to have a plan to let their child go around that age. So that parents can enjoy the things they were not able to for the past 25-30 years since their child's diagnosis. Take a rest from the sacrifices they have made and enjoy their lives... (Cho).*

#### 5.2.4 Culturally Appropriate Service

Another need communicated within the New Zealand participant group regarding future care provision for their children living with disabilities, was the need for culturally appropriate services. Both parents and professionals commented on the lack of culturally appropriate services and provision of information for Koreans.

*I don't think there is a culturally appropriate service for Koreans...[the] Korean community [has] become so diverse that it is hard to meet their needs (Kim).*

*Indian communities have a centre which provides day-care and respite services. Even Pacific Island community has centres that provide day-care and respite.... They have everything there. But Korean centres don't have that (Jo).*

Kim also noted the cultural impact on living options and stated how it is rather difficult to find an appropriate residential setting for Korean children living with disabilities.

*Independent living is not easy either. It is because these children were not raised and supported to live independently. And compared to children in this country, they lack in experiences around group-homes. So, in fact, nowhere is adequate...and it won't be easy to find an appropriate service (Kim).*

Participants highlighted the need for services that are based in and operating with the Korean cultural foundation. A strong preference towards Korean residential care provided and serviced by Korean service providers within the Korean community for Korean children living with disabilities was evident.

A professional participant stated:

*When you look at group homes, parents want Korean children to do it [live] together. It is because, for instance, food. Children like it when they get Korean food. And if there is a "Kiwi" person, it's not easy to do so. Korean mothers favour Korean children to stay together. Most of the parents and children are currently eating Korean food. So, because of [the] food issue and other cultural issues, mothers want Korean children to stay together (Lim).*

*I thought it would be nice for Korean mothers to get together and open a residential care for our Korean children can be cared for and to live...if you look at group-homes as well, Korean parents prefer Korean children to stay together. Because of things like...food. They like it when Korean food is provided. But Kiwi [New Zealand] and other ethnic background people can't provide it. So Korean mothers want Korean children to be staying together. Because, most children are eating Korean food at home now, so, because of food and other cultural issues, Korean mothers prefer Koreans to live together (Cha).*

Parent participants also commented:

*Korean group-homes, because what we know as parents and what we eat are not based on Kiwi culture....Also, my child has been attending Korean based service over the weekends for about 8 years now, and her emotions get uplifted when she goes there. So I want her to live with people she knows, rather than living with complete strangers and frequent changes in people living together (Kim).*

*Because my child won't be able to live with me forever, I think he will have to go under a group-home care. It would be good to have many Korean style group-homes opened, and to have volunteer groups to manage it. Volunteers to come for meal service, and doctors to come in once in a while for care service and things. So to form 5-10 such group-homes. I will become a member who will be volunteering, right? So, not only my child is my child but every child becomes my child (Lee).*

One participant stated that a service operated by Koreans for Koreans' children and their families will benefit the service users as the service will be able to provide continuous ties with the Korean community, which will enable children to attend programmes provided within the Korean community for Korean children, and practise their Korean culture.

*There is an advantage [to services provided by Koreans] as we can make ties with [the] Korean community so that the children can continue attending the programs, and be actively involved so that the children have enough exchange of Korean culture. Also, the workshops and things they have a lot of programs that are suitable for people living with disabilities with New Zealand cultural background. So they [New Zealanders] can enjoy such programs, but for Korean children, there are cases where they are not actually enjoying. So such things could be changed [if services were to be provided by Koreans] (Song).*

It was indicated that some discussions are happening within the Korean community at the moment around actualising the provision of culturally appropriate services for Korean children living with disabilities and their families.

*What parents are thinking at the moment is for parents to come together and form a trust, and have a joint investment, to buy a small appropriate house, and to have a joint management, to employ people, there are a lot of discussions around doing such things to provide culturally appropriate residential care. I am not too sure about the actual actualization at the moment, but there are such movement[s] (Lim).*

### 5.3 Self-Service

As evident throughout these two chapters, disability service systems in Korea are experienced as a ‘Self-Service’ where parents have to actively and directly seek and secure service provision for their children living with disabilities. Such involvement of parents takes place in diverse forms and levels of care provision.

The concept of 'Self-Service' can easily be identified in the plans and options parents are considering as possible future care direction. For instance, as discussed earlier in the previous chapter, it was evident that, in the Korean context, the sense of lack of service choices and options resulted in parents establishing a private living facility or owning and running a small-scale business as an alternative. In other words, parents are directly involved in organising private residential facilities and creating job opportunities for their children to enable and secure their income activity in the future. A professional shared a case she encountered, and also expressed the need for parents' direct involvement in making changes happen to ensure better living conditions for their children in the future.

*Mothers got together and bought a three storied villa. Mothers who are close to each other put some money together and bought it and made it into a group-home. There are parents like that. It is good to be independent and live independently, but I think parent prefer group-homes because we don't know until when the government will support it. But we need a lot of help from parents. Parents need to make efforts to make complaints and fight for it, I think (Goo).*

However, this option was noted to be available only for financially wealthy parents. It was communicated by parents who identified themselves as financially stable and were considering this as an option, but if the parents did not have the financial means, the only other alternative option available would have been having the child under familial care, which is only a different form of 'Self-Service'.

As discussed above, the concept of a 'Self-Service' welfare model was also repeatedly evident in the Korean context in relation to a lack of information. Such experiences around a lack of information was criticised by participants as it leaves the planning process as a personal and

familial problem, which then leads to a ‘self-servicing’ process. This leaves parents experiencing significant difficulty and inconvenience in the planning process as they have to personally search and gather information around available and appropriate services and support for their children. As a professional participant in Korea noted:

*There is nothing. There is no information available for parents to have a look and choose from. So they don't know what they are entitled to and they miss out. They [parents] have to search information one by one (Hwang).*

Hence, as discussed earlier in the chapter, the mothers’ ability to gather information becomes critical and has a profound impact on the current and future care provision for their children.

Further, as discussed in a previous section of the chapter, the concept of a ‘Self-Service’ model of welfare in Korea is also very tightly linked with Korea-based parents’ experiences around the absence of a medium bridging service providers and users. Such absence leaves parents taking the responsibility for the process of searching and facilitating care provision of their children rather than being supported by service providers.

Professional participants noted:

*Nothing. In Korea, you have check everything on your own (Chae).*

*There are a number of different stages in residential living in Korea. But parents have to make direct calls to different providers. Tell the conditions of their child (Hyun).*



Other professionals also noted:

*Even after making applications to go into an institution, mothers can't just do nothing and wait for the ward office's response. So, they get physically involved, make calls. Parents do most of the things (Tak).*

*In the disabilities sector, parents have to do the legwork. There are a number of services available in for people living with disabilities...the situation at the moment is that the parents have to go out and visit different service options, and [see] what is available (Soo).*

Parent participants in Korea also indicated the significant difficulty and inconvenience when planning for children's future care provision as they have to personally search and contact each service provider to check availability. A parent participant caring for a son living with developmental disabilities noted:

*We search and do it all by ourselves. We make the application. Most of the services are like that. We make the calls and ask, and you get services according to how much the other person on the line understood your needs (Ga).*

Nevertheless, parents caring for children living with disabilities in Korea are not only directly involved in searching and gathering information around available and appropriate services and support or in the process of ensuring income activity for their children in the future, but are also directly involved in social change activities. In other words, the concept of 'Self-Service' is not limited to the 'micro level' (individual, personal level of interactions) where parents search and contact possible service providers, but goes further into the 'meso-level' (interactions between the micro and the macro [large, systemic]) levels of society, the

community, organisational level of involvement where parents get directly involved in social change activities. For instance, as discussed previously, parents living in Korea are actively engaged in making proposals to change policies and systems, networking with people involved to enforce such changes, and protesting to ensure welfare security for their children living with disabilities.

*There are limits to the laws around people living with disabilities. And parents know the needs all too well. If we ask the people involved to make changes in the system, we know it's going to take too long. So, at the end of the day, parents jump right into it, and they know the process gets faster where they continuously get involved and ask for changes (Jo).*

A professional participant shared parental involvement in the process of getting funding for a life-long learning centre in the community. He noted that parents were involved from the very beginning of the process where they came up with an ordinance. When the member of the city council showed lack of interest in the project, parents initiated a campaign to obtain signatures from the citizens and successfully obtained 8000 signatures. He further noted:

*And the bill was passed by the local council. Some changes were made but it was passed. We led the process and it passed, which means that our city is the first city to have a bill passed which was organized by a local autonomous entity (Jang).*

As discussed above in the 'Systemic Problems' section, law and policies in Korea around disabilities are criticised for their lacking of actual functionality. Consequently, parents get involved in following up the process of functionalisation and ensure the operation of such laws and policies. For instance, the mother who complained that, although the Act was passed, yet there is lack of involvement and effort made by both the central government and the local

governments in actualising the Act, did not just complain, but she went further and got herself involved in social campaigns and protest to ensure that the Act is up and running.

*If there is no movement around the Act for about 3 years, the Act becomes a dead Act. So we decided to do undertake some policy actions from this year. We presented six policy proposals to Seoul city. But it didn't happen very smoothly so we had no choice but to demonstrate (Do).*

Another involved in the process also commented:

*The actual policy proposal was not done as a work without any plans. We engaged with professionals and did some research and then made the proposal. So this makes it different from policy proposals made just by professionals. So we suggested what we needed and wanted to mediate, but they were not even willing to do that. In the disabilities sector, nothing [has] ever happened without protests yet (Han).*

In contrast to the satisfactory service experiences shared by Korean parents living in New Zealand, as parents who have migrated from a country operating under a 'Self-Servicing' welfare model, they were faced with difficulty in understanding the service systems of a foreign country. Such difficulty was perceived to be different from a mere lack of information on available services, but more to do with the macro level of systemic understanding and grasping the overall operation of the service system.

A parent participant noted:

*I don't know the support services where the children can stay or how they operate (Choi).*

Such issues around lack of understanding of the system among Korean parents in New Zealand and its impact on the planning process were articulated more strongly by the professional participants in the study. According to a professional participant, Korean parents have difficulty understanding the overall welfare system in New Zealand as it is rather different from the 'Self-Service' welfare model in Korea. As he states:

*The biggest problem is that people don't really understand overall New Zealand society. So, the big paradigm of this country's social welfare is about the society taking responsibility together. But when they were in Korea, it was just a theory, and in reality all the responsibility goes back to the individuals later on. But they don't have consensus around that concept (Lee).*

From the comments made by the professional participants, it was evident that such lack of systemic understanding had a substantial impact on the process of future care planning among parents living in New Zealand.

*They seem like they don't really know about the system of this country well. They seem to be behind the parents of the mainstream in terms of how to run a family trust, and how to graft it to residential care, how to meet all the other requirements, the details of it (Lim).*

*They don't know what to do. Although once the transition process starts the coordinator will make appropriate referrals and provide good services, they [parent] have absolutely no idea around what's happening. Whether they will just automatically go to group-homes after graduating or not.... They don't really know how the funding system works and so on (Cho).*

He continued and commented on the impact of language barrier on understanding systems and the process of future care provision planning.

*For Korean parents, [the] language barrier is huge, so in discussions and in the process of things, they don't have 100% understanding. But once they are faced with it, and things don't go as they thought, and a lot of them think they would be just happy if they can get into a group-home. But that's not the case, but they don't know, yet. They only find out once they are faced with it (Cho).*

#### 5.4 Conclusion

In conclusion, the collected data enabled the researcher to answer the questions around the culture and country contextual impacts on future care options and planning, gain an understanding of the parents' worries and desires around their children's future care, and the types of support caregivers find most valuable in the process of planning for their children's future care provision. In particular, analysis of the collected data enabled the study to explore the impact of culture and national context on the reasons behind a perceived lack of planning, aspects to consider when planning, systemic issues, and the needs of the two countries studied. The chapter explored and discussed major themes emerging from the collected data, and the findings from the study show that there are differences and similarities regarding the socially experienced reality of future care planning among Koreans in different national contexts.

There were a number of differences and similarities in the aspects parents take into consideration when planning for future care provision for their children living with disabilities.

Parent participants from both countries studied have disclosed that they are seriously concerned about their child's ability to live independently and their social adaptation, and securing safety and basic standards of care provision. Experiences and advice from senior parents were considered significant, regardless of the country context, and one of the biggest concerns for parents in both countries appeared to be around post-school-age care and transition to out-of-home care provision. Economic capacity has been emphasised exclusively by Korean participants, while cultural barriers were repeatedly identified as one of the predominant aspects to consider when planning for future care by participants in New Zealand.

Finally, participants of the present study, regardless of the country contexts, articulated the need for the carers' openness, active involvement in the communities, as well as the need for education, training and workshops providing general information regarding raising children living with disabilities, available supports and providers, and processes of future care planning. Participants in New Zealand also highlighted the need for parents to recognise the significance of future planning, as well as the need for culturally appropriate services. In the following chapter the major issues that emerged and have been identified in this chapter are discussed in detail under two major themes: Future Care Planning: In Process, and Looking to the Future: Issues to be resolved.

## CHAPTER 6 Discussion

The present cross-national study revealed significant impact of culture on future care planning for their children living with disabilities in Korean parents in Korea and in New Zealand. The findings of the study suggest that the strong familism culture prevalent in Korea discussed in the literature chapter, is creating a ‘Self-Service’ model of welfare in Korea where parents have to actively and directly be involved in almost every aspect of care provision for their children living with disabilities. On the other hand, the strong familism embedded within Korean culture creates dilemmas among migrant parents living in a host country where individualism is perceived to be predominant and favoured. Further, it is evident that Korean parents living in New Zealand perceive the service system as a ‘Safety-Net’, which is argued to lead to state dependency in some parents living in New Zealand.

To answer the research questions around how the country contexts shape the plans and possibilities for future care provision of Korean parents with children living with disabilities in New Zealand and Korea and to gain an understanding of the parents’ worries and desires around their children’s future care, this chapter is divided into two primary themes including Future Care Planning: In Process, and Looking to the Future: Issues to be Resolved. Under the first theme, possible options for future care provision, including no, or very vague, plans, establishing a care centre, familial care, and progressively planning are explored in depth. Some of the major reasons behind the low levels of planning, as well as reasons behind considering each option for their children’s future care provision are also discussed. In the second section of the chapter, Looking to the Future, some of the principal issues concerning parents in the process of future care planning which need to be resolved are discussed in detail. Table below captures and provides a synopsis of the core outcomes of the discussion chapter.

Table 4

*Core Differences and Similarities between Korean Parents in New Zealand and Korea around Future Care Provision Planning*

Themes	Similarities	Differences	
	<i>Both Countries</i>	<i>New Zealand</i>	<i>Korea</i>
<b><i>Future Care planning: In Process</i></b>			
- No or Vague Plans	<ul style="list-style-type: none"> <li>- Most parents from both countries have no or vague plans</li> <li>- Living everyday life</li> <li>- Emotional distress</li> <li>- Negative public perception regarding children leaving the family home</li> <li>-Lack of information</li> </ul>	<ul style="list-style-type: none"> <li>-Cultural barrier</li> <li>-Familism creating dilemma: independent living/ familial care</li> <li>- Lack of information: cultural barrier (language/ systemic understanding, etc.)</li> <li>- Welfare system perceived as Safety-Net</li> </ul>	<ul style="list-style-type: none"> <li>- Emotional distress-general public perception on people living with disabilities</li> <li>-Lack of information: Self-Service/ Familism with lack of state level involvement in information provision/ training etc.</li> <li>- Absence of bridging role: Self-Service/ Familism</li> <li>- Having no choice</li> <li>- Planning on establishing private care facilities</li> </ul>
- Care and Financial Circumstances	<ul style="list-style-type: none"> <li>-Reflects familism values</li> <li>- Parents' economic capacity- determining options for future care provision</li> </ul>	<ul style="list-style-type: none"> <li>- Much less likely to be impacted by economic capacity of the parents</li> <li>- Eligibility for disability allowance and funding-much more focused on the individual themselves</li> <li>- Concerned with access to available funding</li> <li>- Economic aspects related to care provision: State provision perceived as Safety-Net</li> </ul>	<ul style="list-style-type: none"> <li>- Parents' economic capacity- a major reason for lack of planning: range of service providers/ time and space for planning</li> <li>- Concerned with parents own financial capacity</li> </ul>
- Familial Care	<ul style="list-style-type: none"> <li>- Strong familism values</li> </ul>	<ul style="list-style-type: none"> <li>- Having them under their care for as long as they can provide care, and then placing them under the care provided by welfare services as a last resort</li> </ul>	<ul style="list-style-type: none"> <li>- Direct long term involvement of family members</li> <li>- Concept of 'Self-Service'</li> </ul>



		<ul style="list-style-type: none"> <li>- Welfare system perceived as Safety-Net</li> <li>- Lack of other familial support</li> </ul>	<ul style="list-style-type: none"> <li>- Having no alternative option</li> </ul>
<ul style="list-style-type: none"> <li>- Preparing Progressively</li> </ul>	<ul style="list-style-type: none"> <li>- Some perceive planning to be a gradual process, hence are constantly training skills necessary for out-of-home life</li> </ul>		
<ul style="list-style-type: none"> <li>- Trust towards the System</li> </ul>	<ul style="list-style-type: none"> <li>- Impacting future care planning process</li> </ul>	<ul style="list-style-type: none"> <li>- Satisfactory</li> <li>- Perceives the system as Safety-Net: active responsibility of society for the care and support of the population</li> <li>- Lack of active involvement in the planning process</li> </ul>	<ul style="list-style-type: none"> <li>- No expectation nor trust</li> <li>- Familism with lack of state level involvement in supporting the individuals and their families</li> <li>- Self-Service welfare model</li> <li>- Lack of professionals</li> </ul>
<b><i>Looking to the future: Issues to be Resolved</i></b>			
<ul style="list-style-type: none"> <li>- Independent living</li> </ul>	<ul style="list-style-type: none"> <li>- Most important aspect in the process of planning</li> <li>- Parents: emphasis on the details and the process of adaptation related to separation, unexpected behaviours that may be caused in the process of adapting to new care environments after leaving familial care, as well as the ability to adapt to communal living environments.</li> <li>- Professionals: articulated the correlations between the starting time of the adaptation process and its effectiveness</li> </ul>	<ul style="list-style-type: none"> <li>-Quality of life/ continuation of daily activities/ children's happiness</li> <li>- Familism creating Dilemma: Independent living/ familial care</li> </ul>	<ul style="list-style-type: none"> <li>- Child's ability to carry out financial activities</li> </ul>

- Systemic Issues	- Database  -Lack of post school age programmes and networking forums	- Database on case studies encompassing a wide range of cases to provide guidelines on how to support and raise children living with disabilities  - Need for more education/ programmes to be available for the children living with disabilities	- Lack of overarching database of available supports and organizations  - Development of ‘All-in-One’ information package or ‘One-Stop’ organization focusing on information provision encouraged  - Lack of functionality of current disability law and policies  - Lack of systemic support following changes in the legislations, policies etc.  - Lack of professionals  - Pushing parents to the frontline – familism/ Self-Service
- Education/training/ workshops	- Recognizes the need for education, training and workshops where parents are provided with general information	- Need for continuous and further education/training/ workshops for parents	- Lack of any practical and appropriate education/training/ workshops for the parents

	regarding raising children living with disabilities, available supports and providers, and processes of future care planning		
Post School Age	<ul style="list-style-type: none"> <li>- Lack of service provision</li> <li>- Cuts off channels for information exchange</li> <li>- Care and support becomes dependent on the child and family's ability to support themselves and gather information</li> </ul>		
- Cultural Barriers		<ul style="list-style-type: none"> <li>- Need for culturally Appropriate Services</li> <li>- General Korean culture of being rather exclusive and passive may impede planning process and pose challenges among Korean parents taking part in the mainstream community</li> </ul>	
- Peer support and Community Involvement	<ul style="list-style-type: none"> <li>- Senior parents identified as the most valuable and helpful supporter</li> <li>- Increase information exchange</li> <li>- Possibility of better service provision and support</li> <li>- Provide opportunities for their child to live ore inclusively with the community</li> <li>- Increase empowerment and self-advocacy among Koreans</li> <li>-Overcome sigma</li> </ul>		

In support of making the future care planning process to take its place as a natural and conventional phase of caring for children living with disabilities in the future, a number of suggestions and recommendations are made throughout the section.

### 6.1 Future Care Planning: In Process

Drawing on the study findings, it is evident that future care planning is still ‘in process’ in both country contexts. Participants from both countries expressed a pervasive concern and anxiety related to planning for their children’s future care. Most participants in the study have communicated that parents in both countries recognise the need for, and show great interest towards, future care planning and expressed their persistent concerns regarding the issue, yet lacked concrete plans and substantive practice.

The following section attempts to provide an overview of future care planning, the possible care provision options identified and the reasons for considering each option for their children’s future care provision. The section begins with a discussion around no, or only a very vague, plan, reasons for such a lack of planning and how it is different and similar in each country context studied. This involves discussions around: overly settling for and being accustomed to the status quo, emotional distress, cultural barriers, the impact of Korean culture and familism on migrant families, and the lack of information. Further, as one of the principal differences identified between the two countries, ‘having a choice’ in New Zealand and ‘having no choice’ in Korea, are discussed in detail. This is an essential discussion of this section as it leads to the next part of the chapter, establishing a care centre. It is evident in the Korean context that the sense of lack of service choices and options is resulting in parents establishing a private living facility or owning and running a small-scale business as an alternative, resulting in the ‘Self-Service’ welfare model in Korea. Further, it is concluded that this is an option available only for financially wealthy parents, and the only other alternative option identified as available in Korea is having children under familial care. The discussion then moves on to the familial care option, which is the most frequently identified option other than having no, or only a very vague, plan. Discussion around constantly training their child in the skills necessary for out-

of-home life and how some parents perceive future care provision as a gradual process are then provided. This is followed by an in-depth discussion around how the analysis of the plans parents have for their children living with disabilities and the reasons behind relatively low levels of planning are interrelated with parents' trust towards the overall disability system and services in the countries studied.

#### 6.1.1 No or Only a Vague Plan

Pervasive concerns and anxiety related to planning for their children's future care are evident in both countries. Most participants in the study have stated that parents in both countries often recognise the need for, and show great interest towards, future care planning and expressed their persistent concerns regarding the issue, yet they lacked concrete plans and substantive practice.

The reasons behind such a lack of planning include Korean parents living in both Korea and New Zealand settling for and being accustomed to the status quo, hence not perceiving future care planning as a critical and urgent matter. As parents in both countries are perceived to be relatively used to living everyday life with their children living with disabilities, unless there is challenging behaviour or difficulty living with the child, they are noted to be living day-to-day life without making any definite, concrete plans for the future care provision of their child living with disabilities.

Emotional distress is also identified by participants from both countries as a significant reason behind the low levels of parental involvement in future care planning. Parental responsibility, self-blame, guilt, and other complex emotional aspects are some of the frequently visited emotional difficulties related to the future care planning process. Such emotional distress for Korean parents living in Korea is also often identified to be linked with public perception. The

findings of the present study suggest that, while much has changed in Korea regarding people living with disabilities and the treatment towards them has changed substantially, some traditional perceptions regarding people living with disabilities, discussed in the literature review chapter, still remain in how they are perceived and treated by others in contemporary Korean society. It is evident that there is a lack of positive perceptions in the general public's view of people living with disabilities, and some participants in Korea related such negative public perception to being ignorant and uninformed about the disability population. It is perceived that many Koreans in Korea show a tendency to avoid people living with disabilities due to uneasiness connected to not knowing what to do.

Uncertainty avoidance, as a characteristic of a certain culture, determines the extent to which individuals within a given culture are made nervous by situations that they perceive as unclear, unstructured, and unpredictable and the extent to which the individuals try to avoid such situations (Hofstede, 2011). According to Hofstede's (2011) research findings, Korea was identified as a country with a strong uncertainty avoidance culture, which means that Koreans are highly likely to avoid situations where it is considered unclear and uncertain through adopting very strict codes of behaviour (Hofstede, 2011). As Kim-Rupnow (2005) stated, Korean people are very much homogenous, conservative, and have a tendency to avoid uneasiness related to being unclear around what actions need to be taken. This may provide an explanation for the findings of the present study around why Korean children living with disabilities and their families are likely to experience negative public perception and isolation in Korea.

In contrast, comparisons with Korean society were frequently made among New Zealand participants when discussions around public perception took place. Experiences in New Zealand, compared to Korea, are indicated to be much more positive in terms of public perception and treatment of people living with disabilities. Although such comments are not perceived to have a direct impact on future care planning itself, it appears to have a significant influence on the overall trust towards the general system and services in New Zealand among

parents caring for children living with disabilities in New Zealand, and such trust towards the welfare system and services is evident in regard to future care provision for their children. The discussion around satisfaction with the quality of general system and service provision and trust in relations to future care planning is explained in greater detail later in the section.

However, in New Zealand, the socially experienced reality of future care planning among Korean parents is evident to be impacted considerably by cultural barriers. Cultural barriers are argued to be one of the most significant reasons for a lack of planning among Korean parents in New Zealand. Lack of culturally appropriate services for Koreans, New Zealand 'style' provision of services, coercion towards independent living, food, lack of understanding around the social community, and language are some of the cultural differences identified repeatedly in New Zealand. Further, systemic barriers around future care planning, as well as the general use of services among Koreans in the New Zealand context, are also perceived to be created by cultural differences, which appears to have a substantial impact on the process of future care planning among parents living in New Zealand.

Nevertheless, Korean culture and familism clearly have a substantial impact on Korean families living in New Zealand. As discussed earlier, it is perceived that cultural differences create systemic barriers in the socially experienced reality of future care planning as well as the general use of services among Koreans in New Zealand. For instance, as a professional participant in the study stated, cultural impacts on living options are significant for Korean parents living in New Zealand. As she noted, Korean parents in New Zealand experience difficulty finding an appropriate residential setting for Korean children living with disabilities, and much of this comes from a dilemma between independent living, perceived by the parents to be favoured in New Zealand, and the values attached to familism. As discussed above and earlier in the literature chapter, Koreans value interdependence among family members more than independence. They accept that every individual needs support from others continuously over the course of their lives. Members of a family feel obligated to take responsibility, care for other members' basic needs and to keep up their morale. Hence, Korean parents of adult

children living with disabilities often experience conflicts between the child's interdependence and independence. They have a desire to encourage self-sufficiency in their children living with disabilities, while also wanting to protect their children's well-being (Kim-Rupnow, 2001). In the present study, such conflict is observed to be experienced more intensely among parents living in New Zealand than in Korea, as the welfare system and provision is assumed by the participants to favour and operate to support the independent living of people living with disabilities rather than collective familial responsibility and interdependence.

A lack of information is identified unanimously in both countries as one of the primary reasons behind such low level of planning. Further, as discussed in the previous chapter, participants from both countries studied shared their experiences around segmentation and discontinuation of information, services and systems, which are all perceived as systemic problems by Korean parents in both countries. However, it is evident through analysis that such experiences are associated with essentially different factors in the two countries.

Although both countries have in common the perception that planning processes for future care provision are significantly influenced by the systemic issues related to lack of information, service and systems, in the New Zealand context this is often associated with cultural barriers. In New Zealand, the language barrier is often identified to create obstacles for information circulation, which may ultimately perpetuate lack of systemic understanding, limit information gathering and use of available services, and also reduce the level of involvement in communities. Difficulty in understanding the service systems and operation of the host country due to cultural differences is also identified by participants in New Zealand as one of the primary cultural barriers affecting the low level of planning.

On the other hand, the concept of a 'Self-Service' welfare model is repeatedly evident in relations to such experiences in the Korean context. In Korea, lack of public support and systemic foundation are identified as the main causes for the lack of information among parents.



Such lack of public support and systems around information provision is further criticised because it leaves the planning process as a personal and familial problem, which then leads to a 'self-servicing' process, leaving parents experiencing significant difficulty and inconvenience in the planning process as they have to personally search and gather information around available and appropriate services and support for their children. In other words, familism, where the responsibility of care provision is placed on the family over any other individuals or groups, has resulted in a 'Self-Service' model of welfare provision in Korea. Further, the relationship between familism (which places greater emphasis on the families while being criticised for the low level of state involvement) and the concept of this 'Self-Service' welfare model (affecting the low level of service use in Korea) is also often evident through the lack of professional bridging between service users and providers.

One of the principal differences between the two countries, in their service systems, is the bridging role between service users and providers, as well as between the society and the specific population group. The data collected in Korea reveal an absence of medium bridging service providers and users. As stated above, the experiences of parents in Korea regarding the absence of these providers and users are very closely linked with the concept of the 'Self-Service' model of welfare in Korea. Just as the experiences around lack of information where there is lack of public support and systems, there is an absence of organisations or service providers to enable direct contact between the service users and providers. Parents are faced with substantial difficulty and inconvenience when planning for children's future care provision as they have to individually search and contact each possible service provider to check availability. In other words, as parents, they take responsibility in the process of searching and facilitating care provision for their children rather than being supported by service providers, which again reflects the values attached to familism which regards caring for, nurturing and supporting other family members as an unquestioned duty (Yang, 2002), leading to this 'Self-Service' model of welfare among parents living in Korea.

It is evident that the lack of bridging has a negative impact on how professionals are perceived in Korea. Lack of professionalism within social work practice, lack of information and professional knowledge of the population, and a lack of systematic organisation and arrangement of service and systems are indicated to the researcher (by both professional and parent participants of the study) to lead to frustration among parents when working with professionals, which then again results in parents 'self-servicing' to meet their needs. The issues related to lack of professionals is discussed in greater depth later in the chapter, under Looking to the Future: Issues to be Resolved.

In contrast, in the New Zealand context, welfare services and system are revealed to be experienced as a 'Safety-Net', which the system operates to provide all necessary services and support, and to prevent and protect children and families in emergency situations. Service coordinators and referral services through a wide range of disability organisations are available in New Zealand to support direct contact with possible service providers. As discussed in the literature chapter, in New Zealand, the Ministry of Health funds a diverse range of disability support services, and access to most ministry-funded support is through the Needs Assessment and Service Co-ordination Agency (NASC). For example, in the case of Auckland, the NASC is the Taikura Trust, and any individual living with disabilities living in Auckland can be referred to Taikura Trust for free Needs Assessment whereby the person's eligibility for ministry-funded supports is assessed and appropriate services are co-ordinated for the person living with disabilities. Such referral can be made by a GP or paediatrician or anyone under the age of 65 years living with disabilities can self-refer. Hence, in contrast to the 'Self-Service' experienced in Korea where parents are directly involved and self-servicing their welfare needs, services are available to engage families with appropriate supports and service in New Zealand, which is experienced as a 'Safety-Net', where families can, to a certain level, rely on the systems in place. Although such systems may be welcomed by service users, they can potentially be criticised for creating state dependency among Korean parents in New Zealand. It may prevent families from actively engaging with a range of different service providers in the process of future care planning while relying solely on the information and services provided by the organisation supporting them. Hence, at one end of the spectrum there is the

Korean 'Self-Service' welfare model experienced in Korea where parents are heavily reliant on their own ability to seek information and serve their own needs, at the other end, in New Zealand, Korean parents are observed to be comparatively more dependent on the readily available information and services provided by the service providers experienced as a 'Safety-Net'.

Another most significant difference evident in the two countries' data concerns the perceived choices and options parents have regarding future care provision for their children living with disabilities. From the data collected in New Zealand, a sense of 'having a choice' is evident in how their children's future care provision will be arranged. For instance, the sense of having choices was evident through the comments professionals in New Zealand made around the need for parents to actively search for and engage with different service providers to be able to select the most appropriate care provider for their child, indicating how parents living in New Zealand have a range of different service providers to choose from. However, although such wider choice is generally available, it is evident that only a small number of parents are actively involved in searching for the best care provision options for their children living with disabilities.

On the other hand, participants from Korea often mentioned 'having no choice', which was often linked very closely with the economic capacity of the parents, the grading system in Korea and low levels of planning. Having no choice or options to consider over their children's future care provision appears to be one of the most significant and unique reasons that surfaced only in the Korean context. A sense of powerlessness and lack of an alternative leading to unfortunate situations were frequently shared among participants in Korea regarding planning for future care provision for their children living with disabilities. Some of the concerns around lack of service options to consider were related to, and articulated by, the comments on how there are no service providers they can entrust with the care for the child living with disabilities. As a result, although the number is limited, some parents in Korea are thinking about or under

the process of establishing a private living facility or owning and running a small-scale business, where the concept of ‘Self-Service’ welfare model can again be applied.

### 6.1.2 Care and Financial Circumstances

Establishing a private living facility, or owning and running a small-scale business are revealed as possible future care provision options for their children living with disabilities, discussed predominantly among Korean parents living in Korea. This again clearly reflects the ‘Self-Service’ model of welfare provision in Korea, where parents’ direct involvement, such as organising private residential facilities and purchasing a small shopping arcade in the community or initiating a small-scale business in order to create job opportunities for their children to enable and secure their income activity in the future, are evident and perceived to be necessary. This is often linked with the perceived low level of state involvement in support and care provision for people living with disabilities, a sense of having no other alternatives to consider, and a lack of trust towards service providers. However, it is important to note that this is an option available only for financially wealthy parents. It was communicated by parents who identified themselves as financially stable and who were considering this as an option that, if the parents did not have the financial means to secure future care provision for their child themselves, the only other alternative option available would have been having them under familial care, which is merely a different aspect of the ‘Self-Service’ welfare model.

According to Yang (2002), the perception of welfare responsibility can be categorised into a continuous spectrum, from individual responsibility to state responsibility. From the finding of the present study and looking at the options parents are considering, it is clear that current welfare responsibility in Korea is perceived to lie much closer to individual responsibility. In other words, it can be argued that current welfare provision in Korea is operating under a social welfare system that minimises the role of the state in welfare provision, while placing the family at the centre of social welfare. Hence, what the families themselves can offer and

provide for their children living with disabilities is critical in Korean society (familism leading to 'Self-Service'). On the other hand, as discussed previously, parents in New Zealand are perceived to experience the welfare services and system as a 'Safety-Net', which can directly or indirectly reflect that welfare responsibility in New Zealand is experienced as, and perceived to lie closer to, state responsibility over individual responsibility.

In Korea, it is discovered that parents' economic capacity not only determines the range of service providers, but the possibility of thinking about the actual plan itself is also determined by the parents' economic capacity. Both parent and professional participants residing in Korea have articulated economic capacity of the parents as one of the major reasons for lack of future care planning. A number of professional participants in Korea identified economic capacity of the parents as the ultimate standard or determinant of parents' ability and involvement in future care planning. In other words, some of the options regarding future care provision in Korea are perceived to be only available to families wealthy enough to have money and time to dedicate to caregiving activities for their children living with disabilities.

The hardship associated with economic capacity of the parents in relation to future care planning appears to be a matter especially concerning for families that fall in the middle on the spectrum of poor and wealthy: middle-class parents with low income levels. These are the parents who need to be actively engaged in income activities to make living, hence their socially experienced reality does not allow time and space for future care planning. Indeed, even providing adequate care in the present leaves them with no (or very limited) alternatives to consider. Nevertheless, some children for whom parents cannot provide care as they have to continue with their economic activities to make a living, are placed in institutions as they do not have any other alternatives. Further, parents in Korea argue that economic capacity also has a significant impact on their ability to participate in the community, and engage in activities organised by parent societies or associations for people living with disabilities.

Nevertheless, according to research conducted by Oh and Lee (2009), Korean mothers raising children living with disabilities perceived financial burdens to be their primary worries, along with concerns about their children's future. Their research around caregiver burden and social support among mothers raising children living with disabilities in Korea revealed that Korean mothers experience a high level of overall burden, particularly in financial domains. Extra costs related to disabilities were identified to be the strongest predictor of an increased caregiving burden. Similarly, in the present study, Korean families caring for children living with disabilities clearly spend extra money compared with their counterparts in New Zealand to treat disability related illness and additional educational expenses that are not covered by the public education system.

Nonetheless, although the degree of the impact is not as significant as it is in Korea, even in New Zealand economic capacity appears to be one of the issues parents are faced with. For instance, 'Choice in Community Living' is a living option which is offered as an alternative to residential services, which is designed to offer more control and choice over where people living with 'severe' disabilities, who they live with and how they are provided with support. Yet, this option is criticised by participants in the present study as the person living with disabilities must have the financial means to purchase or rent a house or be living in unsustainable living conditions with support needs that would require a referral to a residential service – which is not what the individual or their family desires in order to be eligible to access 'Choice in Community Living'. Hence, similar to the experiences of parents living in Korea, some options for care provision in New Zealand are also only available for those families with financial means. Thus, as discussed earlier, it is arguable that, to some extent, the concept of familism, where the responsibility of care provision primarily lies within family members, is also evident in the New Zealand context.

However, if we look at the eligibility for disability related allowances and funding in New Zealand, we can see that New Zealand is much more focused on the individuals living with disabilities themselves compared to Korea, and that children living with disabilities in New

Zealand are much less likely to be impacted by the economic capacity of the parents. In other words, while the importance of family support and involvement in the care provision are acknowledged in New Zealand, the person living with disabilities is recognised as an individual being and, unlike Korea, parent's economic capacity and financial status are not considered to have impact on the support that the person may be entitled to but these are treated separately. For example, the eligibility for a Child Disability Allowance clearly states that the allowance is a set of amount which does not depend on the carers' income, assets, or costs. Further, again unlike Korea, although the amount of allowance a person may receive under Disability Allowance depends on how much the individual and his or her partner earn, the carers' economic capacity or assets do not determine how much support the person living with disabilities may be provided with.

Nevertheless, from the analysis of the collected data, evidence of Korean parents in New Zealand perceiving the state as a 'Safety-Net' are clearly apparent in regard to the economic aspects related to care provision. For instance, in contrast to parents residing in Korea who appear to be mainly concerned about their own financial capacity, the main economic concern for New Zealand based participants appear to be around accessing available funding. This indicates the level of Korean parents' expectations around state-level financial support in the provision of care for their children living with disabilities in New Zealand. Further, it is evident that Korean parents in New Zealand are more concerned about the financial status of the nation and the government over their individual or familial economic capacity. Similarly, in contrast to comments made by the participants in Korea, the economic capacity of the children did not appear to be of great concern among parents in New Zealand. Yet, most Korean parents in New Zealand communicated that they are currently provided with, and also expecting, a degree of state-level financial support in the future.

### 6.1.3 Familial Care

As mentioned above, a previously discussed option, namely establishing a care centre, is an option available only for financially wealthy parents, and these parents who are considering this option often stated that if they did not have the financial means to secure future care provision themselves, the only other alternative option available would have been having them under familial care. Furthermore, of the future care provision plans and options shared by the participants, other than having either no, or only a very vague, plan, the most frequently identified option was having them under their familial care for as long as possible. This option is perceived to be the most predominant form of care provision which reflects familism where interconnectedness among family members is exceptionally strong, and it is an unquestioned duty to care for, nurture and support other family members (Yang, 2002), thus placing responsibilities for the individual's welfare on the family.

It is important to note that such a pattern of care provision reflecting strong familism is not only perceptible in Korean society, or even Asian communities, but is also evident in Western families. For instance, Bowey and McGlaughlin (2007) concluded in their study (conducted in England) that parents who made future plans generally rely on other family members or siblings to care for the other member living with disabilities, and only a few made alternative plans. Even within New Zealand, some of the services offered that are considered options for children's current and future care provision implicate family members as principal care providers. For instance, the Funded Family Care under Ministry of Health funding, offers people living with disabilities the chance to employ their parents or other family members who they live with to provide them with care or/and Household Management support. However, although familial support pattern is prevalent in many countries, the form and nature of it may differ significantly depending on the country and cultural contexts.



Looking at the findings of the present study, it is evident that both countries studied fit well into the international pattern of familial care provision. Yet, despite such similarities, the two countries differ largely in terms of the extent of familial care planned to be provided for their children living with disabilities. The idea of familial care among New Zealand participants meant having them under their care for as long as they can provide care, and then placing them under the care provided by welfare services as a last resort. This may again be a reflection of Korean parents' perception of the welfare system as a 'Safety-Net' that is in place for families to count on as a refuge. However, as evident in my previous research (Choi, 2014), Korean parents raising children living with disabilities in New Zealand are perceived to have limited, or no, support from other extended family members or friends due to the loss of informal networks in the process of migration. Like the findings of the studies conducted in the United Kingdom (Hatton et al., 2002; Chamba et al., 1999), my previous study also concluded that informal support received by Korean families in New Zealand is not sufficient to meet their needs and that these families are likely to receive less support from their extended family members compared to those families living in their country of origin and the non-migrant population in a similar situation. Hence, for families who immigrated to New Zealand with their nuclear family members, they may have no other choice but to depend on state-level care as they do not have any other extended family member who can provide direct support for them in the future. Whereas in Korea, familial care is communicated as an option that involves other family members, in their nuclear and extended family, in the actual and direct care provision when the parents are no longer available to provide care for their children living with disabilities. A strong familism and the 'Self-Service' model of welfare are evident again where families are planning to provide welfare and support themselves for other family members living with disabilities rather than being supported and provided care by other services or supports.

Accordingly, in order to provide the most appropriate support that serves the needs of the families, it is necessary for professionals working with families caring for children living with disabilities to have an in-depth understanding of the family's plans and the reasons behind their choices. Looking at the two countries studied, although the option of familial care seems to be

similar, what it means and how it has impacted on the families to come to a conclusion that the option is the most appropriate choice are significantly different between the parents living in different country contexts. As mentioned above, Korean parents in New Zealand view state support as a 'Safety-Net', hence, are planning to provide familial care for as long as they can, then place their children under state-level care and support when they can no longer provide it themselves. On the other hand, Korean parents living in Korea, perceived to be largely impacted by strong familism values and the concept of a 'Self-Service' welfare model, are planning to have other family members involved directly in the care provision throughout the course of their child's life. Henceforth, according to how they understand the option and different aspects impacting on their choices, the support and services the families need potentially differ significantly.

Nevertheless, the experiences of the participants from both countries in the present study showed that there is consistent evidence which suggests that parents feel reluctant towards the transition with general concern expressed about the process and feelings of abandonment. It was also found that parents from both countries studied displayed a lack of trust in adult health care providers (for different reasons) through being reluctant to hand over care of the children. However, a number of professional participants in the present study, from both Korea and New Zealand, have highlighted some of the problems associated with continuous familial care and being unwilling to hand over care provision. It is argued that the tendency of 'holding back', evident among Korean parents in both countries, may eventually result in more difficult situations for the children around adaptation to a changed environment.

#### 6.1.4 Progressive Planning

Planning is perceived to be a gradual process by a number of participants from both countries, rather than a product of a sudden arrangement. Some participants in New Zealand also expressed that they consider adaptation and leaving familial care to be a gradual process which requires some level of responsibility, support and care from the parents in the process. A small

number of parents in both countries are constantly training their child in the skills necessary for out-of-home life, which is often discussed as part of planning for their children's future care. These skills include daily self-care skills required for upholding basic personal hygiene and a basic standard of living, and other skills necessary for independent living and social adaptation. This is observed to be impacted by efforts made to overcome the serious concerns parents from both countries have around the child's ability to live independently and social adaptation when they can no longer provide care. Such concerns and other issues that need to be addressed in order to better support and assist parents in the process of planning for their children living with disabilities are discussed in the following section of the chapter.

#### 6.1.5 Trust Towards the System

Overall, analysis of the plans parents have for their children living with disabilities and the reasons behind relatively low levels of planning are revealed to have been impacted on by parents' trust towards the overall disability system and services in the countries studied. There are significant differences in trust towards the overall disability system and services in different national contexts. Although the number of them is small, parent participants from New Zealand expressed their trust in the overall welfare system and services. It appears that Korean parents in New Zealand perceive the country's disability system and service as a 'Safety-Net'. Some parent participants expressed their trust towards New Zealand and its system while making comparisons with how life could have been more difficult if they stayed in Korea. Such trust towards the welfare system and services in New Zealand is also evident in relation to future care provision for their children living with disabilities. We will first look at Korean New Zealand parents' trust towards the system, then move on to the discussion around the experiences and perceptions of Korean parents in Korea later in the section.

A considerable number of participants from New Zealand, both parents and professionals, expressed their satisfaction with the quality of general system and service provision, and shared pleasing experiences the parents had had with the service providers. Participants in New Zealand have expressed their overwhelming satisfaction around the general and overall disability welfare system and services provided in New Zealand that is not necessarily linked with future care provision and the process around planning such provision. However, although such comments were not directly linked with future care planning, it appeared that such overall satisfaction was perceived to be an essential component of the strong trust towards the general system and services in New Zealand discussed throughout the chapter. In other words, the overall satisfaction with the general welfare system and services, together with the sense of having choices, and other positive experiences around public perception and treatment while caring for their child living with disabilities are evident to have created the fundamental platform for the strong trust towards the welfare system and services among the parents living in New Zealand.

Such satisfaction and trust may be because, compared to Korea, in New Zealand (similar to the trend evident in many Western societies including the United States and the United Kingdom), systems and programmes related to social care for people living disabilities have long been progressively developing. The welfare of people living with disabilities in New Zealand, like many other Western countries, emphasises the active responsibility of society for the care and support of the population, and has been developed in a way to rely largely on the roles and services of the government and society rather than the family. It is based on a tradition that emphasises individual autonomy and independence, while issues around disability support have been commonly recognised as a form of social care that the state should be responsible for. Furthermore, there has been significant increase in the attempts to link social care and support for people living with disabilities with human rights such as the right to live and the right to pursue happiness.

However, such strong trust in the state-level system and service provision among Korean parents in New Zealand, and accepting it as a ‘Safety-Net’, is perceived to create a potential point of criticism for their lack of active involvement in the planning process. There were a number of cases shared by the participants where a degree of state dependency was evident, reducing the active recognition and participation of parents in the process of future care provision planning. For instance, of the parents who had no or only very vague plans, some have expressed that they are not too worried about their children’s future care plans as they have trust in the system in New Zealand that their children will be provided with adequate care even when they are no longer available to provide it themselves. On this point, professional participants in New Zealand have articulated that it is vital for parents to realise the importance of planning. They also claimed that parents must recognise the importance of future care planning in order to be fully and actively involved in the planning process, ensure available supports are in place, and to maximize the development of skills children require to live independently, while they are still able to provide support. In this case, perhaps, familism embedded within Korean culture should be encouraged to increase the involvement of parents in the process of future care provision. It is not to say that the role of families should be used as a means to avoid the obligation to provide the welfare by the state, but to encourage and strengthen the function of the families in positive ways so that the families are actively involved in the process of planning for future care provision

Through empowering and enhancing the role of families, a ‘Korean Welfare Model’ reflecting the traditional characteristics of our cultural values may be developed, while reducing the level of state dependency among Korean parents living in New Zealand. In other words, the ‘Korean Welfare Model’ should be about using the support of the state to empower and support the families while also providing services as needed.

In contrast, participants from Korea repeatedly disclosed having neither expectations nor trust in the system and services provided. Some even expressed exceptionally negative views regarding the issue. Welfare systems and service that are perceived to be operating under a

‘Self-Servicing’ model impacted by familism in Korea, sense of having no choice, a lack of both information and professionals, and the impact of economic capacity of parents on their children’s care and support provision for the future and present discussed above appear to have an cumulatively negative impact on trust towards the system and services in Korean society among parents caring for children living with disabilities. Policy and systemic issues concerning and leading to such a lack of trust among parents in Korea, (namely the grading system and the family support obligation rules), is discussed in greater depth in the following section of the chapter.

## 6.2 Looking to the Future: Issues to be Resolved

Although Korean parents in both countries have very deep concerns and anxieties around what might happen to their family member living with disabilities once they cannot continue to provide care, planning for the future care provision for children living with disabilities is a reasonably new concept for them. For a number of different reasons, planning for future care provision of their children living with disabilities was an overlooked area until very recently. This section of the chapter looks closely at the concerns that Korean parents have, as well as some of the issues that need to be resolved in order for the future care planning process to take its place as a natural and conventional phase of caring for children living with disabilities.

There are a number of differences and similarities in the aspects they consider depending on the country they are based in. In the following section, discussion around the concerns related to the child’s ability to live independently and social adaptation that are articulated to be the most important aspects in the process of planning for future care provision by the parents regardless of country context, is provided. Major systematic issues that must be resolved in

both countries in order to increase levels of parental involvement in future care planning process are then identified, which includes issues related to lack of a database. The overall quality of education provided for the children in New Zealand which is a major systemic issue the disability community is faced with, and disability related law and policies (with greater emphasis on family responsibility over state responsibility regarding care provision) and lack of professionals, resulting in the ‘Self-Service’ model of welfare in Korea, are discussed in detail. The need for education, training and workshops in both New Zealand and Korea is then articulated, followed by a discussion around the concerns related to post-school-age care provision in both country contexts. Finally, the need for reduced cultural barriers in New Zealand, and increased parental involvement in the community and peer-support are discussed. As stated earlier, a number of suggestions and recommendations are made throughout the section.

### 6.2.1 Independent Living

Regardless of country context, the child’s ability to live independently and social adaptation are articulated to be the most important aspects considered by the parents caring for children living with disabilities in the process of planning for future care provision. However, there are clear differences between the parent and professional groups in both countries around the specific areas they placed emphasis on concerning the adaptation of the children. Parent participants, from both Korea and New Zealand, were observed to have high levels of apprehension around the details and the process of adaptation related to separation, unexpected behaviours that may be caused in the process of adapting to new care environments after leaving familial care, as well as the ability to adapt to communal living environments. On the other hand, professional participants, again both from Korea and New Zealand, articulated the correlations between the starting time of the adaptation process and its effectiveness.

Safety and standards of provided care were aspects communicated by participants from all groups as one of the most significant aspects to consider when planning future care provision for their children living with disabilities. Such concerns around basic standards of care provision not only include food, clothing, and housing, but also health care and medical treatment.

Parent participants from New Zealand also expressed their concerns around independent living and social adaptation. As discussed earlier, some perceived adaptation and leaving familial care as a gradual process which requires some level of responsibility, support and care from the parents in the process. Such perception was particularly articulated by a very small number parents who identified themselves to be progressively preparing for the future of their child by training skills that are necessary for out-of-home life, including skills needed for independent living and social adaptation.

Quality of life, continuation of daily activities and children's happiness are revealed to be some of the major considerations parents take into account while planning for children's future care provision. The ability to continue regular everyday-life routines is also highlighted frequently by parents from both country contexts. Participants noted that parents have serious concerns about the availability of continual leisure activities and activities related to the child's hobbies when planning for future care provision. Further, it is evident that significant consideration for children's happiness is taken into account in future care planning process among Korean parents in New Zealand. However, this received less emphasis in the Korean participant group where the emphasis was on the child's ability to carry out financial activities and their economic capacity.

Among the Korea based participants, economic capacity and ability to carry out financial activity of children living with disabilities were articulated to be important aspect to be considered in the planning process. In other words, a significant amount of consideration is



required around whether their child living with disabilities can generate income or not, and whether they can participate in financial activities when the parents are no longer available to provide care. On the other hand, as discussed earlier, for Korean parents living in New Zealand, the economic capacity of the children does not appear to be of great concern. It is evident that most Korean families in New Zealand are currently provided with (and also expecting) some level of state-level financial support in the future related to care provision for their children.

However, as participants noted, Korean parents in New Zealand experience difficulty finding an appropriate residential setting for Korean children living with disabilities, and much of this comes from a dilemma between independence, which Korean parents perceive to be favoured by the host country, and the values attached to familism. As discussed earlier, in the literature chapter, and throughout this chapter, Koreans value interdependence among family members more than independence. They accept that every individual needs help from others throughout the course of their lives. Based on familism concepts, members of a family feel obligated to take responsibility, care for other members' basic needs and keep up their morale. Hence, Korean parents of adult children living with disabilities often experience conflicts between the child's interdependence and independence. They have a desire to encourage self-sufficiency of their children living with disabilities, while also wanting to protect their children's well-being (Kim-Rupnow, 2001). In the present study, such conflict is experienced more intensely among parents living in New Zealand than in Korea, as the mainstream welfare system and provision are assumed by the parents to favour and operate to support independent living of people living with disabilities rather than collective, familial responsibility and interdependence.

## 6.2.2 Systemic Issues

### 6.2.2.1 Database

Issues around the lack of an adequate database must be resolved in both countries in order to increase the level of parental involvement in future care planning process. The findings of the study show that both New Zealand and Korean parents are experiencing difficulties around this lack. In New Zealand, case studies of families caring for children living with disabilities must be gathered to create a comprehensive database encompassing a wide range of case studies to provide guidelines on how to support and raise children living with disabilities.

In the case of Korea, the scattered data around available supports and service providers must be pulled and gathered together to overcome concerns regarding the lack of an overarching database of available supports and organisations providing services for people living with disabilities in order to enable integrated and comprehensive information to be available and provided to the carers. A development of 'All-in-One' information package, where all supports and service providers can be accessed through one single form of database, or a 'One-Stop' organisation solely focusing on providing information and making referrals to appropriate service providers for the service users in Korea is encouraged.

### 6.2.2.2 New Zealand: Education system

In the present study, the overall quality of education provided for the children in New Zealand is described as a major systemic issue the disability community is faced with. Both parent and professional participants caring for Korean children living with disabilities in New Zealand argued that the education provided in New Zealand is overly focused on the happiness of the

children while somewhat neglecting children's full potential to learn and progress. Concerns around children being not given appropriate and adequate opportunities to be educated and pushed to test their limits and reach their full potential were expressed by the participants in New Zealand. While the importance and the significance of early childhood education for children living with disabilities were articulated, criticism was made regarding the lack of availability of such services in New Zealand. A sense of fear is evident among New Zealand Korean mothers around current New Zealand services being unable to assist their children to meet their full potential.

### 6.2.2.3 Korea: Policy Implications and Lack of Professionals

Despite Yang's (2002) argument that the welfare system in Korea has been improved, and it has been changed to emphasise the responsibilities of the state and society rather than individual responsibility more than in the past and that the value of familism has weakened, the experiences of Korean participants based in Korea in the present study reflect that the actual reality is rather different.

Participants in the present study were unhappy that disability law and policies in Korea are at their highest level of development on paper, yet they lack in actual functionality. In particular, a number of participants criticised the lack of systemic support following the changes to ensure that such changes are actually taking effect and operating as intended. Hence, such a lack of systemic support around following up and operation are pushing parents to the frontline. In other words, the 'Self-Service' model of welfare where parents are directly involved in diverse levels of children's care and welfare is evident. Parents caring for children living with disabilities in Korea are not only directly involved in searching and gathering information around available and appropriate services and support or in the process of ensuring income activity for their children in the future, but also directly involved in social change activities. As discussed previously, parents living in Korea are actively engaged in making proposals to

change policies and system, networking with people involved to enforce such changes, and protesting to ensure welfare security for their children living with disabilities. For instance, it is evident that parents in Korea were directly involved in the process of getting funding for a lifelong learning centre in the community, and many other social campaigns and protests related to disability policies and support provision. Nevertheless, following up the process of implementation and ensuring the operation of law and policies concerning their child is evidently one of the most significant aspects of such direct involvement among parents caring for children living with disabilities in Korea.

Many have also complained about the grading system in Korea, where the Korean government determines the degree and types of the disabilities according to medical criteria. This then becomes the determinant of the types and amount of services accessible by the person living with disabilities (refer to the literature review chapter for a fuller description of the system). It is argued that this system limits the use of services by people who are in need. As discussed in the literature review, such a system is criticised for its denial of human rights in which different disabilities, circumstances, and needs of individuals are not taken into consideration. Further, participants of the present study claimed that such a system also creates dilemmas for individuals around further personal development and growth. For instance, there were cases shared by the participants in Korea where the opportunities for personal development were questioned or even jeopardised in order to obtain grades 1 to 3, which entitles people to the most services and support accessibility.

There is a continuous movement to abolish the system. The community of people living with disabilities and their advocates have been actively involved in a continuous fight to force the government to abolish the grading system. The government of Korea is aware of increasing complaints regarding the system and has made promises, in the past few years, to abolish it, yet it is criticized for being slow in putting words into action. The Ministry of Health and Welfare announced that it would introduce a new system in 2016 to assess individuals' disability comprehensively and obliterate the controversial grading system. However, these

promised changes did not take place. As a result, the community of people living with disabilities and their advocates are still fighting at present to make changes in the system to ensure human rights and dignity for people living with disabilities. For instance, the disabilities action group, Solidarity Against Disability Discrimination (SADD), staged a protest at the opening ceremony of the Joint World Conference on Social Work Education and Social Development 2016, requesting the government to abolish the grading system and the family support obligation rules, where the family is obliged to provide services first and foremost, not the state. In March 2018, the Korean government once again announced that the system will be phased out gradually starting from July 2019 and be replaced with comprehensive assessments. From 2019, people living with disabilities, regardless of their disability grades, can apply for personal assistant services and are eligible to use the service in accordance to their comprehensive assessment results. Such changes from grades being the sole criteria for service use to comprehensive assessments are planned to widen its spectrum to: transportation in 2020, and financial and employment support for people living with disabilities in 2022. However, 2018 420 SADD was established later that month and started a sleep-out sit-in protest near the Blue House hoping to have a face-to-face meeting with the president Moon. SADD argued that although the government has promised to make changes, the Ministry of Strategy and Finance are not budgeting for the changes to occur. They are saying that the core question is around budgeting and are willing to meet the president to secure the budget. Some are also criticizing that the planned changes to abolish the grading system is predicted to operate as a same function under a different frame. They are arguing that it is necessary to change the fundamental policy direction to ensure basic rights of people living with disabilities and marginalized people, rather than seeing abolishing the grading system as a mere elimination of a single system (Kim, 2018).

The family support obligation rules in Korea were criticised by the participants in the study for not functioning to support independence, rather these discourage independence and encouraging the population to be dependent on the welfare system. There were a number of cases shared where parents chose to have low socioeconomic status and become basic livelihood recipients to ensure their children's welfare benefits security. This is because, as

discussed in the literature review, unless they have no guardians or have guardians incapable of financially supporting them, they are exempt from the basic livelihood allowance. This in other words means, if the individual living with disabilities has a guardian who has properties or income, the individual is not eligible for the allowance, however since people living with disabilities are likely to be faced with difficulties in engaging in economic activities, they continue to financially depend on their family. This results in them not being eligible for the basic livelihood allowance under the guardian criteria (NHRCK, 2014). Hence, it can be argued that the family support obligation rules clearly created some degree of tension and contradiction where, on the one hand they reinforce the emphasis on familism and, on the other, there is creation of behaviours which lead to more reliance and dependency on state support. Such cases bluntly reflect the socially experienced reality of people living with disabilities and their families, and create a point of criticism around Korea's current system and welfare.

Further, the issue of perceived lack of professionals in Korea is also a critical matter that must be addressed urgently. The social work profession in Korea is not only questioned for its lack of involvement as agents for bridging between service users and providers, but also for its absences in linking the society and the population group. It was argued by the participants of the present study living in Korea that there is a lack of actual professionals in the disability field with adequate knowledge, understanding, and skills to be providing services and working with this client group. Social workers in Korea at this stage are further criticised to be overly focused in day-to-day support work, while perceived to be neglecting their roles as advocates, activists, and social change agents.

Perhaps it is arguable that such a lack of professionalism in Korea is a result of, or at least impacted by, familism values embedded within that society's general welfare consciousness, as well as in the welfare policies in Korea. In other words, it could be argued that the lack of emphasis on state responsibility for welfare (while regarding support provision as a family responsibility), as discussed previously, has led to a lack of professional development. Since it is assumed that families are the primary support and care providers based on traditional

familism values, state levels of involvement and professional intervention in Korea have remained at a minimum. However, since it is clearly indicated that such provision of support and care solely by the families with lack of state involvement and responsibility is insufficient to meet the needs of individuals living with disabilities and their families, changes must take place.

As a result of such a lack of professionals in Korea, parents are evidently becoming involved in activism to overcome difficulties related to disability issues. In fact, parents in Korea appear to be actively involved in making proposals to change policies and systems, networking with people involved to enforce such changes, and protesting to ensure welfare security for their children living with disabilities. This is arguably another form of 'Self-Service' in a wider societal level of involvement. In other words, as discussed earlier, the concept of 'Self-Service' model is not limited to 'micro level' (individual, personal level of interactions) where parents search and contact possible service providers, but goes further into the 'meso-level' (interactions between the micro and macro levels which are (–large, systemic, community, organisational) of society of involvement where parents get directly involved in social change activities.

Compared to the parents in Korea, Korean parents in New Zealand appear to be much less involved in social change activities. There are a number of possible explanations for such lack of involvement. Firstly, this may be a result of their status as migrants. My previous research (Choi, 2014) revealed that Korean migrant parents often perceive themselves as passive recipients who have to adjust and conform to the services even in situations where the services did not meet their needs and hence they are not actively involved in such activities. Secondly, this may be influenced by the general nature of Korean culture. As a professional participant of the present study mentioned earlier, the Korean community in New Zealand can be rather exclusive and passive, and this may have posed challenges among Korean parents in taking active parts in the mainstream community. Thirdly, as Korean parents in New Zealand have a trust in, and are generally satisfied with, the overall welfare system and services, they may not

see the need for any further social changes. As discussed, parents living in New Zealand appear to perceive the country's disability system and service as a 'Safety-Net', where the government and society take active responsibility for the care and support of the population over the family. Therefore, since the state is perceived to be taking an active role in the provision of basic support and services, and protecting their children and families in emergency situations, they may not see the need for a major systemic changes or to be actively involved in such activities. Yet, as discussed earlier, such lack of involvement in social change activities may lead to state dependency among Korean parents living in New Zealand, and also potentially further segregate the Korean community from mainstream society.

### 6.2.3 Education

The need for education, training and workshops where parents are provided with general information regarding raising children living with disabilities, available supports and providers, and processes of future care planning were communicated by participants regardless of country context. Yet, while similar comments were made by participants in New Zealand and Korea regarding the need for education and training opportunities, it is evident that Korean parents in New Zealand were seeing the need for *continuous* and *further* opportunities, whereas in Korea, there is a perceived lack of actual tangible and appropriate education and training available for the parents at this stage.

Although some level of satisfaction around the education, workshop, and training opportunities is evident among parents in New Zealand, desires and needs for further parental education are also evident. Further, as discussed earlier under systemic issues as one of the major concerns for Korean parents in New Zealand, the desire for continuous training opportunities and education for the children are also articulated.



Similarly, parent participants in Korea expressed both the need and their desires for parental education around what to expect, the developmental expectations, as well as available service and programme options. However, it is different in New Zealand, where desire for and the need for *continuous* and *further* opportunities are expressed, as these parents in Korea are claiming that there is a lack of, or close to no, available solid and applicable education and training provided in Korea. Further, the need for early intervention, from the stage of diagnosis, is evident in Korea. Participants in Korea were surprised to know that in New Zealand interventions take place as early as in the initial diagnosis stage and that families are provided with support from that time. They argued that such systems and services should be available for *all* parents of children living with disabilities regardless of where they live in the world, yet it is evident that parents in Korea at this stage are left with fears of not knowing what to expect and where to find support other than from their family members.

#### 6.2.4 Post-School-Age Programmes

One of the biggest concerns for parents, living in both Korea and New Zealand caring for children living with disabilities appear to be around post-school-age care provision. According to the participants in both countries, the lack of information, discussed throughout the chapter, becomes even more problematic once the child enters adulthood or completes school years as it cuts off any channels for possible information exchange. From a number of examples that participants shared, this then led to parents experiencing future care planning process as an individual problem, one which needed to be resolved on a very personal level. On that note, some suggested that it would be beneficial for parents to start working on their child's future care provision planning while the child is still at school as parents have more information, strength and financial means to undertake the process while their children are still under the care of the school system.

Closer attention needs to be paid to available support and services for post-school-aged children and families and caring for them in order to resolve such concerns. It was evident in the collected data that professionals and parents from both countries hold immense concerns around support and service quality and availability for children living with disabilities once they enter adulthood or graduate from school. Criticisms were made around lack of available services for children living with disabilities after school age and the reality that everything becomes dependent on the child and their family's ability to support themselves and gather information once the children graduate from school. The desire and need for continuation of education and training for children after they leave school, and parents indicated that a loss of trained ability to carry out certain aspects of life independently in their children after completing school years (as they are no longer provided with education and training from the schools) also reflect the lack of services and programmes available for post-school-aged children living with disabilities.

Professional participants from both New Zealand and Korea emphasise parental education and peer networking as ways to resolve concerns around lack of information among parents caring for post-school-aged children. The significance and the need for peer-support and community involvement are discussed later. The need for extended and continuous services for children living with disabilities even after school age was evident, while both countries are criticised for a lack of available services and programmes for children out of school. Thus, it is possible to argue that the criteria around the eligibility for the service use should not be the age of the children living with disabilities, rather it should be based on their needs.

#### 6.2.5 Cultural Barriers

In order to overcome the low level of future care planning among Korean parents caring for children living with disabilities in New Zealand, closer attention to the issues related to cultural barriers needs to be given as the socially experienced reality of future care planning among

these parents is found to be impacted by cultural barriers. Most of the professional participants from New Zealand argued that cultural barriers were among the most significant reasons for a lack of planning among Korean parents in New Zealand. Lack of culturally appropriate services and provision of information for Koreans, New Zealand 'style' provision of services, coercion towards independent living, food, lack of understanding around service systems and social community, and language were some of the cultural differences identified repeatedly by the participants.

A primary concern and a need identified within the New Zealand participant group regarding future care provision for their children living with disabilities, was the need for culturally appropriate services. Participants highlighted the need for services that are based on and operating under Korean cultural foundations. A strong preference towards Korean residential care provided and serviced by Korean service providers within the Korean community for Korean children living with disabilities is evident. One participant stated that a service operated by Koreans for Koreans' children and their families in New Zealand will benefit the service users as the service will be able to provide continuous ties with the Korean community, which will enable children to attend programmes provided within the Korean community for Korean children, and to practise their Korean culture.

In addition to the connections between lack of planning and cultural barriers and perceived lack of appropriate cultural services, participants of the present study have also commented on aspects of general Korean culture that impede future care provision planning process among Korean parents living in New Zealand. For instance, a professional participant has noted how the Korean community is rather exclusive and passive, and that such passive attitudes pose challenges among Korean parents in taking part in the mainstream community and pushing their own boundaries. A comparable pattern was also evident in my previous (2014) study. The 2014 study revealed that Korean migrant parents often perceived themselves as passive recipients who have to adjust and conform to the services even in situations where the services did not meet their needs. Similarly, in the present study, a huge contradiction was evident

between a mainstream social worker and parents interviewed in regard to service utilisation among Korean parents. Although the number was too small to make any generalisation, one New Zealand professional from a mainstream organisation in her interview clearly stated that Korean parents are very willing and actively engaged in the community and with service providers, which rather a contradictory statement in respect of the majority of data collected. This indicates that Korean parents may, by disguising their true feelings and reflections of the service provided, adjust themselves and become passive recipients of provided services, yet are perceived as active service users from the providers' viewpoint. This clearly indicates the need, not only for culturally sensitive practice in the fields, but also for further research concerning the minority communities in a culturally sensitive manner within a trusting relationship, as otherwise we will run the risk of never finding out the true experiences and reflections of such communities.

#### 6.2.6 Peer Support and Community Involvement

The need for parents caring for children living with disabilities to be more open about sharing their experiences and actively engaged in communities is articulated in both country contexts. The need for such involvement and engagement is often interconnected with an increase in information exchange and possibilities of better service provision and support, as well as providing opportunities for their child to live inclusively within the community. Participants from both countries have also argued that there is a need for the parent and the child's active involvement in the communities in order to overcome stigma, negative public perception, and to work towards a more inclusive society for their children to live in.

Further, as many participants identified, other senior parents who had experienced and followed similar paths were among the most valuable and helpful supporters. Forming and strengthening peer-support and networks were other significant reasons supporting the need for community involvement. Regardless of their country context, both professional and parent

participants identified other senior parents who had experienced similar journeys as most valuable and helpful supporters and resources. The experiences and advice from the senior parents are considered significant and motivational, both in general caregiving, as well as in future care provision planning. Such support from seniors is evident amongst children living with disabilities themselves, where they build trust and rely on other senior persons living with disabilities, and professionals try to pair them up with their senior members when children go into communities for independent living to create a reference point for them.

### 6.3 Conclusion

In conclusion, this chapter discussed two primary themes including Future Care Planning: In Process, and Looking to the Future: Issues to be Resolved. The chapter concluded that future care planning is still ‘in process’ in both country contexts as participants from both countries expressed a pervasive concern and an interest related to planning for their children’s future care, yet lacked concrete plans and substantive practice. The present discussion argues that such low levels of planning and difficulties experienced among Korean parents in both countries is influenced by the cultural principles that parents hold, as well as the cultural values reflected in the system and policies of the countries studied. The discussion around the findings of the study suggests that the strong familism culture prevalent in Korea is creating a ‘Self-Service’ model of welfare in Korea. It is evident that the traditional emphasis on family and family provision of care were creating tensions between state and individual involvement. Parents in Korea are often perceived to be directly involved in care provision for their children living with disabilities, in other words ‘Self-Servicing’ their own needs, while parents’ economic circumstances play a significant role in determining their service provision options. On the other hand, in New Zealand where greater emphasis is placed on the government and state responsibility, the system is perceived to create a ‘Safety-Net’, resulting in greater satisfaction and trust yet also generating a certain level of state dependency. Further, Korean parents living in New Zealand are perceived to be significantly impacted by cultural barriers, including: a lack of culturally appropriate services and provision of information for Koreans;

pressure of independent living; suitable food provision; lack of understanding around service systems; and language. These cultural barriers in the New Zealand context are identified to be the most significant reasons for lack of planning among Korean parents in New Zealand. The chapter identified a number of issues that need to be resolved in order for the future care planning process to take its place as a natural and conventional phase of caring for children living with disabilities including independent living; systemic issues; education; post-school-age programmes; reducing cultural barriers and increasing community involvement. With what has been discussed in this chapter, the following chapter draws conclusions and makes some recommendations.

## CHAPTER 7 Conclusion and Recommendations

The present cross-national study revealed significant impacts of national context and culture on future care planning for children living with disabilities for Korean parents in Korea and in New Zealand. It is evident that the strong familism culture is still prevalent in Korea and is creating a 'Self-Service' model of welfare where parents caring for children living with disabilities in Korea need to directly and actively be involved in most aspects of care provision. Such strong familism embedded within Korean culture can also be evident among Korean migrant families in New Zealand. It is evident that traditional familism values are creating dilemmas among Korean parents living in New Zealand where individualism is perceived to be favoured by the system and society in general. It is also evident that Korean parents in New Zealand perceive the service system as a 'Safety-Net', and is argued to be generating a level of state dependency among parents caring for children living with disabilities in New Zealand.

The fundamental argument of the discussion is not to say that familism is undesirable, nor should it be eliminated, nor that the state should provide all welfare support, but to suggest a development of a 'Korean Model of Welfare' or the 'New East Asian Model of Welfare' through state-level involvement in encouraging, empowering, and strengthening family functioning while reflecting the traditional characteristics of our cultural values. Hence, this chapter, while concluding the major findings and discussions of the study, aims to provide a number of recommendations to empower and enhance family functioning in Korea to reduce the tendency of placing families as the primary and almost the only responsibility holders in the care provision for children living with disabilities in Korea with minimal governmental intervention by clinging onto familism values and concepts, while also stimulating family functioning among the Korean parents living in New Zealand to minimize the level of state dependency evident among some parents. Such proposed conceptions are articulated throughout the chapter with some examples and literature to better illustrate the argument.

Drawing on the research findings, the study concludes that future care planning is still ‘in process’ in both Korea and New Zealand contexts. Although Korean parents living in Korea and New Zealand all appear to have very deep concerns and anxieties around the issue, planning for the future care provision is a reasonably new concept for them. In other words, for a number of different reasons, planning for future care provision for their children living with disabilities has been an overlooked area until very recently.

Parents from both countries display a pervasive concern and anxiety related to future care planning for their children living with disabilities. It is evident that parents in both countries recognise the need for, and show great interest in, future care planning, while also being persistently concerned about what the future will look like for their children when they can no longer provide care for them, yet lacked concrete plans and substantive practice. Planning is also perceived to be a gradual process by Korean parents caring for children living with disabilities regardless of where they are placed in the world, rather than a product of a sudden arrangement. Hence, a small number of parents in both countries are constantly training their children in the skills necessary for out-of-home life, which is often discussed as part of planning for their children’s future care.

The reasons behind such lack of planning included Korean parents living in both Korea and New Zealand settling for and being accustomed to the status quo and emotional distress. Emotional distress in Korea is often related to negative public perceptions towards people living with disabilities, while experiences in New Zealand, compared to Korea, are shown to be much more positive in terms of public perception of and treatment of people living with disabilities.

Yet, future care planning process among Korean parents in New Zealand are evidently affected by cultural barriers. Lack of culturally appropriate services for Koreans, New Zealand ‘style’ provision of services, coercion of independent living, food, lack of



understanding around the social community, and language are some of the cultural differences identified to have an impact on future care planning process among Korean parents in New Zealand. Nevertheless, Korean culture and familism clearly have a substantial impact on Korean families living in New Zealand. As mentioned, it is evident that Korean families in New Zealand are faced with a dilemma between independence, which Korean parents perceive as favoured by the host country, and the values attached to familism.

Lack of information was identified unanimously in both countries as one of the primary reasons behind the low levels of future planning. However, while cultural differences and language barriers are evidently creating barriers around information circulation and gathering in New Zealand, values attached to familism appear as the main cause of a lack of information among parents in Korea. In the Korean context, it appears that familism, where the responsibility of care provision is placed on the family over any other individuals or groups, leads to a lack of public support and systemic foundations, leaving the planning process as a personal and familial problem, which ultimately results in a 'Self-Service' model of welfare provision in Korea.

Further, one of the principal differences in service systems between the two countries is the bridging role between service users and providers, as well as between the society and the population group. Just as is experienced around the lack of information, there is an absence of organizations or service providers to enable direct contacts between the service users and providers. Hence, in Korea, parents have the responsibilities in the process of searching and facilitating care provision of their children rather than being supported by service providers, which again reflects values attached to familism. On the other hand, in the New Zealand context, welfare services and systems are constituting a 'Safety-Net', which the system operates to provide all necessary services and support, and to prevent and protect children and families in emergency situations and also to provide some support for service choices. Service coordinators and referral services through a wide range of disability organisations

are available in New Zealand to support direct contact with possible service providers. However, although such a system may be welcomed by service users, it can potentially create state dependency among Korean parents in New Zealand as it may prevent families from actively engaging with a range of different service providers in the process of future care planning.

Another most significant difference between the two countries studied in relation to reasons behind the lack of planning is around the perceived choices and options parents have regarding future care provision for their children living with disabilities. While a sense of ‘having a choice’ is evident around how their children’s future care provision will be arranged in New Zealand, having no choice and options to consider appear to be one of the most significant and unique reasons that surfaced only in the context of Korea. As a result, some parents in Korea who are wealthy enough are thinking about or in the process of establishing a private living facility or owning and running a small-scale business, where the concept of familism leading ‘Self-Service’ welfare model again appears.

However, establishing a care centre is an option that is only available to parents with enough financial means. Nevertheless, economic capacity in general is evidently one of the most significant factors impacting on future care provision planning among parents living in Korea. For parents residing in Korea, it is perceived that parents’ economic capacity not only determines the care provision plans, but the possibility of even thinking about the actual plan itself is also determined by the parent’s economic capacity. In other words, what the families themselves can financially offer and provide for their children living with disabilities is critical in Korean society. On the other hand, provision of welfare in New Zealand is much more centred around the needs and status of the individuals living disabilities themselves compared to provision in Korea. In other words, children living with disabilities in New Zealand are much less likely to be impacted by the economic capacity of the parents. Further, in relation to financial support related to care provision, the state is again perceived as a ‘Safety-Net’, indicating certain level of expectations around state-level financial support in

the provision of care for their children living with disabilities among Korean parents living in New Zealand. As stated earlier, the option of establishing a care centre in Korea is an option available only for financially wealthy parents, but if the parents do not have the financial means to secure future care provision themselves, the only other alternative option revealed to be available is to have them under familial care, which is merely a different aspect of the 'Self-Service' welfare model.

Of the future care plans and options identified in both country contexts, other than having only a very vague plan or no plan at all, the most frequently identified option was having the children under their familial care for as long as possible. This option is perceived to be the most predominant form of care provision which again reflects familism. However, while the notion of familial care among parents in New Zealand implies having them under their care for as long as they can, and then placing them under the care provided by welfare services as a last resort, in Korea, the option is commonly one that involves other family members in the actual and direct care provision. Such difference may have resulted from how the welfare system in the countries studied are viewed by the parents. As discussed throughout the chapter, Korean parents in New Zealand perceive the welfare system as a being a 'Safety-Net', hence services are in place for families to count on as a refuge when they are no longer able to provide care for their children. On the other hand, in the Korean context, a strong familism and the 'Self-Service' model of welfare is evident again where families are planning to provide welfare and support themselves rather than being supported and provided care by other services or supports.

Nevertheless, there are significant differences in trust towards the overall disability system and services in different national contexts, and the analysis of the plans parents have for their children living with disabilities and the reasons behind relatively low levels of planning is revealed to have been greatly impacted by parents' trust towards the overall disability system and services in the countries studied. Korean parents caring for children living with disabilities in New Zealand are evidently satisfied with the quality of the general system and service provision. Yet, the strong trust in the state-level system and service provision, and accepting

the ‘Safety-Net’ is perceived to result in lack of active involvement in the planning process. In contrast, parents in Korea pervasively appear to have neither expectations nor trust in the system and services provided. Welfare systems and services that are perceived to be operating under the ‘Self-Servicing’ model in Korea, along with other issues including having no choice, a lack of information and a lack of professionals, and the impact of economic capacity are revealed to have an accumulative negative impact on trust towards the system and services in Korea, which ultimately is highly likely to have negative impacts on the planning process.

Further, there are also a number of similarities and differences in aspects parents consider in the planning process depending on the country they are based in. Correspondingly, there are issues and concerns that need to be resolved in both countries studied in order for the future care planning process to take its place as a natural and normal phase of caring for children living with disabilities in the future. Regardless of country contexts, the child’s ability to live independently and social adaptation are articulated to be the most important aspects concerning the parents caring for children living with disabilities in the process of planning for future care provision. Much of the concerns around these are arguably strongly related to the human rights of people living with disabilities, which should be recognised, protected and promoted. Under the first article of the Universal Declaration of Human Rights (UDHR): “all human beings are born free and equal in dignity and rights” and that they are entitled to the human rights without distinction of any kind, which the UNCRPD incorporated in 2007. Some of the principles of the Convention include: respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons; non-discrimination; equality of opportunity; respect for the evolving capacities of children living with disabilities and respect for the right of children living with disabilities to preserve their identities.

State Parties to the UNCRPD, which include both New Zealand and Korea, should recognise the rights of people living with disabilities to an adequate standard of living for individuals and their families, including adequate clothing, food, and housing, and to the consistent development of their living conditions, and should take adequate steps to ensure and promote

the realisation of this right without discrimination on the basis of disability. Further, in accordance to the Convention, both New Zealand and Korea hold obligations to recognise that people living with disabilities have the right to the enjoyment of the highest possible health standards without discrimination on the basis of disability. The right to social protection and to the enjoyment of that right should also be recognised and protected by the states without discrimination on the basis of disability. The states need to recognise the equal right of every individual living with disability to live in the community, with equal choices to others, and should take appropriate and effective approaches to facilitate full enjoyment of the rights and their full inclusion and participation in the community.

Further, as the parents living in Korea appear to be particularly concerned about the economic capacity and ability to carry out financial activity of children living with disabilities, Korea, as a nation, should promote and safeguard the realisation of the right to work by taking appropriate steps, including through legislation. Under the UNCRPD, the nation needs to recognise the right of individuals living with disabilities to work, on an equal basis with others living without disabilities, which includes “the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities” (UNCRPD, 2006, p. 17).

Although the Korean government made efforts to support and protect equal work opportunities for the people living with disabilities under the Employment Promotion and Vocational Rehabilitation for Disabled Persons Act 1990, since the employment system for people living with disabilities in Korea is criticised for lack of systematic level of involvement and penalties when such provision is neglected, it is observed that changes to the system are necessary. Perhaps having a ‘Subsidized Employment System’ whereby the government subsidises part of wages for people living with severe disabilities to ensure these people are guaranteed the minimum wage, as implemented in many other major OECD countries may ensure that people living with disabilities in Korea are not paid less than minimum by reason of low productivity (NHRCK, 2014).

Nevertheless, as discussed as one of the primary reasons behind lack of planning in Korea, parents' economic capacity poses a significant level of anxiety and pressure around future care provision and the process of planning. The present study suggests that a system must be developed and put in place to ensure basic standards of living for people living with disabilities which reflect the clients' situation, allowing diverse options, regardless of the economic capacity of the parents. Further, regarding people living with disabilities and their families living in situations of poverty, both New Zealand and Korea, under human rights conventions, hold responsibilities to ensure access to assistance from the state with expenses related to disabilities, including adequate financial assistance, counselling, training, and respite care. However, it is argued that the services provided and the systems related to disability and poverty in Korea, such as the basic livelihood allowance and the family support obligation rules, are inadequate to meet families' needs.

The current disability law and policies in Korea are criticized by parents and professionals for being at the highest level of development on paper only, lacking in actual functionality. For instance, the grading system and the family support obligation rules in Korea are criticised for not functioning to support independence, rather discouraging independence and reinforcing the idea that the population should dependent on the welfare system. This indicates, despite Yang's (2002) argument that the welfare system in Korea has been improved, and that the value of familism has weakened, the experiences of Korean parents caring for children living with disabilities in Korea reflect that the actual reality is rather different.

Phillips and Jung also (2013) concluded that they have identified and evidenced unmet needs among disadvantaged people which were closely associated with the family support obligation. According to their statements, in Korea, the role of the family has been strongly emphasised in coping with the issues around poverty and inequality, forcing individuals to seek support from their members of the family rather than claiming it as a right of social citizenship from the state. Justified by the traditional Confucian conceptualisation, the priority of family support is

politically encouraged, promoted, and remains pervasive. They noted “despite its growth in coverage, and reflecting policy adherence to familism, the new public assistance program maintained the criterion requiring the absence of expected income support from any other family member” (Phillips & Jung, 2013, p. 20).

Phillips and Jung (2013) argue that, by clinging to outdated Confucianism concepts of familial piety as justification of extremely selectivist access to what is nothing more than a subsistence level of financial support for disadvantaged and poor people, the proposition of a poverty safety-net in contemporary South Korea is compromised and is missing its objective of reducing inequality and poverty. According to their arguments, although there have been suggestions to incorporate traditional familism into the reinforcement of the Korean social welfare system, participants of their study supported an alternative view that there are a number of key risks in a familistic welfare regime, and reflected Korea’s slow development or underdeveloped social assistance as a mean of addressing poverty and wider social inequality issues. Their study poses challenges to what can be perceived as an outdated cultural ideal in Korea that articulates an individual’s responsibilities and a reliance on a Confucian model of family piety, and argue that this is because the traditional values of familial responsibility for welfare are no longer compatible with the current progress of economic and social changes in Korea (Phillips & Jung, 2013).

Nevertheless, it could be argued that while their notion of familism seems to be high, Korean parents based in Korea also tend to have high level of expectation from the state. However, this may be because Korean people in general regard children and elderly living with disabilities as the primary welfare support recipients, whom the government should provide for (Shin & Park, 1995; Yang, 2002). As discussed earlier, according to Yang (2002), the supports for people living with disabilities, single mothers, and children of families without parents are perceived to be primary welfare subjects that the government should provide for, whereas familial responsibility was identified to be anticipated over state responsibility in the areas of poverty and elder care. Further, from the findings of her research, the need for non-familial responsibility for people living with disabilities has been argued most strongly by the participants compared to any other groups. She argues that such results can be seen as a result

of the attempts and consensus to shift disability from private responsibility to public responsibility. However, to achieve such welfare status where the government holds the primary responsibility for welfare provision for persons living with disabilities, it was evident that more organisational and social involvement were needed for this population (Yang, 2002).

From the findings of the present study, it is clearly evident that, ultimately, the state needs to support families themselves rather than reinforcing the family support system. In other words, as Chang (1997) argues, the essential goal of policy concerning family support should be around providing social and economic resources needed by families in overcoming diverse obstacles to integrated family life. Further, as argued throughout the discussion, in order to develop social welfare for the future, family-oriented traditions should not be used as a means to avoid the obligation of the state to provide the welfare, but rather encourage state levels of development and provision of social work services that are designed as a mechanism to strengthen the function of the family in positive, individualised and diverse ways (Yang, 2002).. In other words, the traditional familism values should provide a policy implication in a way that such values could be utilised as a positive reinforcement mechanism to empower and enhance family functioning, which may enable development of a ‘Korean Welfare Model’ or the ‘New East Asian Welfare Model’ reflecting the traditional characteristics of our social and cultural value. According to Yang’s (2002) argument, it would be possible to make an assumption that it will then affect the welfare consciousness – which weakens the nurturing and protecting function of the family and amplifies the government intervention and the demand for it.

While Koreans have been criticized (Yang, 2002) for having a weak welfare consciousness as they regard provision of support as family responsibility based on familism values, and limiting the welfare responsibility of the state as well as developing such a welfare system on the basis of traditional values, since the 1990s, some changes are evident. Yang (2002) concluded in her study that the traditional familism, which emphasises the family over the individual, has been maintained in contemporary Korean society, but it has also undergone



some changes in a positive direction over the years with efforts to resolve social issues created by familism and the values attached to it, such as efforts to achieve gender equality (Yang, 2002). As evident in the present study, efforts to achieve such positive changes in the disability field are also stirring in Korea. However, there is still criticism that much of the effort is generated by the parents and individuals living with disabilities with rather limited involvement of professionals in the field. Hence, social workers in Korea, with their professional knowledge and skills, must increase their involvement in leading social and systemic changes through working together with service users as social activists to empower, advocate for people living with disabilities and their families.

Furthermore, there is a serious and urgent need for fostering social work professionals with expertise in the disability field in the Korean context. There is a need to promote a group of disability specialists as service coordinators, in the hope that these disability coordinators will provide an integrated 'One-Stop' service and information, creating links between different service providers as an umbrella body of disability services, as well as engaging actively in developing a comprehensive database around factual knowledge of service needs and wants, which reflects the socially experienced reality of disability services and systems. Further, social workers in Korea must work together with service users as social activists to lead social and systemic changes in Korea. Such development is likely to reduce the level of 'Self-Servicing' welfare provision, hence the high level of familism associated with care provision for children living with disabilities, through using the support of the state to empower and support the families while also providing services as needed.

In order to provide such competent and continuous services, the system of rotation happening in the Community Service Centres in Korea, where social work professionals shift between the welfare departments (including disabilities, elderly, and youth) within the centres, approximately every two years, needs to change. In order to enrich the professionalism of each welfare department, professionals should be given enough time and sufficient opportunities to practise and develop knowledge, skills, understanding, and abilities to become competent

professionals – both professional and parent participants in the present study claimed that two years is not enough time to achieve such comprehensive professionalism.

Meanwhile, the values attached to familism are also evident in affecting future planning for Korean parents living in New Zealand. Korean parents in New Zealand are perceived to be experiencing difficulty finding an appropriate residential setting for Korean children living with disabilities, and, as discussed earlier, much of this comes from a dilemma between independence, which Korean parents perceive as favoured by the host country, and the values attached to familism. Similar to the findings in Kim-Rupnow's (2001) study, participants in the present study expressed their desire to encourage self-sufficiency of their children living with disabilities, while also wanting to protect their children's well-being.

Studies argue that ethnic minorities often have differing perceptions around disabilities compared with the values embodied in the health care system in the host society (Bywaters et al., 2003; Fatimilehin & Nadirshaw, 1994; Westbrook et al., 1993). For instance, a study conducted by Westbrook and his research team (1993) discovered a significant mismatch between the expectations and attitudes of people from different ethnic communities and mainstream health care programmes. For instance, Baquedano-Lopez, Alexander, and Hernandez's (2013) study on equity issues in parental and community involvement in schools noted that current school goals are largely based on middle-class and white values and expectations, and argued that this is posing difficulties for families from non-dominant backgrounds. It is important to understand that such a mismatch has the potential to result in ineffective treatment and dissatisfaction for both the service users and the providers (Westbrook et al., 1993).

Hence, in order to resolve such concerns related to finding the most appropriate residential setting for their children in the host country, education is critical. Through provision of education and information, parents should always be empowered and encouraged to be

involved in the matters concerning their children's well-being and provision of care and support. Parents should be provided with information of every possible option, and have a full understanding of each option before they make decision on their children's future care provider. They must understand that there are other options that recognise the importance of familial involvement in care provision and does not necessarily implicate complete independence, such as 'Funded Family Care' and 'Choice in Community Living' discussed above.

Further, another approach to resolve such issues is the development of a culturally appropriate service for Korean children living with disabilities in New Zealand. A strong preference towards Korean residential care provided and serviced by Korean service providers within the Korean community for Korean children living with disabilities is evident among Korean families living in New Zealand. It is argued that a service operated by Koreans for Koreans children and their families in New Zealand will benefit the service users. A similar suggestion was also apparent in a study I conducted earlier (Choi, 2014) on experiences and perceptions of Korean parents caring for children living with disabilities in New Zealand. The participants in my previous study made a recommendation for an establishment of an organisation for Koreans by Koreans. It was noted that there are potential benefits in creating and establishing an organisation for Korean children living with disability by Korean professionals and parents of those children. It was expected that such services would reduce issues around culture, language and food, and provide more culturally appropriate services for the children living with disabilities and their families. It was proposed that if the Korean community can establish an organisation or service that operates practising Korean culture, while understanding and comprehending New Zealand's policy and systems, this may resolve cultural issues such as food and communication, and increase parental involvement in service provision (Choi, 2014). Such an approach may encourage familism embedded within Korean culture while reducing the level of state dependency evident among Korean parents living in New Zealand, as discussed earlier. Further, it was proposed that this may also create job opportunities, and thus lead to greater financial independence for Korean parents with children living with disabilities as well as children themselves in New Zealand (Choi, 2014). Yet, such initiatives must be approached with great consideration and care as it may pose the potential

risk of isolating minority communities further from the mainstream society, and limiting service provision options.

From a number of studies conducted to explore experiences and service utilisation among Asian people living with disabilities, it is evident that there is lack of culturally appropriate services provision for Asian communities (Azmi, Hatton, Emerson, & Cain, 1997; Baquedano-Lopez et al., 2013; Choi, 2014; Hatton et al., 1998; McGrother, Bhaumik, & Thorp, 2002). My previous (Choi, 2014) study revealed that, in order to ensure culturally appropriate services, there is a need for more Korean professionals to be involved in the field. A similar suggestion was also raised in a study carried out in the United Kingdom. The study conducted by Azmi and her colleagues (Azmi, Hatton, Emerson, & Caine, 1997) discovered that existing services for Asian clients in the UK are inappropriate in terms of numbers and positions of Asian staff members in mainstream services. Furthermore, Hatton and his research team (1998) also argued, in order to improve service for Asian communities, there is a need for improvements relative to communication between Asian families and service providers. One of the suggestions they made to achieve such improvements is to employ more Asian staff with appropriate language skills in mainstream services to reduce difficulties around communication between the service users and professionals. Such a suggestion around employing and engaging more Korean professionals in the mainstream health care field to enhance communication between carers and services, and thus ensure the needs of the carers to be met were also raised in my previous study.

Nevertheless, although it was not dealt in this study, from my previous study it was evident that Korean parents living in New Zealand were concerned with the language use of their children. Parents were observed to be experiencing difficulties around balancing which language their children should use as children need to communicate with family members in Korean at home, while there is a need to be able to communicate in English when they are in schools or other mainstream services. Hence, by employing more Asian staff with appropriate

language skills in mainstream services, the issues and concerns around children's language use may be resolved or at least be reduced.

Other than cultural issues and concerns, the overall quality of education provided for the children in New Zealand is criticised by Korean parents as a major systemic issue the disability community is faced with. Both parents and professionals caring for Korean children living with disabilities in New Zealand argued that the education provided in New Zealand is overly focused on the happiness of the children while somewhat neglecting children's full potential to learn and progress. They seem to fear that current New Zealand services may not assist their children to meet their full potential. Hence, the present study suggests comprehensive early intervention supports and services be provided with increased diversity and availability in New Zealand.

Guralnick (2017) states that a particular setting in which a certain level of structure is necessary and valuable is in preschool. The provision of comprehensive early intervention supports and services for children living with developmental delays continues to be a high priority in almost all nations throughout the world. The potential contributions of such support and services to children's development and to the well-being of families, in general, are well-recognised by the international community (World Health Organisation & UNICEF, 2012). There are indications that comprehensive, early intervention programmes can, at minimum, help prevent the decline in intellectual development that mostly takes place across the early childhood period for children living with developmental delays (Guralnick, 2005). According to Guralnick (2017):

Early intervention systems capable of coordinating other services and supports in conjunction with inclusive preschool programmes that centre on families and promote other aspects of family patterns of interaction will provide the type of comprehensive system essential to maximizing children's cognitive as well as their social competence.

Early intervention programmes, designed primarily to enhance the developmental competence of children and to prevent or minimise developmental delays, provide a range of therapeutic and educational programmes to children and their families. Such interventions include programmes and services aimed at maximising or maintaining the child's development. Nevertheless, most interventions also support families in coping effectively with challenges they face daily at home and in the wider community, and increase the level of collaboration between professionals (Majnemer, 1998). It is increasingly appreciated that self-initiated, active interactions with the environment are essential to produce developmental effects, supporting interventions that assist active and ongoing participation of the child and are child-focused. Environmental experiences allow young children to interact and solve problems, hence stimulating new developmental skills. More recent researchers claim that such interventions can modify biological insults as well as maximise developmental gains through enriched experiences. It is argued that such experiences must take place early in order to achieve the maximal effect (Majnemer, 1998). Further, in the field of intellectual disabilities, early intervention is playing an increasingly prominent role, creating expectations that comprehensive, systematic, experientially based interventions will modify developmental trajectories and prevent secondary complications. Such expectations include that much can be accomplished during the first five years of a child's life through thoughtful implementation of such early intervention programmes. In other words, it is anticipated that early intervention programmes will enhance the development of children already displaying intellectual delays through modifying their developmental trajectories (Guralnick, 2005, 2017; Majnemer, 1998).

It is suggested that benefits to children's social and cognitive competence are some of the direct results of improved developmental influences on children's outcomes related to various aspects related to parent-child transactions, family-orchestrated child experiences (for example, community participation) and children's health and safety. It is expected that an extensive investment in comprehensive and systematic early intervention will produce long-term benefits

for children and their families, benefits that will be sustained over time and which are cost effective (Guralnick, 2005). Perceived parental benefits of participation in early intervention includes: advocating for their child, assisting in their child's development and working with professionals, which appears to result in increased parental confidence in their ability to carry out their roles as well as responsibilities related to their child living with disabilities (Guralnick, 2005).

Nevertheless, the need for education, training and workshops for parents where parents are provided with general information regarding raising children living with disabilities, available supports and providers, and processes of future care planning are identified regardless of country contexts. In order to resolve concerns around education and training opportunities in both countries, the issues around the lack of a comprehensive database need to be resolved. For New Zealand, once the issues around the lack of databases around case studies to provide guidelines on how to support and raise children living with disabilities is resolved, it would be possible for the development of new programmes, while also supplementing the existing programmes, for the parents and children, that are continuous and practice-based on the case studies. For Korea, once data are gathered to overcome concerns regarding lack of an overarching database of organisations which provide services for people living with disabilities, it will enable collective and comprehensive information to be available and provided to the carers. Nevertheless, as argued by participants in Korea, an intervention which takes place from as early as diagnosis must be introduced, implemented and provided for the parents caring for children living with disabilities as soon as possible in Korea. It is necessary and essential to be able to address the needs of families during the most stressful and traumatic period and to focus on the aspects that may support, strengthen and empower the families and maximise the development of the children (Guralnick, 2005). Further, it is clearly evident that appropriate interventions and routinely provided treatments at an early age can go a long way to easing concerns around the future, as they lead to enhanced levels of skills and independence for the individuals living with disabilities (Dillenburger & McKerr, 2011; Keenan, Kerr, & Dillenburger, 2000).

Further, with the improved database, the welfare system will be better equipped to respond in the future through careful evaluation of how currently implemented formal supports are actually supporting families. Areas to target in system monitoring, as Lunsky, Tint, Robinson, Gordeyko, and Ouellette-Kuntz (2014) state, should include information on who needs services, what services are needed, and families' perceptions around the caregiving experiences. Information on the different types of supports families are providing to their family member living with disabilities, including residential, case management, recreational, transportation, social, permanency planning or advocacy (publicly funded, informal, and paid), could assist the current system to predict potential future needs which the formal system may be called upon to meet and to improve the quality of the services.

In addition, the need for Korean parents caring for children living with disabilities to be more open about sharing their experiences and actively engaged in communities needs emphasis in both country contexts. Community participation can be defined as the fulfilment of social roles and performance at the societal level, which includes social interaction with the environment while being involved in a range of different life situations (Chang, Coster, & Helfrich, 2013). It is essential to understand the contribution of community participation in enhancing the lives of individuals. Community participation is vital as families generally know what works best for them and professionals in the field have the need to learn from the families. Families make contribution of resources including information, labour, material, and money, families become committed to activities they developed together, and families may build knowledge, skills, and experiences that can assist them in caring for their children now and in the future (Sharma, 2007). Participating in community activities is often identified as one of the health goals for people living with disabilities as well. Involvement in communities is interrelated to diverse other important outcome indicators including social functioning, quality of life, and health. Conversely, lack of community participation is argued to be related to the development of functional limitations, depressive symptoms, morbidity, and mortality (Chang et al., 2013).

According to De Mooij and Hofstede (2011), people from collectivist cultures (e.g., Koreans)



are likely to process information in a different manner than individuals from individualistic cultures. They stated that in collectivist cultures, individuals gather information more through implicit, interpersonal communication and also base their decisions on emotions and trust in the provider, whereas people of individualistic cultures actively gather information through media and read more books and newspapers (De Mooij & Hofstede, 2011). Hence, it is likely that Koreans who are of collectivistic culture will rely on word of mouth communication due to the high rate of contact among group members.

Accordingly, through participating in community, Korean parents are likely to be better informed through gathering knowledge and information from a wide range of sources and working together with professionals in supporting their child, hence increasing empowerment and self-advocacy while potentially decreasing power difference between professional and parents. In other words, through active community involvement and empowering families, the issues related to power imbalance discussed earlier may be resolved or at least be minimised, and parents could be acknowledged as active agents who can advocate and intervene on behalf of their children living with disabilities. Petriwskyj et al.'s (2016) study exploring power dynamics in future planning among parent carers for people living with disability articulated that the power relationships between services and parents were varied and shifted when parents actively attempted to change those relationships to create opportunities.

However, professionals working with Korean parents with children living with disabilities in New Zealand must approach them with great respect and sensitivity regarding community involvement. As discussed, parents living in New Zealand appeared to have comparatively fewer parental networks and presented as being more exclusive and passive. It is important for the professional to have an understanding around the general culture and customs, as well as the impact community participation may have especially within a relatively small community setting. Although available studies (Cho et al., 2000; Hyun, 2001; Park & Cho, 1995) suggest that informal support is one of the most significant and beneficial supports within Asian families with a family member living with disabilities, it was evident in my previous study

(Choi, 2014) that Korean parents raising children living with disabilities in New Zealand often had no informal support and experienced a lack of interpersonal relationships and a sense of strong relationship within the community. Similarly, Shin's (2002) study concluded that Korean parents tend to prefer family care giving while being not very open about their child's impairment to people other than their family members due to negative messages they receive from their informal networks. Also, as discussed earlier in the chapter, the emphasis on social conformity embedded within collectivist cultures has the potential to result in greater social stigma. Consequently, in a relatively small Korean community, the fear of families being exposed to social stigma and confidentiality being breached are highly likely to have an impact on Korean parents' help-seeking behaviour. This also relates to the findings of the present study on public perception where participants identified negative traditional perceptions and a lack of positive perceptions from the general public towards people living with disabilities as one of the major reasons behind the low level of planning. Hence, while seeking opportunities to develop and increase parents' empowerment and self-advocacy through community involvement and peer networking between parents, professionals should respect clients' understanding and knowledge of their own world and help them make choices and gain autonomy through offering fully informed support, which is also a part of empowerment.

Finally, there are a number of areas for further research on this topic. The overall lack of available research around the topic in general, as well as lack of relevant New Zealand literature suggests there are huge opportunities for researchers in this area. As discussed in the methodology chapter, there is a potential that group interviews may create an atmosphere for participants to feel more connected and thus to provide more in-depth and insightful data that may not be available in individual interviews, while also providing an opportunity for participants to share ideas around their future care plans, and learn and grow new insights from one another. Hence, the study suggests a study on future care planning to be conducted using different data-collection methods. Practice research around Korean group homes in New Zealand may provide empirical data on this care provision approach rather than mere assumptive reflections on its effectiveness. Also, there would be merit in other comparative studies between Korea and other countries from Asia or between migrants from countries with

different cultural backgrounds and New Zealand, allowing the significance of the cultural context to be taken further.

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## Appendix 1 Ethical Approval

**Office of the Vice-Chancellor**  
Finance, Ethics and Compliance



The University of Auckland  
Private Bag 92019  
Auckland, New Zealand  
Level 10, 49 Symonds Street  
Telephones: 64 9 373 7509  
Extension: 87830 / 83761  
Facsimile: 64 9 373 7432

### UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE (UAHPEC)

24-Feb-2016

#### MEMORANDUM TO:

Assoc Prof Michael O'Brien  
Counselling, HumServ & SocWrk

#### **Re: Request for change of Ethics Approval Ethics Approval (Our Ref. 016688): Amendments Approved**

The Committee considered your request for change for your project entitled **Future Care Planning for Children Living with Disabilities: Plans, and Perceptions of Korean Immigrant Parents in New Zealand and Korea** and approval was granted for the following amendments on 24-Feb-2016.

The Committee approved the following amendments:

1. To allow the assistance of a third party to transcribe audio recording

The expiry date for this approval is 18-Jan-2019.

If the project changes significantly you are required to resubmit a new application to the Committee for further consideration.

In order that an up-to-date record can be maintained, it would be appreciated if you could notify the Committee once your project is completed.

The Chair and the members of the Committee would be happy to discuss general matters relating to ethics approvals. If you wish to do so, please contact the UAHPEC Ethics Administrators at [ro-ethics@auckland.ac.nz](mailto:ro-ethics@auckland.ac.nz) in the first instance.

Please quote reference number: **016688** on all communication with the UAHPEC regarding this application.

*(This is a computer generated letter. No signature required.)*

UAHPEC Administrators  
University of Auckland Human Participants Ethics Committee

c.c. Head of Department / School, Counselling, HumServ & SocWrk  
Assoc Prof Michael O'Brien  
Dr Hongjae Park

Ms Jung Choi  
Assoc Prof Christa Fouche

## Appendix 2 Participant Information Sheet for Parents in Korea (English)



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www.education.auckland.ac.nz  
The University of Auckland  
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Auckland 1142, New Zealand

# PARTICIPANT INFORMATION- (PARENTS)- in KOREA

## Project Title

Future Care Planning for Children Living with Disabilities: Plans and Perceptions of Korean Immigrant Parents in New Zealand and Korean Parents in Korea

## About the project

This study is conducted by Jung Won Choi, a PhD Candidate under supervision of Associate Professor Mike O'Brien and Dr Hong Jae Park at the School of Counselling, Human Services and Social Work, Faculty of Education and Social Work, The University of Auckland. The aim of this research is to explore Korean Parents' plans for future care provision for their children living with disabilities. This study will enable service providers to gain deeper understanding of Korean migrant carers around their future care plans, and make recommendations to the policy makers on support models that would affect the lives of people living with disabilities and their families.

## Why are you being invited?

You are invited to take part in this study because you are believed to be a parent in Korea who is knowledgeable about the research topic in the Korean community. Your participation is completely voluntary. This means that you are not under any obligation to participate in this project, and your decision will not affect your relationship with the researcher. You also have the right to withdraw your participation in the study within two weeks once transcription is received without having to give any reasons. You can choose to speak either Korean or English depending on your preference.

## What will happen in the interview?

Your involvement in this project will involve you in an interview that is anticipated to take about an hour. Jung Won Choi, as the student researcher, will conduct the interview at a time and place nominated by you. The interview will be recorded by a digital voice recorder. You may request, however, that the recorder be turned off at any time. If the interview is not recorded, notes will be taken and you will have the opportunity to see these notes and sign them. You can also refuse to answer any question, or terminate the interview at any time.

### After the interview?

If the interview has been recorded, it will be transcribed. You will receive a copy of the transcript of your recording if you choose to have it. You can make changes or withdraw any information provided if you wish, and return your transcript with corrections or additions to the student researcher at the address below within two weeks once the transcription is received. At the completion of the study you will receive a summary of major findings if you wish. The data obtained will be used for analysis and writing of the researcher's thesis. The findings may be also used in the future in other academic work or conference presentations.

### Any risks or benefits?

Since the research deals with parental concerns and plans around their children's future when they are no longer able to provide care, it is possible to trigger some emotional responses. You will be given enough time to recover from your emotions before continuing the interview, or the interview can be stopped completely on the day and you will be given an opportunity to meet again at a future date. You will also be offered contact details of local professionals/ services offering counselling support if required.

Although this study will not benefit you personally, we hope that our results will add to the knowledge about Korean parents' future care plans for their children living with disabilities and make relevant recommendations to policy makers. Your privacy and confidentiality will be protected at all times during the project and after it is completed. All research data will be stored by the main supervisor in a secure place at the University of Auckland and destroyed after the period of six years.

### If you wish to participate in the project?

If you would like to take part in this research, please look through the Consent Form and sign it for us. If you have questions or would like more information about this research project please contact:

Researcher:

Jung Won CHOI  
Tel: 010 2674 8595



Email: [jcho199@aucklanduni.ac.nz](mailto:jcho199@aucklanduni.ac.nz)

Supervisors:

Associate Professor Mike O'Brien

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Dr Hong-Jae Park

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Head of School:

Associate Professor Christa Fouche

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Email: [c.fouche@auckland.ac.nz](mailto:c.fouche@auckland.ac.nz)

[If I have concerns about ethical issues in the project?](#)

For any queries regarding ethical concerns you may contact:

The Chair

The University of Auckland Human Participants Ethics Committee

The University of Auckland, Office of the Vice Chancellor

Private Bag 92019, Auckland 1142

Tel: (09) 373-7599 ext. 83711

Email: [ro-ethics@auckland.ac.nz](mailto:ro-ethics@auckland.ac.nz)

Thank you for considering this invitation.

**Approved by the UNIVERSITY of AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE on ...18-Jan-2016... for (3) years, Reference Number ...016688...**

## Appendix 3 Participant Information Sheet for Professionals in Korea (English)



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Auckland 1142, New Zealand

# PARTICIPANT INFORMATION- (PROFESSIONALS)- in KOREA

## Project Title

Future Care Planning for Children Living with Disabilities: Plans and Perceptions of Korean Immigrant Parents in New Zealand and Korean Parents in Korea

## About the project

This study is conducted by Jung Won Choi, a PhD Candidate under supervision of Associate Professor Mike O'Brien and Dr Hong Jae Park at the School of Counselling, Human Services and Social Work, Faculty of Education and Social Work, The University of Auckland. The aim of this research is to explore Korean Parents' plans for future care provision for their children living with disabilities. This study will enable service providers to gain deeper understanding of Korean migrant carers around their future care plans, and make recommendations to the policy makers on support models that would affect the lives of people living with disabilities and their families.

## Why are you being invited?

You are invited to take part in this study because you are believed to be a professional in Korea who is knowledgeable about the research topic in the Korean community. Your participation is completely voluntary. This means that you are not under any obligation to participate in this project, and your decision will not affect your relationship with the researcher. You also have the right to withdraw your participation in the study within two weeks once transcription is received without having to give any reasons. You can choose to speak either Korean or English depending on your preference.

## What will happen in the interview?

Your involvement in this project will involve you in an interview that is anticipated to take about an hour. Jung Won Choi, as the student researcher, will conduct the interview at a time and place nominated by you. The interview will be recorded by a digital voice recorder. You may request, however, that the recorder be turned off at any time. If the interview is not recorded, notes will be taken and you will have the opportunity to see these notes and sign them. You can also refuse to answer any question, or terminate the interview at any time.

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If the interview has been recorded, it will be transcribed. You will receive a copy of the transcript of your recording if you choose to have it. You can make changes or withdraw any information provided if you wish, and return your transcript with corrections or additions to the student researcher at the address below within two weeks once transcription is received. At the completion of the study you will receive a summary of major findings if you wish. The data obtained will be used for analysis and writing of the researcher's thesis. The findings may be also used in the future in other academic work or conference presentations.

### Any risks or benefits?

We anticipate that there are no risks associated with participating in this study. Although this study will not benefit you personally, we hope that our results will add to the knowledge about Korean parents' future care plans for their children living with disabilities and make relevant recommendations to policy makers. Your privacy and confidentiality will be protected at all times during the project and after it is completed. All research data will be stored by the main supervisor in a secure place at the University of Auckland and destroyed after the period of six years.

### If you wish to participate in the project?

If you would like to take part in this research, please look through the Consent Form and sign it for us. If you have questions or would like more information about this research project please contact:

Researcher:

Jung Won CHOI  
Tel: 010 2674 8595  
Email: [jcho199@aucklanduni.ac.nz](mailto:jcho199@aucklanduni.ac.nz)

Supervisors:

Associate Professor Mike O'Brien  
Tel : 9 623 8899 ext 46357  
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Dr Hong-Jae Park  
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Head of School:  
Associate Professor Christa Fouche  
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The University of Auckland Human Participants Ethics Committee  
The University of Auckland, Office of the Vice Chancellor  
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Email: [ro-ethics@auckland.ac.nz](mailto:ro-ethics@auckland.ac.nz)

Thank you for considering this invitation.

**Approved by the UNIVERSITY of AUCKLAND HUMAN PARTICIPANTS  
ETHICS COMMITTEE on ...18-Jan-2016... for (3) years, Reference Number  
...016688...**

## Appendix 4 Participant Information Sheet for Parents in New Zealand (English)



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The University of Auckland

Private Bag 92601, Symonds Street

Auckland 1142, New Zealand

# PARTICIPANT INFORMATION (PARENTS)- in NZ

## Project Title

Future Care Planning for Children Living with Disabilities: Plans and Perceptions of Korean Immigrant Parents in New Zealand and Korean Parents in Korea

## About the project

This study is conducted by Jung Won Choi, a PhD Candidate under supervision of Associate Professor Mike O'Brien and Dr Hong Jae Park at the School of Counselling, Human Services and Social Work, Faculty of Education and Social Work, The University of Auckland. The aim of this research is to explore Korean Parents' plans for future care provision for their children living with disabilities. This study will enable service providers to gain deeper understanding of Korean migrant carers around their future care plans, and make recommendations to the policy makers on support models that would affect the lives of people living with disabilities and their families.

## Why are you being invited?

You are invited to take part in this study because you are believed to be a parent in New Zealand who is knowledgeable about the research topic in the Korean community. Your participation is completely voluntary. This means that you are not under any obligation to participate in this project, and your decision will not affect your relationship with the researcher. You also have the right to withdraw your participation in the study within two weeks once transcription is received without having to give any reasons. You can choose to speak either Korean or English depending on your preference.

### What will happen in the interview?

Your involvement in this project will involve you in an interview that is anticipated to take about an hour. Jung Won Choi, as the student researcher, will conduct the interview at a time and place nominated by you. The interview will be recorded by a digital voice recorder. You may request, however, that the recorder be turned off at any time. If the interview is not recorded, notes will be taken and you will have the opportunity to see these notes and sign them. You can also refuse to answer any question, or terminate the interview at any time.

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### If you wish to participate in the project?

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Researcher:

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Tel: 010 2674 8595  
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Supervisors:

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Thank you for considering this invitation.

**Approved by the UNIVERSITY of AUCKLAND HUMAN PARTICIPANTS  
ETHICS COMMITTEE on ...18-Jan-2016... for (3) years, Reference Number  
...016688...**



## Appendix 5 Participant Information Sheet for Professionals in New Zealand (English)



School of Counselling,  
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Auckland, New Zealand  
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The University of Auckland  
Private Bag 92601, Symonds Street  
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# PARTICIPANT INFORMATION

(PROFESSIONALS)-in NZ

## Project Title

Future Care Planning for Children Living with Disabilities: Plans and Perceptions of Korean Immigrant Parents in New Zealand and Korean Parents in Korea

## About the project

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Researcher:

Jung Won CHOI  
Tel: 021 0279 7535  
Email: [jcho199@aucklanduni.ac.nz](mailto:jcho199@aucklanduni.ac.nz)

Supervisors:

Associate Professor Mike O'Brien

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Dr Hong-Jae Park

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Email: [hj.park@auckland.ac.nz](mailto:hj.park@auckland.ac.nz)

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Associate Professor Christa Fouche

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If I have concerns about ethical issues in the project?

For any queries regarding ethical concerns you may contact:

The Chair

The University of Auckland Human Participants Ethics Committee

The University of Auckland, Office of the Vice Chancellor

Private Bag 92019, Auckland 1142

Tel: (09) 373-7599 ext. 83711

Email: [ro-ethics@auckland.ac.nz](mailto:ro-ethics@auckland.ac.nz)

Thank you for considering this invitation.

**Approved by the UNIVERSITY of AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE on ...18-Jan-2016... for (3) years, Reference Number ...016688...**

## Appendix 6 Participant Information Sheet for Parents in Korea (Korean)



School of Counselling,  
Human Services and Social Work  
Gate 3, 74 Epsom Avenue  
Auckland, New Zealand  
www.education.auckland.ac.nz  
The University of Auckland  
Private Bag 92601, Symonds Street  
Auckland 1142, New Zealand

# PARTICIPANT INFORMATION

## 제목

한국 장애 자녀 부모님들의 자녀를 위한 미래계획

Project Title: Future Care Planning for Children Living with Disabilities: Plans and Perceptions of Korean Immigrant Parents in New Zealand and Korean Parents in Korea

## 본인소개

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Who am I? You are invited to take part in this research project, conducted by Jung Won Choi at the School of Counselling, Human Services and Social Work, Faculty of Education and Social Work, The University of Auckland.

## 연구 참여 기준

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You are invited to take part in this study because you are believed to be a parent in Korea who is knowledgeable about the research topic in the Korean community. Your participation is completely voluntary. This means that you are not under any obligation to participate in this project, and your decision will not affect your relationship with the researcher. You also have the right to withdraw your participation in the study within two weeks once transcription is received without having to give any reasons. You can choose to speak either Korean or English depending on your preference.

## 연구 참여에 대한 안내

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What will happen in the interview? Your involvement in this project will involve you in an interview that is anticipated to take about an hour. Jung Won Choi, as the student researcher, will conduct the interview at a time and place nominated by you. The interview will be recorded by a digital voice recorder. You may request, however, that the recorder be turned off at any time. If the interview is not recorded, notes will be taken and you will have the opportunity to see these notes and sign them. You can also refuse to answer any question, or terminate the interview at any time.

### 연구 참여 후의 안내

귀하의 인터뷰 내용은 연구자가 기록합니다. 기록된 연구 자료는 받아보시기를 희망하신 참여자들에게 보내드립니다. 만일 연구자료를 받아보신다면, 기록된 자료에 귀하의 의견이나 감상을 적으셔서 인터뷰를 기록한 자료를 제공받은 후 2주안에 연구자에게 되돌려주시기를 부탁드립니다. 귀하는 이 연구의 결과를 볼 수 있습니다. 만일 귀하가 이 연구의 결과를 알기 원하신다는 것을 동의서에 표시해주시면 연구가 완성된 후 연구 결과의 요약본을 보실 수 있을 것입니다. 연구결과는 장래에 연구활동을 위한 출판이나 학술회의의 발표로도 사용할 수도 있습니다.

After the interview? If the interview has been recorded, it will be transcribed. You will receive a copy of the transcript of your recording if you choose to have it. You can make changes or withdraw any information provided if you wish, and return your transcript with corrections or additions to the student researcher at the address below within two weeks once the transcription is received. At the completion of the study you will receive a summary of major findings if you wish. The data obtained will be used for analysis and writing of the researcher's thesis. The findings may be also used in the future in other academic work or conference presentations.

### 연구 참여의 위험이나 혜택?

본 연구는 장애 자녀들의 미래계획의 이해를 발전 시키는데 그 목적이 있기에 감정적인 반응을 유발할 수 있습니다. 그런 경우 인터뷰를 재개하기 전 감정에서 회복할 충분한 시간이 주어질 것이며 상황에 따라서는 그날 인터뷰를 완전히 중단하고 향후에 인터뷰를 재개할 것입니다. 지역 상담을 지원하는 전문가/서비스의 연락처 또한 제공될 것입니다.

비록 이 연구 참여에 따른 개인적인 보상은 없지만, 연구에 참여함으로써 한국에서의 장애 자녀를 양육하는 부모님으로써 귀하의 자녀 미래계획에 관한 경험이나 느낌들 그리고 의견이나 생각을 통해 장애 자녀 미래계획의 중요성과 이해를 높여주고 장애 복지 정책을 권고하는 것에 기여하실 수 있습니다. 귀하의 연구참여와 연구 참여 중에 수집될 모든 정보들은 절대 비밀이 보장됩니다. 연구자료는 귀하의 신분이 노출되지 않도록 일정한 부호를 사용할 것입니다. 녹음된 인터뷰나 기록된 모든 연구자료는 동의서와는 별도로 시건 장치가 된 서류함에 이 연구의 주 지도교수가 보관할 것이며 6년 후 폐기 될 것입니다.

Any risks or benefits? Since the research deals with parental concerns and plans around their children's future when they are no longer able to provide care, it is possible to trigger some emotional responses. You will be given enough time to recover from your emotions before continuing the interview, or the interview can be stopped completely on the day and you will be given an opportunity to meet again at a future date. You will also be offered contact details of local professionals/ services offering counselling support if required. Although this study will not benefit you personally, we hope that our results will add to the knowledge about Korean parents' future care plans for their children living with disabilities and make relevant recommendations to policy makers. Your privacy and confidentiality will be protected at all times during the project and after it is completed. All research data will be stored by the main supervisor in a secure place at the University of Auckland and destroyed after the period of six years.

이 연구에 참여하고 자 하는 경우, 또는 질문이 있거나 이 연구 프로젝트에 대한 더 자세한 내용을 알고 싶으시다면 학생 연구자나 지도교수들에게 연락해주시기 바랍니다.

If I wish to participate in the project? If you would like to take part in this research, or have questions or would like more information about this research project please contact:

Researcher:

Jung Won CHOI

Tel: 010 2674 8595

Email: [jcho199@aucklanduni.ac.nz](mailto:jcho199@aucklanduni.ac.nz)

Supervisors:

Associate Professor Mike O'Brien

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## Appendix 7 Participant Information Sheet for Professionals in Korea (Korean)



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You are invited to take part in this study because you are believed to be a professional in Korea who is knowledgeable about the research topic in the Korean community. Your participation is completely voluntary. This means that you are not under any obligation to participate in this project, and your decision will not affect your relationship with the researcher. You also have the right to withdraw your participation in the study within two weeks once transcription is received without having to give any reasons. You can choose to speak either Korean or English depending on your preference.

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Researcher:

Jung Won CHOI

Tel: 010 2674 8595

Email: [jcho199@aucklanduni.ac.nz](mailto:jcho199@aucklanduni.ac.nz)

Supervisors:

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## Appendix 8 Participant Information Sheet for Parents in New Zealand (Korean)



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You are invited to take part in this study because you are believed to be a parent in New Zealand who is knowledgeable about the research topic in the Korean community. Your participation is completely voluntary. This means that you are not under any obligation to participate in this project, and your decision will not affect your relationship with the researcher. You also have the right to withdraw your participation in the study within two weeks once transcription is received without having to give any reasons. You can choose to speak either Korean or English depending on your preference.

## 연구 참여에 대한 안내

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What will happen in the interview? Your involvement in this project will involve you in an interview that is anticipated to take about an hour. Jung Won Choi, as the student researcher, will conduct the interview at a time and place nominated by you. The interview will be recorded by a digital voice recorder. You may request, however, that the recorder be turned off at any time. If the interview is not recorded, notes will be taken and you will have the opportunity to see these notes and sign them. You can also refuse to answer any question, or terminate the interview at any time.

### 연구 참여 후의 안내

귀하의 인터뷰 내용은 연구자가 기록합니다. 기록된 연구 자료는 받아보시기를 희망하신 참여자들에게 보내드립니다. 만일 연구자료를 받아보신다면, 기록된 자료에 귀하의 의견이나 감상을 적으셔서 인터뷰를 기록한 자료를 제공받은 후 2주안에 연구자에게 되돌려주시기를 부탁드립니다. 귀하는 이 연구의 결과를 볼 수 있습니다. 만일 귀하가 이 연구의 결과를 알기 원하신다는 것을 동의서에 표시해주시면 연구가 완성된 후 연구 결과의 요약본을 보실 수 있을 것입니다. 연구결과는 장래에 연구활동을 위한 출판이나 학술회의의 발표로도 사용할 수도 있습니다.

After the interview? If the interview has been recorded, it will be transcribed. You will receive a copy of the transcript of your recording if you choose to have it. You can make changes or withdraw any information provided if you wish, and return your transcript with corrections or additions to the student researcher at the address below within two weeks once the transcription is received. At the completion of the study you will receive a summary of major findings if you wish. The data obtained will be used for analysis and writing of the researcher's thesis. The findings may be also used in the future in other academic work or conference presentations.

### 연구 참여의 위험이나 혜택?

본 연구는 장애 자녀들의 미래계획의 이해를 발전 시키는데 그 목적이 있기에 감정적인 반응을 유발할 수 있습니다. 그런 경우 인터뷰를 재개하기 전 감정에서 회복할 충분한 시간이 주어질 것이며 상황에 따라서는 그날 인터뷰를 완전히 중단하고 향후에 인터뷰를 재개할 것입니다. 지역 상담을 지원하는 전문가/서비스의 연락처 또한 제공될 것입니다.

비록 이 연구 참여에 따른 개인적인 보상은 없지만, 연구에 참여함으로써 뉴질랜드에서의 장애 자녀를 양육하는 부모님으로써 귀하의 자녀 미래계획에 관한 경험이나 느낌들 그리고 의견이나 생각을 통해 장애 자녀 미래계획의 중요성과 이해를 높여주고 장애 복지 정책을 권고하는 것에 기여하실 수 있습니다. 귀하의 연구참여와 연구 참여 중에 수집될 모든 정보들은 절대 비밀이 보장됩니다. 연구자료는 귀하의 신분이 노출되지 않도록 일정한 부호를 사용할 것입니다. 녹음된 인터뷰나 기록된 모든 연구자료는 동의서와는 별도로 시건 장치가 된 서류함에 이 연구의 주 지도교수가 보관할 것이며 6년 후 폐기 될 것입니다.

Any risks or benefits? Since the research deals with parental concerns and plans around their children's future when they are no longer able to provide care, it is possible to trigger some emotional responses. You will be given enough time to recover from your emotions before continuing the interview, or the interview can be stopped completely on the day and you will be given an opportunity to meet again at a future date. You will also be offered contact details of local professionals/ services offering counselling support if required. Although this study will not benefit you personally, we hope that our results will add to the knowledge about Korean parents' future care plans for their children living with disabilities and make relevant recommendations to policy makers. Your privacy and confidentiality will be protected at all times during the project and after it is completed. All research data will be stored by the main supervisor in a secure place at the University of Auckland and destroyed after the period of six years.

이 연구에 참여하고 자 하는 경우, 또는 질문이 있거나 이 연구 프로젝트에 대한 더 자세한 내용을 알고 싶으시다면 학생 연구자나 지도교수들에게 연락해주시기 바랍니다.

If I wish to participate in the project? If you would like to take part in this research, or have questions or would like more information about this research project please contact:

Researcher:

Jung Won CHOI

Tel: 021 0279 7535

Email: [jcho199@aucklanduni.ac.nz](mailto:jcho199@aucklanduni.ac.nz)

Supervisors:

Associate Professor Mike O'Brien

Tel : 9 623 8899 ext 46357

Email: [ma.obrien@auckland.ac.nz](mailto:ma.obrien@auckland.ac.nz)

Dr Hong-Jae Park

Tel: 09 623 8899 ext 48690

Email: [hj.park@auckland.ac.nz](mailto:hj.park@auckland.ac.nz)

Head of School:

Associate Professor Christa Fouche

Tel: 09 623 8899

Email: [c.fouche@auckland.ac.nz](mailto:c.fouche@auckland.ac.nz)

[If I have concerns about ethical issues in the project?](#)

For any queries regarding ethical concerns you may contact:

The Chair

The University of Auckland Human Participants Ethics Committee

The University of Auckland, Office of the Vice Chancellor

Private Bag 92019, Auckland 1142

Tel: (09) 373-7599 ext. 83711

Thank you for considering this invitation.

**Approved by the UNIVERSITY of AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE on ...18-Jan-2016... for (3) years, Reference Number ...016688...**

## Appendix 9 Participant Information Sheet for Professionals in New Zealand (Korean)



School of Counselling,  
Human Services and Social Work  
Gate 3, 74 Epsom Avenue  
Auckland, New Zealand  
www.education.auckland.ac.nz  
The University of Auckland  
Private Bag 92601, Symonds Street  
Auckland 1142, New Zealand

# PARTICIPANT INFORMATION

## 제목

한국 장애 자녀 부모님들의 자녀를 위한 미래계획

Project Title: Future Care Planning for Children Living with Disabilities: Plans and Perceptions of Korean Immigrant Parents in New Zealand and Korean Parents in Korea

## 본인소개

제 이름은 최정원 (클라라) 이며 오클랜드 대학의 사범대 학생입니다. 이 연구는 상담, 휴먼 서비스와 사회복지 학부내의 사회복지 박사학위 과정의 일환으로 수행되는 것입니다.

Who am I? You are invited to take part in this research project, conducted by Jung Won Choi at the School of Counselling, Human Services and Social Work, Faculty of Education and Social Work, The University of Auckland.

## 연구 참여 기준

저는 귀하를 이 연구에 초대합니다. 귀하께서는 뉴질랜드에 거주하는 전문가 한 분으로서 이 연구에 참여하실 수 있습니다. 본 연구의 목적은 한국 장애 자녀 부모님들의 자녀를 위한 계획의 이해를 발전 시키는데 그 목적이 있습니다. 귀하의 연구 참여는 철저히 자발적이며 인터뷰는 귀하의 선택에 따라 한국어나 영어로 진행될 것입니다.

You are invited to take part in this study because you are believed to be a professional in New Zealand who is knowledgeable about the research topic in the Korean community. Your participation is completely voluntary. This means that you are not under any obligation to participate in this project, and your decision will not affect your relationship with the researcher. You also have the right to withdraw your participation in the study within two weeks once transcription is received without having to give any reasons. You can choose to speak either Korean or English depending on your preference.

## 연구 참여에 대한 안내

인터뷰는 약 60분 정도 소요될 것으로 예상됩니다. 인터뷰의 내용은 디지털 음성 녹음기로 녹음이 되며 귀하는 별다른 사유가 없어도 인터뷰도중 아무 때나 음성녹음기를 끄거나 인터뷰 종단을 요청하실 수 있습니다. 귀하는 인터뷰의 질문에 모두 대답하지 않으셔도 되고 언제든지 연구 참여를 취소할 수 있는 권리가 있습니다.

What will happen in the interview? Your involvement in this project will involve you in an interview that is anticipated to take about an hour. Jung Won Choi, as the student researcher, will conduct the interview at a time and place nominated by you. The interview will be recorded by a digital voice recorder. You may request, however, that the recorder be turned off at any time. If the interview is not recorded, notes will be taken and you will have the opportunity to see these notes and sign them. You can also refuse to answer any question, or terminate the interview at any time.

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### 연구 참여의 위험이나 혜택?

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Any risks or benefits? Since the research deals with parental concerns and plans around their children's future when they are no longer able to provide care, it is possible to trigger some emotional responses. You will be given enough time to recover from your emotions before continuing the interview, or the interview can be stopped completely on the day and you will be given an opportunity to meet again at a future date. You will also be offered contact details of local professionals/ services offering counselling support if required. Although this study will not benefit you personally, we hope that our results will add to the knowledge about Korean parents' future care plans for their children living with disabilities and make relevant recommendations to policy makers. Your privacy and confidentiality will be protected at all times during the project and after it is completed. All research data will be stored by the main supervisor in a secure place at the University of Auckland and destroyed after the period of six years.

이 연구에 참여하고 자 하는 경우, 또는 질문이 있거나 이 연구 프로젝트에 대한 더 자세한 내용을 알고 싶으시다면 학생 연구자나 지도교수들에게 연락해주시기 바랍니다.

If I wish to participate in the project? If you would like to take part in this research, or have questions or would like more information about this research project please contact:

Researcher:

Jung Won CHOI

Tel: 021 0279 7535

Email: [jcho199@aucklanduni.ac.nz](mailto:jcho199@aucklanduni.ac.nz)

Supervisors:

Associate Professor Mike O'Brien

Tel : 9 623 8899 ext 46357

Email: [ma.obrien@auckland.ac.nz](mailto:ma.obrien@auckland.ac.nz)

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Tel: 09 623 8899 ext 48690

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[If I have concerns about ethical issues in the project?](#)

For any queries regarding ethical concerns you may contact:

The Chair

The University of Auckland Human Participants Ethics Committee

The University of Auckland, Office of the Vice Chancellor

Private Bag 92019, Auckland 1142

Tel: (09) 373-7599 ext. 83711

Thank you for considering this invitation.

**Approved by the UNIVERSITY of AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE on ...18-Jan-2016... for (3) years, Reference Number ...016688...**

## Appendix 10 Consent Form (English)



School of Counselling,  
Human Services and Social Work  
Gate 3, 74 Epsom Avenue  
Auckland, New Zealand  
www.education.auckland.ac.nz  
The University of Auckland  
Private Bag 92601, Symonds Street  
Auckland 1142, New Zealand

# CONSENT FORM

THIS FORM WILL BE HELD FOR A PERIOD OF SIX YEARS

### Project Title

Future Care Planning for Children Living with Disabilities: Plans and Perceptions of Korean Immigrant Parents in New Zealand and Korean Parents in Korea

**Researcher:** Jung Won CHOI

I agree to take part in this research. I have read the Participant Information Sheet, and have understood the nature of the research and why I have been invited to participate. I have had the opportunity to ask questions and have them answered to my satisfaction.

- I understand that the interview will take about 60 minutes.
- I understand that I am free to withdraw participation, and to withdraw any data traceable to me within two weeks once transcription is received.

I understand that the transcript could be edited and returned within two weeks after receiving the transcript.

- I (agree / do not agree) that my interview will be recorded by a digital voice recorder.
- I understand that if interview has been recorded, it will be transcribed.
- I (wish / do not wish) to have a copy of the transcript of my recording returned to me when it is completed. If you wish to receive a transcript, please include your email address here \_\_\_\_\_
- I (wish / do not wish) to receive the summary of findings. If you wish to receive a summary, please include your email address here \_\_\_\_\_
- I understand that the researchers will protect my privacy and confidentiality at all



times and that my name will not be identified throughout the production of the research or in any publication.

- I understand that data will be securely stored at the University of Auckland and will be destroyed after the period of six years.
- I understand that my consent form will be stored separately from any other data collected.

Name: .....

Signature: ..... Date: .....

**Approved by the UNIVERSITY of AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE on ...18-Jan-2016... for (3) years, Reference Number ...016688...**

## Appendix 11 Consent Form (Korean)



School of Counselling,  
Human Services and Social Work  
Gate 3, 74 Epsom Avenue  
Auckland, New Zealand  
www.education.auckland.ac.nz  
The University of Auckland  
Private Bag 92601, Symonds Street  
Auckland 1142, New Zealand

# 연구 참여 동의서

이 동의서는 6년간 보관됩니다. This Form will be held for a period of 6 years

### 제목:

한국 장애 자녀 부모님들의 자녀를 위한 미래계획 Future Care Planning for Children Living with Disabilities: Plans and Perceptions of Korean Immigrant Parents in New Zealand and Korean Parents in Korea

### 연구자 성명: 최정원

- 본인은 위 연구에 참여하는 것을 동의합니다. 본인은 연구 참여에 관한 안내문을 숙지하였고, 연구의 목적 등을 이해하였으며 본인이 참여하게 된 기준을 이해하고 있습니다. 본인은 이 연구 참여에 대해 충분히 생각했으며 연구에 관련되어 질문할 기회를 가졌으며 본인의 의문사항은 충분히 답변 되었습니다. I agree to take part in this research. I have read the Participant Information Sheet and have understood the nature of the research and why I have been selected. I have had time to consider whether to take part in the study and the opportunity to ask questions and have them answered to my satisfaction.
- 본인의 연구 참여는 철저히 자발적 임을 이해하고 있습니다. I understand that participation is entirely voluntary.
- 본인은 인터뷰가 약60분 정도 소요될 것이라는 것을 이해하고 있습니다. I understand that the interview will take about 60 minutes.
- 본인은 인터뷰는 음성녹음기로 녹음될 것이며 도중에 언제라도 녹음기를 끄도록 요청 할 수 있음을 알고 있습니다. I understand that the interview will be audio-taped and I may choose to have the recorder turned off at any time.

- 본인은 녹음된 인터뷰가 글로 옮겨질 것을 알고 있습니다. I understand that if interview has been recorded, it will be transcribed.
- 본인은 제공한 연구자료는 인터뷰를 기록한 자료를 제공받은 후 2주안에 수정할 수 있음을 알고 있습니다. I understand that the transcript could be edited and returned within two weeks after receiving the transcript.
- 본인은 내가 제공한 정보는 보호될 것이며 나의 신분이 전혀 노출되지 않는 방법으로 보고될 것을 이해하고 있습니다. I understand that no identifiable details will be recorded and no material could identify me will be used in any reports on this study.
- 본인은 연구자와 지도 교수들만이 내가 제공한 연구자료들을 열람할 수 있으며 또한 그들이 나의 신분이나 수집된 정보들의 비밀을 책임진다는 것을 압니다. I understand that only the researcher and the supervisors will have access to the data and they will take responsibility to ensure my confidentiality.
- 본인은 인터뷰를 기록한 연구 자료를 받아 보기를 원합니다/ 원하지 않습니다. I wish / do not wish to receive a copy of the transcript.
- 본인은 연구 결과의 요약을 받아보기 원합니다/원하지 않습니다. I wish / do not wish to receive the summary of findings.
- 본인은 연구 참여를 취소할 수 있으며 제공한 연구자료는 인터뷰를 기록한 자료를 제공받은 후 2주안에 취소할 수 있음을 압니다. I understand that I am free to withdraw participation, and to withdraw any data traceable to me within two weeks once transcription is received.
- 본인은 연구자료는 6년간 보관될 것이며 그 이후에 파기될 것을 알고 있습니다. I understand that the data will be kept for 6 years, after which they will be destroyed.

성명 Name \_\_\_\_\_ 날짜 Date\_\_\_\_\_

서명 Signature \_\_\_\_\_

우편/이메일 주소 (만일 인터뷰 기록이나 이 연구결과의 요약을 받기 원할 경우)

Mail/Email (If I want a copy of the transcript / a summary of this research):

\_\_\_\_\_

이 연구 사업은 오클랜드 대학교의 연구 윤리 위원회의 심의를 통과하여 3년의 기한으로 승인되었습니다. **Approved by the UNIVERSITY of AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE on ...18-Jan-2016... for (3) years, Reference Number ...016688...**

## Appendix 12 Transcriber Confidentiality Agreement



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# TRANSCRIBER CONFIDENTIALITY AGREEMENT

### Project Title

Future Care Planning for Children Living with Disabilities: Plans and Perceptions of Korean Immigrant Parents in New Zealand and Korean Parents in Korea

**Supervisor:** Associate Professor Mike O'Brien and Dr Changzoo Song

### Transcriber:

I agree to transcribe the audio-recordings for the above research project. I understand that the information contained within them is confidential and must not be disclosed to, or discussed with, anyone other than the researcher and her supervisors.

Name: .....Yoon Sook Jang.....

A handwritten signature in black ink, appearing to read 'Yoon Sook Jang'.

Signature: ..... Date: .....12.12.2016.....

## **Appendix 13 Interview Questions**

### Interview Questions for Parents:

- 1) What is/are your plan(s) for your child's future care provision for when you are no longer able to provide it?
- 2) What actions have you taken in order to achieve your plan(s)?
- 3) What are some of the major aspects you consider(ed) when making plans for your child's future care provision?
- 4) What worries you the most in terms of your child's future care provision?
- 5) What would be most valuable/ helpful when planning for your child's future care provision?
- 6) Are there any other comments you would like to make?

### Interview Questions for Professionals:

- 1) In your professional perception, how well do you think Korean parents are prepared for children's care provision when they are no longer able to provide it themselves?
- 2) What are some of the future care plans you came across while working with children living with disabilities and their families?
- 3) What do you think are the major aspect that parents should consider when planning for their children's future care provision?
- 4) What do you think are the challenges and difficulties that Korean parents experience when planning for their children's future care provision?
- 5) What do you think would be most valuable support for parents and their children living with disabilities in terms of future care provision and the process of planning?
- 6) Are there any other comments you would like to make?