

# **Women Ageing with Polio in Taiwan: a Life Course Approach**

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謝謝妳們，讓我們得以看見台灣身心障礙女性珍貴的生命經驗。

## **Abstract**

Despite the growing interest in the ageing experiences of disabled people, little is known about the ageing experience of people living with lifelong impairments and the challenges they face over time. This thesis aims to explore the experiences of women ageing with childhood-onset polio in Taiwan, taking a life course approach. The methodology adopted is qualitative, with life history interviews being conducted with ten women with childhood-onset polio aged from 50 to 60 years, who contracted polio before the age of five. Analysis of these interviews provides an understanding of what life is like for these women who have grown old with childhood-onset polio, and how their previous life experiences shape their current lives.

The women experience multiple oppression based on disability, gender, age and class, and this prevents them from fully participating in society throughout the course of their lives. Lack of early support creates disadvantages for the women, and puts them at a risk as they grow old. Disabled women are often perceived as passive, dependent and weak, but these women's experiences can be read as a counter-narrative to discrimination against disabled women. It shows how disabled women develop strategies to resist oppression and regain control of their lives. The research findings extend the limited understanding of women ageing with lifelong impairments. A number of insights are provided for policy development, service provision and future research.

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## List of Abbreviations

<b>CRPD</b>	Convention on the Rights of Persons with Disabilities
<b>DPP</b>	Democratic Progressive Party
<b>EPZ</b>	Export Processing Zones
<b>ICF</b>	International Classification of Functioning, Disability and Health
<b>ICIDH</b>	International Classification of Impairments Disabilities and Handicaps
<b>KMT</b>	Kuomintang (Chinese Nationalist Party)
<b>NVILA</b>	New Vitality Independent Living Association
<b>OPV</b>	Oral Polio Vaccine
<b>PE</b>	Physical Education
<b>PPS</b>	Post-Polio Syndrome
<b>ROC</b>	Republic of China
<b>SME</b>	Small-medium Enterprise
<b>UPIAS</b>	Union of the Physically Impaired against Segregation
<b>WHO</b>	World Health Organisation

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# **Chapter One**

## **Introduction: Setting the Scene**

Ageing is a global issue in the 21st century, and this applies equally to the disabled population. Ageing is a gendered issue, with women and men experiencing ageing differently. There is a wealth of evidence to show that women experience more difficulties in old age than men, but as yet, little is known about the ageing experience of disabled women. It is well documented that disabled women face oppression due to the intersection of gender and disability. It is significant to explore the experience of women growing old with lifelong impairments and examine what oppression disabled women face across the course of their lives. Existing studies on disability and ageing have mainly been conducted in western culture, meaning studies on the ageing experiences of disabled people in eastern cultures remain underrepresented.

This thesis explores the experiences of women ageing with childhood-onset polio in Taiwan. It examines how women from various cultural backgrounds experience ageing with lifelong impairments. This introductory chapter firstly provides background information and the motivation for the study. The second section gives a brief review of the history of polio in a global context. Following this, the historical background to polio in Taiwan is considered, and then several research questions are addressed. Finally an outline of the study is provided.

### **1.1 A Starting Point: Women Ageing with Childhood-onset Polio in Taiwan**

Becoming an older person is one thing, but becoming an older disabled person, especially a woman, is quite another issue (Macfarlane, 1994: 155).

Ostrove and Rinaldi (2011) suggest that researchers in disability studies should recognise the relationship between the researcher and their studies. They find that their family backgrounds and life experiences profoundly influence their motivation to conduct disability studies. As a Taiwanese woman with polio, my

personal experiences direct me to choose the research topic. I was born in 1981 and contracted polio at six-months old. In my childhood, I was often told that I needed to be tough, because I could not rely on my family. In my teenage years, I had little confidence in my physical appearance and found it difficult to establish intimate relationships. I realised that disabled women face many inequalities and challenges in society throughout their life.

My past experience influenced my career choice. I decided to become a social worker. I worked at an organisation for disabled people for a few years, and this gave me an opportunity to provide support for disabled people. The organisation provided services for people with physical impairment, and therefore I had the opportunity to meet women with polio. Most of these women were in their 50s or 60s. Some of them had experienced physical degeneration and expressed worries about ageing. As a woman with polio in my 30s, I had never thought about the issue of ageing. These experiences motivated me to conduct the study. I would like to know what the experiences of women growing old with childhood-onset of polio are; what challenges they face over time; and how their past experiences impact their current lives.

The world population is ageing, with the aged population rapidly increasing in recent decades. Worldwide, there were 901 million people aged 60 years or over in 2015, an increase of 48 per cent over the 607 million older people globally in 2000 (United Nations, 2015: 9). The older population in low-income regions is growing faster than in high income regions. It has taken Europe and North America more than half a century to double their population of older people, from 7 per cent to 14 per cent, however the East Asian countries are experiencing higher rates of population ageing. It has taken less than 30 years for Japan, China, Singapore, Taiwan and Thailand to reach similar growth (Fu and Hughes, 2009: 3). In Taiwan, the proportion of the ageing population has significantly increased over the last decade. Older people comprised 7 per cent of the total population in 1993, and that proportion increased to 12 per cent by 2015 (Executive Yuan, 2015a: n.p)

This trend can also be seen in the disabled population. Over the last few decades, the life expectancy of disabled people has significantly increased. In the UK, for example, by the end of 2012, nearly 6 per cent of children were disabled, compared to 45 per cent of adults over State Pension age (GOV.UK, 2014: n.p). In Taiwan, as of 2011, approximately 35 per cent of disabled people were aged between 45 and 65, and 36 per cent of disabled people were aged 65 or over (Ministry of Interior, 2011: 02). It is difficult to compare disability

statistics globally, since methods of identification of the disabled population are different across countries (Eide and Loeb, 2006). The disability statistics in the UK and Taiwan show that older disabled people make up the majority of the disabled population in both countries.

Ageing is a gendered issue. Women historically live longer than men, and therefore are more likely than men to be widowed. In Taiwan, nearly 46.6 per cent of women aged over 65 are widows, only 14.7 per cent of men aged over 65 are widowers (Ministry of Health and Welfare, 2008: 21). Similarly, approximately 29.30 per cent of older disabled women are widows, while only 7.01 per cent of older disabled men are widowers (Ministry of Interior, 2011: 78). Previous studies have shown that women are more likely to experience inequalities in access to material resources in early years, and this leads to economic disadvantages in old age (Minkler and Stone, 1985; Arber and Ginn, 1991).

This study aims to explore the experiences of women ageing with childhood-onset polio in terms of a life course approach. The social model of disability serves as a lens to identify barriers and inequalities experienced by women with childhood-onset polio throughout the course of their lives. Additionally, the study examines how these women's past life experiences affect their current lives. I conduct life history interviews with ten women with childhood-onset polio aged between 50 and 60, who contracted polio before the age of five. In the next section, I provide a brief review of the history of polio in a global context.

## **1.2 Polio in a Global Context**

Poliomyelitis (polio) is a highly infectious viral disease. Polio can strike at any age but it mainly affects children under five years of age (WHO, 2014). Poliovirus enters the body through the mouth and multiplies in the intestines. Initial symptoms include fever, fatigue, headache, vomiting, stiffness in the neck, and pain in the extremities (McFee, 2013: 446). There are two types of polio. The first is paralysis polio, in which the poliovirus destroys nerve cells that activate muscles, which leads to irreversible paralysis, usually of the legs. The second is bulbar polio, which causes more extensive paralysis, in which the poliovirus attacks the nerve cells of the brain stem, reducing breathing capacity and causing difficulties in swallowing and speaking. 5 to 10 per cent of people with bulbar polio die as their breathing muscles become immobilised (Global Polio Eradication Initiative, 2010).

The concept of 'polio career' has been discussed by several researchers, which means that the functional status of polio survivors can vary across the course of their lives (Kaufert and Locker, 1990; Scheer and Luborsky, 1991). The acute phase begins with the onset of polio which is usually followed by intensive medical treatment. After the acute phase, individuals receive rehabilitation therapy to regain their functional and physical capacity. Following a period of rehabilitation, polio survivors can maintain a stable functional status for several years. Many polio survivors experience post-polio syndrome (PPS) 30 to 40 years after the original onset, which causes new functional losses such as muscular atrophy, weakness, pain and fatigue (Kaufert and Kaufert, 1984; Kaufert and Locker, 1990; Wenneberg and Ahlström, 2000; Howard, 2005).

Small sporadic outbreaks of polio began to be seen in the mid-18<sup>th</sup> century in European countries. During the 19<sup>th</sup> century polio epidemics grew more severe and more frequent, and then spread rapidly across countries, particularly in industrialised parts of Europe and North America (Melnick, 1996). The state of sanitation is a mediating factor of polio epidemics. Polio epidemics are more likely to occur in areas with proper sanitation. In regions with poor sanitation, children are infected with poliovirus at very young age, but poliovirus rarely produces harmful effects on new-born babies, because they have immunity from their mother's body that can exist for six months. When these children fully recover, they acquire lifelong immunity from polio (Fisher, 1967; Ting, 1982). As sanitation improves, young children are less likely to be exposed to natural infection of poliovirus, and are therefore unable to acquire the immunity to protect them. Children who lack immunity are at great risk of polio infection (Fisher, 1967).

An extraordinary epidemic occurred in the United States in 1916, when nearly 9,000 cases of paralysis were reported in New York City (Paul, 1971). A polio outbreak then occurred across several countries during the 1940s and 1950s, when nearly 8,000 cases of polio were reported in the UK (GOV.UK, 2013: 313). A notable polio outbreak appeared in Japan in the 1960s (Infectious Agents Surveillance Center, 1997). In Taiwan, major polio outbreaks occurred during the mid-1950s and the mid-1960s (Chang, 2013). The treatment for polio was developed after the large outbreak in the United States. President Franklin D. Roosevelt, a polio survivor, established a specific treatment centre and research foundation to develop an effective treatment for polio (Wilson, 1998). The milestone in polio prevention was the considerable progress in

vaccine research made by Dr. Jonas Salk and Dr. Albert Sabin in 1954 and 1961, respectively (Blume and Geesink, 2000). Sabin's oral polio vaccine (OPV) is safe and effective, and is used in polio eradication programmes in many countries (Global Polio Eradication Initiative, 2010).

At that time, a number of children with polio were sent away from home to hospitals and underwent numerous painful episodes of surgery in order to regain physical function (Saxon, 2001). Those who had breathing problems were placed in a machine called an 'iron lung' and segregated to specific wards (Drinker and McKhann, 1986). Children with polio were told that they should make a great effort to 'beat' the polio by undertaking rehabilitation therapy. Some children stayed in rehabilitation institutions for several years and experienced both psychological and emotional distress (Bruno and Frick, 1991). Since the 1980s, several international polio eradication programmes have been implemented by the World Health Organisation (WHO). By the end of 2015, polio remains endemic in only two countries, Afghanistan and Pakistan (WHO, 2015). After this brief history of polio in a global context, the next section shifts the focus to Taiwan.

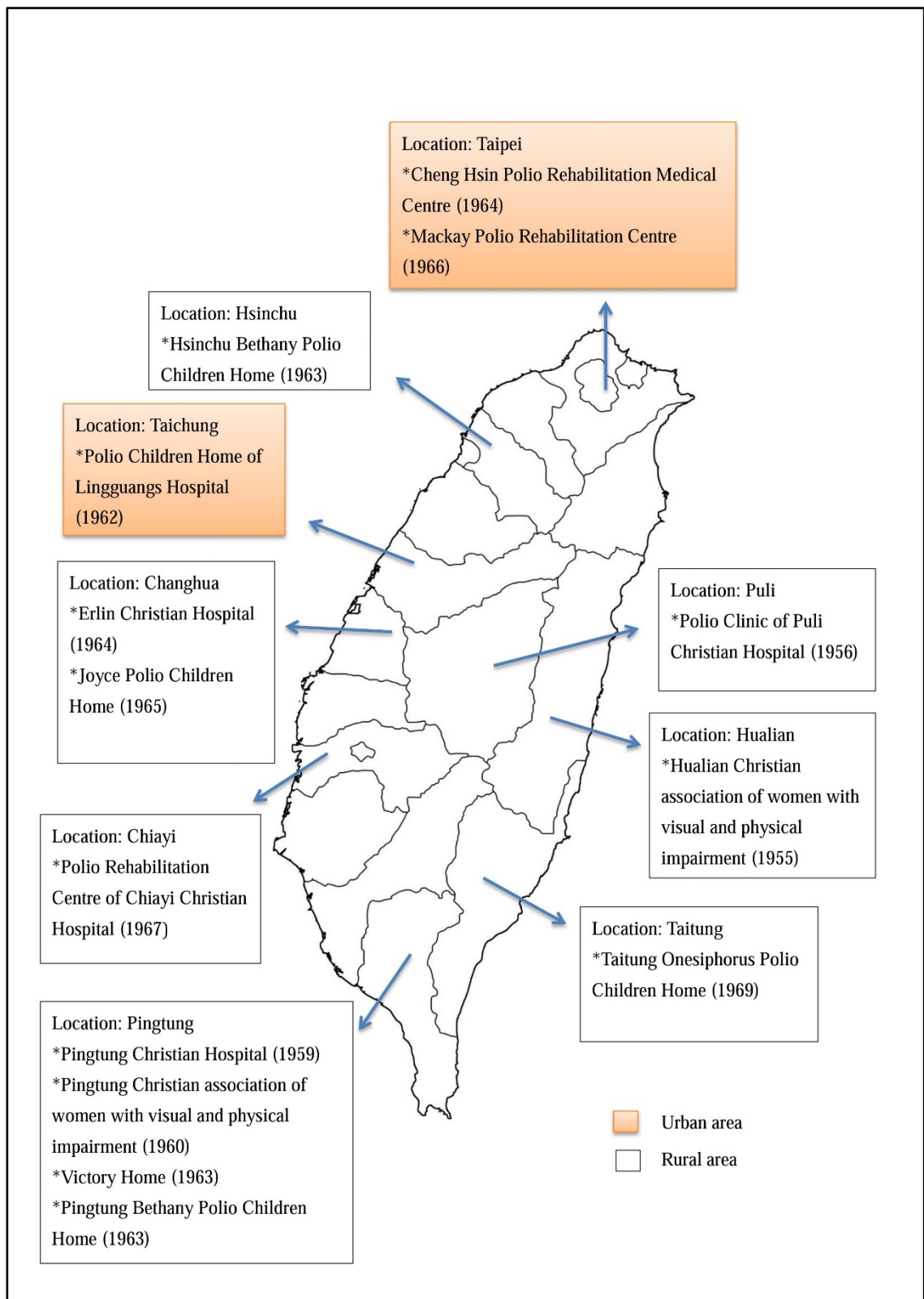
### **1.3 History of Polio in Taiwan**

Polio was first reported in Taiwan in 1913 and become officially notifiable in 1955 (Kim-Farley et al., 1984). As mentioned above, polio epidemics are more likely to occur in areas with proper sanitation. Before World War II the state of sanitation in Taiwan was poor, most children were infected with poliovirus shortly after birth, and thus polio rarely caused harmful effects. In the post-war period, the environmental sanitation improved considerably, and the number of polio cases significantly increased in the 1950s (Ting, 1982). A major outbreak occurred between 1956 and 1965, with 500-700 cases reported annually. The figure dramatically declined when the Sabin oral vaccine was introduced in 1966. Due to the failure of the vaccination programme, a second large polio outbreak occurred in 1982, with 1,042 cases reported (Centre of Disease Control, 2001: 26). There are nearly 5,149 polio survivors in Taiwan, but the actual number might be underestimated due to the failure of the notifiable disease system (Wang, 2006: 10).

The increasing number of polio survivors in Taiwan attracted the attention of international Christian organisations. In the 1950s and the 1960s, several foreign medical missionaries established hospitals and rehabilitation institutions

in Taiwan to provide treatment for children with polio (Chang, 2013). Figure 1.1 shows the distribution of hospitals and rehabilitation institutions for children with polio in Taiwan in the 1950s and 1960s. Initially, several hospitals and institutions were established in rural areas where medical resources were relatively sparse. Until the mid-1960s, only three hospitals had been set up in urban areas. In past times, polio was regarded as a punitive sin from a previous life. Many children with polio were kept at home by parents because they brought shame to their families (Huang, 2011). Missionaries actively approached children with polio and convinced their parents to take their children to hospitals (Chang, 2013). A number of children were taken to hospitals and rehabilitation institutions and underwent corrective surgery and rehabilitation therapy. The technology of scoliosis surgery was introduced in the early 1970s. Between 1975 and 1990, nearly five hundred polio survivors underwent scoliosis surgery (Shen, 2010).

**Figure 1 Hospitals and Rehabilitation Institutions for Children with Polio in Taiwan in the 1950s and 1960s**



Data Sources: the figure is created by the researcher based on existing literature on the history of polio in Taiwan (Yu, 2000; Kang, 2008; Centre of Disease Control, 2001; Sørheim-Queseth, 2013; Chang, 2013).



Polio epidemics not only changed the lives of polio survivors, but also led to social and cultural changes. The increasing demand for rehabilitation for polio survivors prompted the development of professional rehabilitation medicine in Taiwan (Chang, 2013). In 1964, the 'Cheng-Hsin Polio Rehabilitation Medical Centre' was established to provide surgical treatment, rehabilitation care, social service, and assistive devices for children with polio. Several occupational therapy professionals from western countries were invited to the hospital to provide training for local rehabilitation professionals (Yu, 2000). In addition, the increasing need for assistive devices for polio survivors accelerated the development of the assistive technology industry in Taiwan (Chang, 2013). Polio survivors' stories were responsible for constructing social images of disabled people in Taiwan. Barnes (1992a) indicates that disabled people are often misrepresented as 'super cripples', who are praised excessively for ordinary achievement. Similarly, in Taiwan, polio survivors are often represented as 'fighters' who have strong willpower to beat the disease. Such stories emphasise the spirit of 'disabled, but useful', which has had a great impact on public attitudes toward disabled people (Chen, 1976).

Several polio eradication projects were launched by the government during the 1990s, resulting in a remarkable decline in the number of polio patients (Wang et al., 2007). In 2000 Taiwan was declared a polio free area by the WHO. Kaufert and Kaufert (1984) argue that since polio has been effectively controlled, it has become a 'non-issue'. Polio survivors have gradually lost their high profile in the public's eyes. Many polio survivors in Taiwan are now reaching middle age and have experienced new functional losses. A study by Liu and Hsu (1985) shows that many polio survivors in Taiwan experienced PPS symptoms around 20 years after the original onset, which led to new functional losses such as articular pain and increased muscular weakness. However, the issue of ageing with polio remains underrepresented in both service provision and academic discussion.

Due to the number of polio survivors declining, most of the rehabilitation institutions initially established for children with polio have extended their services to people with various other impairments (Kang, 2008). Although a few studies have been undertaken on ageing with polio, these studies mainly focus on the pathological description and medical treatment of people with PPS (Chen, 1986; Yen et al., 1994; Yang, 2001; Wai et al., 2001). Nevertheless, the experiences of people ageing with polio cannot be recognised only as an

individual medical problem, it is necessary to go beyond a biological perspective and pay attention to disabling environments. In addition, existing studies on ageing with polio solely focus on polio survivors' experiences in old age, little is known about the impacts of past experiences on their present lives. Furthermore, the existing studies pay little attention to the impact of gender on the ageing experience of polio survivors. To enrich the understanding of ageing experiences among people with childhood-onset polio, this study focuses on the experiences of women ageing with polio, taking a life course approach.

## **1.4 Research Questions**

This study addresses the following research questions:

- What, if any, inequalities and barriers do women with childhood-onset polio experience across the course of their lives?
- How do women with childhood-onset polio respond to disabling environments?
- How do the past life experiences of women with childhood-onset polio affect their current life?
- What social and cultural factors influence the life experiences of women with childhood-onset polio across the course of their lives?

## **1.5 Outline of the Study**

The thesis is divided into nine chapters. Chapter Two reviews the existing literature, with particular reference to three areas, disability, gender and life course. It begins by discussing the definition of disability in a western context, then the concept of multiple oppression is examined. Themes related to the experiences of disabled women in the existing studies are discussed, including sexuality, motherhood and employment. Finally, the chapter examines the current debate on ageing and disability with particular reference to a life course perspective, which provides a conceptual framework through which to understand the experiences of women ageing with childhood-onset polio.

Chapter Three discusses the methods employed in the present study. Primary data are generated through life story interviews with ten women with childhood-onset polio aged between 50 and 60, who contracted polio before the age of five. The participants are given an opportunity to share their experiences in relation to barriers and inequalities at various life stages. The analysis of

primary data addresses the research questions. The limitations of the approach adopted in the fieldwork and data interpretation are considered. Finally the researcher's reflections on the research process are presented.

Chapter Four provides a historical background to Taiwan. This chapter gives details of the changing disability policy in a Taiwanese context since World War II. It begins with a brief overview of Taiwan, followed by a discussion of social changes and the development of disability policy over time. The context provided by this chapter gives a better understanding of the experiences of women ageing with childhood-onset polio in Taiwan.

The next four chapters discuss the findings of the study. These four chapters are structured to reflect the participants' experiences in four life stages. Chapter Five explores the childhood experiences of the participants, including parental reaction to children with polio; the participants' experiences in medical settings; and the factors that prevent participants from accessing education.

Chapter Six explores the participants' experiences in their youth. The chapter discusses several factors influencing their decisions on their future careers, then examines social barriers experienced by participants in post-school education and vocational training. The participants' experiences in the establishment of intimate relationship are explored.

Chapter Seven looks at two themes in the participants' early adulthood, employment and family life. The possibilities of entering the labour market, and the barriers to employment are discussed, along with the participants' experiences in self-employment and unemployment. It then examines the social barriers that hinder participants from fulfilling caregiving roles in their families.

Chapter Eight focuses on participants' experiences in middle adulthood. The chapter firstly addressed functional changes associated with ageing, and then examines the difficulties experienced by participants in providing care for their ageing family members. The participants' concerns about ageing are discussed, including maintaining independence, financial security and living arrangements.

Chapter Nine concludes the thesis by reviewing the empirical findings in terms of each research question. It discusses the theoretical implications derived from the research findings, gives insights for policy makers and service providers, and finally makes recommendations for future research.

## **Chapter Two**

### **Disability, Gender, and Life Course**

#### **Introduction**

The previous chapter outlined the background, aims and objectives of the research. This chapter reviews the existing literature and research on the experiences of women ageing with lifelong impairments. I begin by discussing the definition of disability in a western context. Following this, the literary debates on feminism and disability are examined. Then, I explore the concept of multiple oppression in relation to several themes within existing studies relating to the experiences of disabled women. Finally, I examine current debates on ageing and disability with particular reference to a life course perspective, which provides a framework for understanding the experiences of women ageing with lifelong impairments.

#### **2.1 Changing Concepts of Disability**

The interpretation of 'disability' varies with cultural context. According to the traditional model, disability is constructed by religion and culture in any society. Disability is seen as a punishment or the result of ancestral sin or retribution by the divine (Coleridge, 1993: 71). Despite the fact that the interpretation of disability in Taiwan is affected by traditional culture, it is also influenced by the western perspective. This section focuses on two theoretical approaches to disability in a western context, the individual model and the social model of disability. Over the last few decades, the concept of disability has shifted from the individual model to the social model of disability. The social model perspective has radically changed the definition of disability and significantly influenced the disability rights movement globally (Barnes, 2012a). I begin with discussion of the individual model of disability.

##### **2.1.1 The Individual Model of Disability**

The individual model of disability is underpinned by the personal tragedy theory of disability. Disabled people cannot fully participate in social activities because

of their physical and psychological limitations (Oliver, 1986). The individual model can be regarded as an individualistic medical model. Oliver (1996a: 31) describes it as 'an individual model of disability of which medicalisation is one significant component'. The bodies of disabled people are usually represented as 'deviant' because they are not able to meet the socially constructed standards of a 'normal body' (Davis, 1997). In this view, disabled people become objects to be cured, treated, trained and changed to make them 'normal' according to a particular set of cultural values (Barnes, 2003a: 9-10). Oliver's (1993) article "What's so Wonderful about Walking" indicates that the ideology of normality is embodied in rehabilitation enterprises. In rehabilitation practice, the pursuit of the ability of walking can be seen as a form of oppression against those who are not able to walk or reject walking. This is a reason why many children with polio have undergone numerous painful operations designed to enable them to regain walking capacity (Stone, 1995).

The individualistic medical approach reinforces the power of medical professionals to control the bodies of disabled people. Albrecht (1992) argues that disability is defined as a medical problem by medical professionals, and is attributed to the needs of the 'disability businesses'. People who are certified as having a 'disability' become the 'raw material' for a series of businesses within the larger rehabilitation industry (Albrecht, 1992: 21). Consequently, the bodies of disabled people are controlled by medical professionals. For instance, when disabled people fail to achieve the rehabilitation goals set by professionals, they are often blamed for having problems in adjusting to the disability (Oliver and Sapey, 2012). In addition, social policies and service provision are underpinned by the personal tragedy approach, and this leads to the dependency of disabled people (Oliver, 1986). Disabled people are often perceived as passive and dependent, and their lives are profoundly controlled by non-disabled professionals and service providers. Finkelstein (1993) terms this situation 'the administrative model of service intervention'. Even though services have shifted away from medical control toward community-based services, non-disabled professionals still occupy the administrative position in service provision.

The individual medical model is embodied in the definition of disability at the international level. The World Health Organisation (WHO) launched its International Classification of Impairments Disabilities and Handicaps (ICIDH) in 1980. The definition of disability in the ICIDH is 'any restriction or lack of ability to perform an activity in the manner or within the range considered

normal for a human being' (WHO, 1980: 29). The ICDH has been criticised by several scholars because for its individual medical thinking. It recognises functional limitation as a cause of disability. Borsay (1986) argues that the ICDH approach overly concentrates on personal adjustment and fails to address environmental factors. In addition, the ICDH highlights the ideology of normality and assumes that disabled people want to achieve normality (Oliver, 1996b). Several British disabled activists and disabled scholars have challenged the individual model and claim a new paradigm to redefine disability, known as the social model of disability (Hunt, 1966; Finkelstein, 1980; Abberley, 1987; Oliver, 1990). The next section provides more detail on the social model of disability.

### **2.1.2 The Social Model of Disability**

Paul Hunt's (1966) early work 'Stigma: the Experience of Disability' adopts a socio-political approach to examine the social relations between disabled people and able-bodied people. He argues that disabled people are excluded from social participation because of social prejudice, rather than impairment itself. In 1976, the 'Union of the Physically Impaired against Segregation' (UPIAS) made an explicit distinction between impairment and disability (UPIAS, 1976: 3-4).

- Impairment: lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.
- Disability: the disadvantage or restriction of activity caused by a contemporary social organisation which takes no, or little, account of disabled people who have physical impairments, and thus excludes them from participation in the mainstream of social activities.

The UPIAS definition breaks the causal link between impairment and disability. Impairment refers to physical or bodily dysfunction, whereas disability is a result of physical and attitudinal barriers rather than personal impairment. The UPIAS definition serves as a foundation for the development of the social model of disability. Oliver (1996c) claims that the social model is not about personal experiences of impairment, but the collective experience of disablement. According to the social model perspective, disability is not an

individual or medical problem, but can be seen as a form of oppression (Oliver, 1986; Abberley, 1987). 'Disablism' is identified as a specific form of oppression that stems from the subordination of people because of their impairment. People with impairment are categorised as a distinct group on the grounds of their body deficiency or abnormality, and treated differently (Barnes and Mercer, 2003: 20). Barnes (1991) introduces the term 'institutional discrimination' to describe the discrimination against disabled people. Institutional discrimination' is embodied in an inappropriate policy and welfare system, which systematically ignores and inadequately addresses the needs of disabled people.

Several scholars have examined the oppression experienced by disabled people in terms of a historical materialist perspective (Finkelstein, 1980; Oliver, 1990; Oliver and Barnes, 2012). From this perspective, the development of capitalism changes social responses to disabled people and produces a category of disability (Oliver, 2004). Finkelstein (1980) examines social responses to disabled people in three phases of historical development. Phase one is the pre-industrial period. During this period, the majority of disabled people were able to participate in agricultural activities and live in the community. Phase two begins with the industrial revolution. Industrialisation created a new mode of production based on able-bodied norms. Many disabled people were excluded from the labour force because they were incapable of keeping pace with the 'disciplinary power' of the new machines in the factory-based production system (Oliver and Barnes, 2012: 27). Consequently, those who were incapable of working were perceived as a social problem that needed to be solved. Many disabled people were removed from communities to segregated institutions. Phase three refers to the period to which we are heading towards, in which the development of technology and the equal relationship between disabled people and professionals leads to the liberation of disabled people (Finkelstein, 1980; Oliver, 1990).

In addition to economic exclusion, disabled people are marginalised from cultural representation. Charlton (1998) indicates that customs, rituals, institutions such as religion and the mass media represent social attitudes that contribute to disability oppression. For example, the religious views of Hinduism and Islam see individual impairment as misfortune, sent by the deity, fate or karma, and often associated with parental sin (Miles, 1995: 52). Oliver and Barnes (1998) suggest that popular culture and the mass media often stereotype disabled people as passive, dependent and in need of relying on

welfare services. In western culture, dependence implies the inability to do things for one's self and the need to rely on others' help. Independence means having the ability to do things on one's own and be self-reliant (Morris, 1991).

The meaning of independence has been challenged by the Independent Living Movement in the UK since the late 1970s. Brisenden (1989: 8) argues that the concept of 'independence' is not necessarily related to the physical or intellectual capacity to care for oneself without assistance. It means having control over one's life, but not necessarily performing every task oneself. Oliver (1990) suggests that no one in a modern industrial society is completely independent, we all live in a society of interdependence. It can be seen that the social model has reversed the social position of disabled people. Disability is a result of the disabling environment that excludes disabled people from participation in mainstream society economically, socially and culturally. However, the social model of disability is not without its critics. The following section discusses the criticisms of the social model that have emerged from the disabled people's movement and disability studies.

### **2.1.3 Criticisms of the Social Model of Disability**

The social model of disability has been criticised for only focusing on the external disabling environment and failing to address the experiences of impairment (Morris, 1991; Crow, 1992; French, 1993). Morris (1991: 10) criticises the social model for denying personal experiences of the physical or intellectual restrictions, of illness, of the fear of dying. Crow (1992) argues that it is imperative to bring back the experience of impairment into the social model of disability. In Crow's view, the recognition of impairment does not necessarily mean that impairment causes disability, but it does enable us to examine various social responses to personal impairment. More importantly, it provides an opportunity for disabled people to develop an alternative interpretation of their own impairments and challenge able-bodied people's views of disabled people's bodies (Crow, 1996). Shakespeare and Watson (2001) criticise the impairment/disability dualism within the social model. They claim that an adequate theory of disability should include all the dimension of disabled people's experiences, including the bodied, psychological, cultural, social and political dimensions.

Defending the social model, Oliver (1996a) suggests that the social model does not deny the reality of impairment and acknowledges that appropriate medical



interventions are important for disabled people. The social model of disability is a 'pragmatic' attempt to identify and address issues can be changed through collective action rather than medical or professional intervention (Oliver, 1996b: 48). Barnes (1996a) indicates that the overemphasis on the experience of impairment might reinforce negative cultural stereotypes of disabled people, and shift the focus away from the material and cultural oppression which disadvantages disabled people.

Thomas (1999) adopts a social relational approach to theorise the relationship between impairment and disability. She uses the term 'impairment effects' to describe how restrictions activities are directly associated with having a physical, sensory or intellectual impairment, rather than caused by disability (Thomas, 1999: 43). In Thomas's view, impairment effects are a medium of disability in a particular social relational context. This does not necessarily mean that impairment causes disability, but it is the raw material upon which disability works (Thomas, 2004: 41). Thus, it is important to recognise the impact of impairment effects on disabled people and examine how the interaction between impairment effects and disability shapes the life experiences of disabled people (Thomas, 1999).

A further criticism of the social model is that it treats disabled people as a unitary group, and overlooks the diversity of experience related to gender, race, age, sexuality and so on (Hanna and Rogovsky, 1991; Morris, 1991; Begum, 1992; Zarb and Oliver, 1993; Vernon, 1996; Shakespeare et al., 1996). Stuart (1995) argues that black disabled people face a specific form of oppression based on the interaction of disability and race, whilst their experiences are overlooked by the social model. Moreover, the social model has been criticised for its binary public/private thinking within the political agenda. Several scholars mention that the social model concentrates solely on the material barriers disabled people experience in the 'public world' such as education and employment, whilst it neglects the way oppression can operate in private life, such as family and personal relationships (Morris, 1991; Thomas, 1999; Shakespeare et al., 1996).

Thomas (1999) suggests that the UIPAS definition of disability should extend to all forms of oppression, including the social structural and psycho-emotional dimension. She introduces the concept of 'psycho-emotional dimension of disablism', which means that the oppression disabled people experience can operate in the social interaction between disabled people and non-disabled people. This undermines the psycho-emotional wellbeing of disabled people

and makes them feel of lesser value, worthless or unattractive (Thomas, 2004). Reeve (2004) indicates that the psycho-emotional dimension of disablism can be manifested in internalised oppression. Disabled people might internalise the social prejudice held by the dominant group, and this leads to low self-esteem and a sense of worthlessness.

The social model thinking significantly influences the definition of disability at international level. It is embodied in the WHO's recent attempt to redefine disability through a 'bio-psycho-social model' (Oliver and Barnes, 2012). The model attempts to integrate the medical and social model perspectives to provide a comprehensive understanding of health. The 'International Classification of Functioning, Disability and Health (ICF)', previously known as ICIDH-2, was developed using the bio-psycho-social model. The ICF sees disability as an outcome of interactions between health conditions and contextual factors. The contextual factors include external environmental factors, such as social attitudes, architectural characteristics, legal and social structures and internal personal factors including gender, age, social background and education. The interaction between these factors influences how disability is experienced by an individual (WHO, 2002: 10). Nevertheless, the ICF has been criticised for still being based on the medical notion of disability (Hurst, 2000). Although the ICF adopts a much broader definition of disability, it is still based on the medical model perspective. It recognises the restriction of impairment as a factor that hinders an individual from participating in society (Barnes and Mercer, 2010). Furthermore, Imrie (2004) argues that the ICF offers a complex structure of data collection, but lacks a coherent theory as a basis for understanding disability.

Based on the discussion above, the definition of disability has shifted from an individual approach towards a social-political approach. Oliver (2013) argues that the existing criticisms of the social model do not necessarily bring positive changes into disabled people's lives. He restates his view that the social model is still an important tool that can be used to initiate political action to improve disabled people's lives. In the present study, the social model of disability is used to explore the experiences of women ageing with childhood-onset polio in Taiwan. This, firstly, breaks a causal relationship between impairment and disability. Disability is created by the disabling environment, rather than impairment itself. It can be used to identify social barriers and prejudicial attitudes experienced by disabled people. Secondly, the social model recognises impairment effects on the social lives of disabled people. It focuses

on the interaction between impairment effects and disability and how it shapes the life experiences of disabled people (Thomas, 1999). It provides a framework to examine the social and cultural responses to people with different level of impairment. Finally, the social model of disability can be implicated globally. It provides a socio-political analysis to explain the problems encountered by disabled people throughout the world (Barnes and Mercer, 2005). Although the social and cultural barriers faced by disabled people may be different across countries, the social model can still be used to identify the commonality of exclusion experienced by disabled people in different socio-economic contexts (Flood, 2005). It can be a useful framework for examining the structural inequality and social exclusion experienced by women with childhood-onset polio in Taiwan.

## **2.2 Gendered Experiences of Disability**

The experience of disability is always gendered. Disabled men and disabled women may experience different forms and impacts of disablism in terms of their gendered locations and gender relations (Thomas, 1999). This section firstly examines the current debates on feminism and disability, then explores the concept of multiple oppression which is particularly related to the experiences of disabled women with multi-identity. Finally, several themes raised by the existing studies of disabled women are discussed.

### **2.2.1 Feminism and Disability**

Previous studies have criticised the fact that the experiences of disabled women are significantly absent from both the feminist movement and the disabled people's movement (Fine and Asch, 1988; Lloyd, 1992; Morris, 1993a; 1996; 1998; Thomas, 1999). It is necessary to mention here that the existing studies pay much attention to the oppression experienced by disabled women, but this does not mean that the experiences of disabled men are not important. Previous studies have explored the intersection between masculinity and disability (Morris, 1991; Shakespeare, 1999; Robertson, 2004). Several disabled feminists have mentioned that disabled women are alienated by non-disabled feminists. Fine and Asch (1988) argue that non-disabled feminists have made a great effort to advance powerful, competent female icons. Nevertheless, disabled women are usually perceived as passive, vulnerable

and dependent, and these characteristics might reinforce traditional stereotypes of women. Morris (1993a) criticises feminist scholarship for paying attention to the diversity of women's experiences such as ethnicity or social class, but neglecting the experiences of disabled women. For instance, in debates on community care, non-disabled feminists make a clear distinction between caregivers and the dependents who are 'cared' for. Disabled women are often regarded as the dependents whose existence restricts non-disabled women's economic opportunities (Morris, 1993a). A study conducted by Morris (1993b) shows that many disabled women are the main caregivers in their families.

In addition to the feminist movement, several scholars argue that the disabled people's movement in the UK is male-dominated and fails to recognise the experience of disabled women (Lloyd, 1992; Morris, 1993a; Thomas, 1999). This creates a problem for disabled women because their experiences are underrepresented in the political agenda. For example, the disabled people's movement tends to focus on personal assistance which enables paid employment and other activities outside the home, while disabled women might need personal assistants to help them look after children or run a home (Morris, 1996). Barnes (1996a) responds to the criticisms by disabled feminists. He argues that it is inaccurate to suggest that the disabled people's movement is dominated by men. In fact, disabled women occupy important positions in the disabled people's movement and make a significant contribution to the understanding of disability.

Over the last few decades, several scholars have explored the interaction between feminism and disability and tend to combine the two fields of study. They suggest that feminist theory can bring rich insights to disability studies (Morris, 1992; Wendell, 1996; Garland-Thomson, 2002; 2005; Kristiansen and Traustadóttir, 2004; Hall, 2011). Morris (1992) indicates that disability studies can learn from the feminist principle that 'the personal is political'. In Morris's view, feminist analysis is based on women's subjective experiences and emphasises the relationship between the oppressed and the oppressor. The analysis framework can be used to examine the oppression experienced by disabled people. In addition, feminist theory focuses on analysing the cultural interpretation of human variation, which can be applied to examining the socio-cultural meaning attached to the bodies of disabled people (Garland-Thomson, 2005). For instance, feminist theory provides a framework to examine the interaction between the politics of physical appearance and the medicalisation

of subjugated bodies, and this provides an understanding of the experience of disabled women in medical treatment (Garland-Thomson, 2002).

Furthermore, feminist studies acknowledge the significance of women's agency, rather than view women as passive victims. This perspective has been highlighted by several scholars in their studies of disabled women (Thomas, 1999; Hans, 2015). As Morris (1996: 2) describes, 'a representation of disabled women is itself a part of the struggle against the discrimination and prejudice experienced by disabled women, and focuses not just on their exclusion, but also on their survival'. Similarly, Hans (2015) argues that it is necessary to recognise how disabled women deal with the unequal treatment they experience and how they develop multiple strategies to combat discrimination. Next, I discuss the concept of 'multiple oppression' and its implications for the experiences of disabled women.

### **2.2.2 Disabled Women and Multiple Oppression**

The concept of intersectionality originated in gender studies and it refers to the relationships between various social groups, with an emphasis on boundaries and perceptions of difference (Woodin, 2014: 89). It is firstly used to address the experience of women of colour who face discrimination based on race and gender (Crenshaw 1989). The debate on intersectionality is whether to interpret the intersectionality of social division as an additive approach or a mutual constructive approach (Yuval-Davis 2006). Intersectionality has been introduced into disability studies by several scholars to explore the experiences of disabled people who have multi-identity (Hanna and Rogovsky, 1991; Stuart, 1993; Vernon, 1999; Cramer and Plummer, 2009; Erevelles and Minear, 2010). It can be argued that disabled women experience 'double disadvantage' associated with their dual stigmatised identities of being a woman and a disabled person, and this hinders them from full participation in society (Fine and Asch, 1981; Hanna and Rogovsky, 1991; Begum, 1994). Fine and Asch (1981) argue that disabled women face 'double disadvantage' caused by the intersection of disablism and sexism, and thus they might experience more constraints economically, socially and psychologically than disabled men and non-disabled women. A study conducted by Hanna and Rogovsky (1991) suggests that disabled women face 'two handicaps plus', which is attributed to the intersection of being a woman and a disabled person, as well as being a disabled women. This makes it more difficult for disabled women to get access to work and intimate relationships.

However, the concept of 'double disadvantage' has been criticised by several scholars. Morris (1993a) says that the concept of 'double disadvantage' is inadequate to represent the experiences of disabled women. It reinforces negative stereotypes of disabled women and views them as passive victims of oppression. Furthermore, the notion 'double disadvantage' sees disabled women as a 'minority interest', and thus their interests are more likely to be treated as a side issue to the concerns of both the feminist movement and the disabled people's movement (Morris, 1998). Black disabled feminists criticise 'double disadvantage' as being too simplistic. Such an additive approach cannot fully address the intersection between multi-stigmatised identities of disability, race, gender, class and ethnic minority (Stuart, 1993; Vernon, 1999). Begum (1994) argues that each form of oppression is not lived out separately or in a hierarchical structure. The notion of 'double disadvantage' or 'triple jeopardy' has obstructed an understanding of multiple oppression experienced by ethnic minority disabled people.

Stuart (1993) suggests that 'double disadvantage' fails to address the experiences of black disabled people. In Stuart's view, black disabled people experience 'simultaneous oppression' that prevents them from accessing social resources. This means that different forms of oppression occur simultaneously and cannot be understood separately. Nevertheless, Vernon (1999) further argues that the notion of 'simultaneous oppression' is inadequate to explain the experiences of people with multiple identities. Firstly, it does not consider the significant impact of class on an individual's experience. In addition, the effect of each stigmatised identity such as disability, race, gender or sexuality, is not necessarily experienced at same time; it can be experienced multiply, simultaneously or singularly, depending on the context.

Furthermore, the effects of disability on individuals are often modified or exacerbated by the presence or absence of privileged status. For example, disabled people of high social class status are more likely to have access to material resources that enable them to reduce the effects of the disabling environment (Vernon, 1999). Male status can be seen as a privileged identity that modifies the effects of disability. As Fine and Asch (1981: 240) describe, disabled men are more likely to 'escape' from the negative role of being a disabled person by reinforcing their male characteristics such as assertiveness and independence. However, disabled women are less likely to have such options because women are often perceived as dependent and passive, which are similar to the characteristics of disabled people.

There is a growing body of literature exploring the multiple oppression experienced by disabled women. For instance, Macfarlane's (1994) article is an early attempt to explore the ageing experience of disabled women in the UK. Zarb and Oliver (1993) investigate the experience of people ageing with physical impairment with particular reference to black disabled people and disabled women. The results show that all forms of oppression such as ageism, sexism and disablism are dimensions in the experiences of people ageing with physical impairment. Several studies have explored disabled women's lives in various physical regions which are often perceived as 'low-income countries' (Abu-Habib, 1997; Hans and Patri, 2003; Emmett and Alant, 2006; Hans, 2015).

The concept of intersectionality is not without its critics. McCall (2005) suggests that intersectionality is a complex concept. It has introduced new methodological problems and limited the range of methodological approach to study intersectionality. Davis (2008) criticises that the concept of intersectionality is ambiguous and lacks of a clear-cut definition. It did not provide a methodological framework to study intersectionality. The present study adopts the concept 'multiple oppression' introduced by Vernon (1999) as a conceptual framework to examine the experiences of women ageing with childhood-onset polio. As discussed earlier, the concept 'multiple oppression' provides a comprehensive understanding of a complex interaction between different forms of oppression based on disability, gender, race, age and class, and how it shapes participants' experiences in various contexts. In addition, it explains the way that the absence or presence of privileged status can modify or exacerbate the effects of social barriers on disabled people. This provides a useful framework for analysing the interaction between the various forms of oppression experienced by the participants. Next, I explore several themes which emerge from the existing studies on the experience of disabled women, including sexuality, motherhood and employment.

### **2.2.3 Key Themes in Studies of the Discrimination of Disabled Women**

Article 6 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) indicates that 'state parties shall recognise that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms' (United Nations, 2006). Over the last

few decades, there has been a growing body of literature exploring the oppression experienced by disabled women (Fine and Asch, 1981; 1988; Begum, 1992; 1994; Hanna and Rogovsky, 1991; Lloyd, 1992; Morris, 1989; 1996; Thomas, 1997; 1999; Garland-Thomson, 2005; Hall, 2011). An early work by Fine and Asch (1981) suggests that disabled women experience 'rolelessness', which means that disabled women face many barriers that hinder them from fulfilling productive roles considered appropriate for males, as well as the reproductive roles conventionally reserved for females. Campling's (1979) 'Better Lives for Disabled Women' is one of the early studies on the experiences of disabled women in the UK. The research is based on disabled women's accounts, and raises several issues around sexuality, pregnancy, motherhood, employment etc. Morris (1989) further examines the social oppression encountered by women with spinal cord injury in several aspects of their lives, such as medical treatment, body image, sexuality, family life, employment and ageing. The following sections review the existing literature about the problems disabled women experience, including sexuality, motherhood and employment.

### **Sexuality of Disabled Women**

It is commonly argued that disabled people are treated as asexual and as being unattractive. Shakespeare et al. (1996) indicate that disabled people are subject to infantilisation, which means that they are perceived like children who are assumed not to have any sexuality, and are similarly denied their sexual feelings. For instance, people with learning difficulties are often treated as children, irrespective of age, and hence are regarded as incapable of making sexual choices (Wilkerson, 2011). Paradoxically, disabled people are also stereotyped as hypersexual, and their sexual behaviours are controlled by others (Hall, 2011). For example, disabled women are more likely to experience forced sterilisations, usually recommended by family members or medical professionals (Frohman and Ortoleva, 2013).

Previous studies have demonstrated that disabled women experience barriers that restrict them from establishing intimate relationships (Prilleltensky, 2003; Nosek et al., 2001a). Disabled women are often perceived as being not attractive because they cannot meet the socially constructed standards of beauty (Begum, 1992). They are also considered unfit as sexual partners because they are rarely regarded as sexual objects by men (Hanna and Rogovsky, 1991). Rintala et al. (1997) investigate the dating experience of disabled women and find that disabled women face physical barriers that



restrict them from having contact with potential partners, and also have to deal with the assumption that disabled women are asexual and unable to have a sexual life.

Such negative stereotypes create problems for disabled women in establishing intimate relationships. Physical appearance is an important factor influencing an individual's sense of self, particularly in adolescence. Prilleltensky (2003) indicates that young disabled girls are often excluded from 'girl talk' by their non-disabled peers and this may undermine their self-esteem. Furthermore, parents may deny the sexuality of their disabled daughters and often discourage them from developing sexual relationships (Rousso, 1988). The low expectations of family members considerably influence disabled women's sense of self and their attitudes towards intimate relationships (Prilleltensky, 2003).

There is often an assumption that disabled people will 'stick with their own kind', which means that disabled people are more likely to form relationships with other disabled people (Shakespeare et al., 1996). However, such stereotypical thinking might be a cause of internalised oppression experienced by disabled women. Rintala et al. (1997) indicate that some disabled women may presume that they do not deserve an able-bodied partner and refuse to date able-bodied people. Some disabled women may prefer to establish relationships with able-bodied people, not just because they can receive physical assistance from their able-bodied partners, but also because their non-disabled partners are seen as 'a passport into the world of normal people', that makes them feel they are 'normal' (Morris, 1991: 36).

In addition to intimate relationships, previous studies suggest that disabled women are at higher risk of sexual assault compared to their non-disabled counterparts (Nosek et al., 2001; Martin et al., 2006; Casteel et al., 2008). Nosek et al. (2001) suggest that disabled women are more likely to experience sexual abuse in the helping relationship and in specific disability-related settings, such as institutions, special schools or medical settings. Thiara and Hague (2012) conducted a survey of domestic violence against disabled women in the UK. The results show that disabled women might experience a longer duration of abuse than non-disabled women because it is more difficult for them to receive support from existing services. For example, most shelters for victims are not accessible to women with mobility difficulties (Young et al., 1997). Wilkerson (2011) states that the current discussion victimises disabled women by overstating their vulnerabilities to sexual violence, rather

than addressing the problems of the disabling environment. For instance, a lack of adequate sex education and information may leave disabled women exposed to sexual abuse in medical settings, domestic settings and in intimate relationships (Kallianes and Rubenfeld, 1997).

In terms of a social model perspective, the problem of sexuality is not an inevitable outcome of body differences or functional limitation. The problem is that social barriers restrict disabled people from exercising sexual agency (Shakespeare et al., 1996). Several studies show that disabled people, like other sexual minorities, face a greater challenge of sexual citizenship. Disabled people demand control of their bodies and relationships, and have the right to gain access to representation, relationships and public space (Shakespeare, 2000; Wilkerson, 2011; Siebers, 2012). The existing literature challenges the negative sexual expression of disabled people. For instance, a study by Singh and Sharma (2005) challenges the assumption that women with spinal cord injury cannot have a sexual life. It shows the majority of participants report that they are still satisfied with their sexual lives after spinal cord injury. Karlen (2002) investigates the sexual life of women with lupus. Several participants claim that their experience of coping with lupus brought improved sexual function and relationships with their partners. In addition to sexuality, disabled women face many challenges in being mothers. The next section discusses the experience of motherhood of disabled women.

### **Motherhood of Disabled Women**

From a feminist perspective, motherhood itself is considered an oppressive institution for women which should be challenged. However, many disabled women are excluded from the discourse on motherhood (Malacrida, 2009). It is necessary to mention here that not all disabled women have a preference for marriage or motherhood. Some disabled women, just as non-disabled women, may have no desire for marriage, childbearing or heterosexual relationships, while others take on these non-traditional roles through a process of default rather than a personal choice (Fine and Asch, 1988). A growing body of research suggests that disabled women are often stereotyped as 'unfit' to ideal motherhood and experience barriers that hinder them from becoming mothers (Thomas, 1997; Thomas and Curtis, 1997; Grue and Lærum, 2002; Lewiecki-Wilson and Cellio, 2011).

Disabled women are often discouraged from having children because of a fear that they would pass their conditions to their children (Kallianes and Rubenfeld,

1997; Boardman, 2011). Thomas (1997) investigates the reproductive experiences of disabled women. The study finds that disabled women are often persuaded not to have children or forced to terminate pregnancies by family members or medical professionals in order to avoid producing disabled children. This suggests that the medical discourse on reproductive risk profoundly undermines the reproductive rights of disabled women. Kallianes and Rubinfeld (1997) argue that the assumption that disabled women's conditions would be passed to their children has been exaggerated. In fact, a large proportion of impairments are not congenital, but develop later in life. In some cases the possibility of a child inheriting a hereditary disease remains uncertain, but people often hold the assumption that disabled people would automatically transmit their conditions to their children (Boardman, 2011).

The development of reproductive, genetic testing has controlled disabled women's bodies and reinforced the discrimination against disabled people (Chakravarti, 2015). Morris (1991) argues that the lives of disabled people are devalued by able-bodied people as 'unworthy lives'. Such judgements have rationalised the use of selective abortion and assisted suicide to control the lives of disabled people. Boardman (2011) suggests that the availability of genetic testing technology emphasises the moral responsibilities of disabled women, and forces them to consider their 'genetic responsibility' towards their children. Prejudicial attitudes towards disabled women make it more difficult for them to have access to maternity services. Most health care professionals are not sensitive to the needs of disabled women due to lack of knowledge and skills (Walsh-Gallagher et al., 2013). In addition, disabled women cannot have access to maternity services because of inaccessible physical environments and lack of accessible information in medical settings (Thomas, 1997). It could be difficult for disabled women to receive information from a role model who has similar experiences of pregnancy and childcare (Lindgre, 2011).

Disabled women are usually perceived as incapable of looking after their children because of functional limitations (Prilleltensky, 2003). The debate on 'young carers' assumes that disabled parents are usually dependent on their children, but this assumption has been challenged by several scholars (Keith and Morris, 1995; Olsen and Clarke, 2003). Morris (1998) argues that the discussion of 'young carers' does not recognise that disabled parents have limited access to material resources and services and this may force them to rely on their children. Wates (2002) examines service provision for disabled adults in the UK. The research findings show that most service providers do not

recognise the needs of disabled parents, and suggest that disabled people's parenting needs should be routinely covered within the service provision for disabled adults.

Inadequate services can also prevent disabled women from fulfilling the role of mother. Grue and Lærum (2002) suggest that disabled women find it difficult to receive assistance that enables them to carry out care activities, because they are often looked upon by service providers as care receivers, not caregivers. Service providers often perceive disabled women as 'dependent' and tend to do things for them, rather than enable them to manage tasks themselves (Keith and Morris, 1995; Thomas and Curtis, 1997). Some disabled women are unwilling to seek help from social services because they are afraid that they would be labelled by the service providers as unfit to be 'good mothers' (Olsen and Clarke, 2003). The situation can be worse for single disabled mothers. A study conducted by Cassiman (2011) shows that disabled single mothers have to deal with the social stigma associated with their multiple identity as a welfare recipient, a single mother and a disabled woman, and this prevents them from having access to material resources to look after their children.

From the discussion above, we can see that disabled women face multiple challenges in fulfilling their mother roles. Nevertheless, some studies, most based on disabled women's accounts, demonstrate how disabled mothers resist social oppression and redefine the discourse of motherhood and parenting (Prilleltensky, 2003; Malacrida, 2009; Lindgre, 2011; Boardman, 2011). Malacrida (2009) indicates that disability itself can be an advantage that enables disabled women to look after their children. Some disabled women can provide better mothering than non-disabled mothers because their experiences of dealing with disabling environments enable them to cope with the challenges of childcare. A similar finding can be seen in a study conducted by Boardman (2011) on the parenting experiences of women with Spinal Muscular Atrophy (SMA). The results indicate that the experiential knowledge of living with SMA can be regarded as a positive resource for parenting, and can be used to reclaim their authority to challenge the judgements of medical professionals. Linger's (2011) study challenges the negative stereotype of disabled mothers. She describes how she established a partnership with her husband and paid assistants to look after her two children. This suggests that disabled mothers can find creative ways to provide care for their children with appropriate social support.

The studies reviewed here shed light on the mothering experiences of disabled women. We can see that disabled women challenge the stigma attached to disabled mothers and tend to transform the discourse of ideal motherhood. As Olsen and Clarke (2003: 9) describe, disabled parents themselves have challenged to the conception of parenting. They place greater emphasis on the role of parents in providing love, support, leadership, organisation and so on, rather than on the physical tasks associated with parenting. Apart from motherhood, disabled women face discrimination in employment. More detail on the employment experiences of disabled women is provided in the following section.

### **Employment of Disabled Women**

The labour force participation rate of women has significantly increased over the last decade. According to statistics from the International Labour Organization, the gap between male and female labour force participation has narrowed. The corresponding figures for males and females are 79.9 per cent and 76.1 per cent respectively (International Labour Office, 2016: xi). Despite the fact that women are offered more opportunities to enter the labour market today, disabled women still face constraints that prevent them from gaining access to work. There is mounting evidence that disabled women are more likely to experience unemployment and unequal pay, and are less likely to have access to education and vocational training, compared to disabled men (Russo and Jansen, 1988; Baldwin and Johnson, 1995; Naami et al., 2012; Pawłowska-Cyprysiak and Konarska, 2013).

Education can be seen as a strategy for disabled people to overcome barriers to employment, while disabled women experience inequalities in access to education compared to their male peers (Russo and Jansen, 1988). Agnihotri and Patel (2015) indicate that disabled girls with mobility difficulties are often excluded from schooling due to lack of accessible facilities in schools and the problem of travelling. The absence of accessible toilets can be particularly problematic for disabled girls. A study by Rousso (2004) shows that some disabled girls need help to manage menstruation in school. Lack of accessible toilets and sanitary equipment makes it more difficult for them to manage their periods in a safe way.

In addition, parental attitude towards their disabled daughters may influence their educational opportunities. Maya Dhungana (2006) investigates social barriers experienced by disabled women in Nepal. The research indicates that

negative parental attitudes towards disabled daughters hinder them from accessing education and vocational training. Naami et al. (2012) suggest family socioeconomic status impacts whether disabled women have access to education. Disabled women who are from low-income countries are more likely to live in poverty and be denied their right to education. Conversely, Rousso (2004) indicates that disabled girls who are from middle and upper class families are not only more likely to attend school than those from poor families, but also have greater access to both educational and vocational opportunities than their non-disabled counterparts.

Disabled women, like non-disabled women, experience gender segregation in vocational training courses and employment. Previous studies find that disabled women enrol in training courses which are perceived as appropriate for women such as office work, childcare, tailoring and handicraft making, which are low skilled and less marketable jobs. In contrast, disabled men often concentrate on computer training and electrical training that have high demand jobs and receive good salaries (Maya Dhungana, 2006; Agnihotri and Patel, 2015). Furthermore, rehabilitation services are gender-blinded and do not consider the needs of disabled women. Vandekinderen et al. (2012) indicate that disabled women's caring roles are usually disregarded in vocational training programmes. For instance, some disabled women are likely to withdraw from vocational training programmes because they need a flexible training schedule that enables them to look after children. Gender segregation also affects the career options of disabled women. Lindstrom et al. (2004) explore factors that influence the career choices of women with learning difficulties, and finds that gender role expectations restrict those choices.

In addition to vocational training, existing studies demonstrate that disabled women face inequality and barriers to employment. Disabled women are more likely to be employed in low status, lower paid jobs (Pawłowska-Cyprysiak and Konarska, 2013). O'Hara (2004) examines wage discrimination against disabled women by comparing them with their non-disabled counterparts. The results show that disabled women are almost twice as likely to work in a service occupation as non-disabled women. In general, service occupations have lower skill and pay levels, and this has enlarged the wage gap between disabled women and non-disabled women. Similarly, Baldwin and Johnson (1995) suggest that disabled women experience greater wage discrimination in the workplace, compared to disabled men and non-disabled women. Even though

disabled women are overqualified for jobs, employers offer them the usual wage.

In addition, disabled women are more likely to experience employment instability than their male counterparts. Agnihotri and Patel (2015) indicate that disabled women are more likely to become self-employed when other options in formal sectors are not available. Naami et al. (2012) suggest that disabled women are encouraged to attend training programmes that help them run small businesses, but they often cannot receive sufficient funding or equipment to establish their own businesses after finishing the training. Previous studies have shown that women face dual demands from work and family. Women are more likely to leave their jobs or be employed in part-time jobs because of childbearing or caring for other family members (Minkler, 1990; Arber and Ginn, 1991) (see section 2.3.3).

Disabled women, like non-disabled women, face challenges in managing their dual roles as a paid worker and a caregiver, and need support to enable them to balance the dual demands of work and caregiving. The significance of reconciling employment and family life for disabled women is highlighted in the 'European Conference on the Vocational Rehabilitation and Employment of People with Disabilities'. The conference report suggests that it is imperative to develop additional support for disabled women to work, including access to childcare, care for other dependants, accessible transport to workplaces and access to personal assistance (International Labour Organization, 2003: 16). The studies reviewed here demonstrate that disabled women experience barriers due to the interaction of gender and disability that exclude them from equal participation in education, vocational training and employment. The next section examines the current debates on ageing and disability, with particular reference to the life course perspective, which provides a theoretical framework through which to understand the ageing experience of disabled women.

### **2.3. Growing Old with Lifelong Impairments**

As mentioned in Chapter One, the ageing population has become a global issue over the last few decades. The same trend applies in the disabled population. Beresford and Thomas (2015) suggest that although the issues of ageing and disability attract attention on the political and research agendas, they are often perceived as negative. The relationship between ageing, older people and disability is still an area that is neglected. This section begins with a brief overview of current debates on ageing and disability. I then discuss the life

course perspective and how it theorises the experience of ageing. Finally, I examine the association between gender, inequality and life course, and its implications for understanding the experiences of women ageing with lifelong impairments.

### **2.3.1 Ageing and Disability**

For the last few decades, there has been a growing body of literature exploring the issues of ageing and disability (Zola, 1988; Zarb, 1993; Zarb and Oliver, 1993; Macfarlane, 1994; Bigby, 2002; Putnam, 2002; Prakash, 2003; Grassman et al., 2012; Grassman and Whitaker, 2013). Several scholars argue that the existing studies on ageing overlook the experience of older disabled people (Minkler, 1990; Crewe, 1991; Harrison, 2006). Crewe (1991) criticises traditional stage theories as overemphasising what constitutes successful adaptations for the ageing process, and failing to recognise that disabled people might cope with ageing in different ways. Minkler (1990) argues that new ways of thinking of old age, such as 'successful ageing', overstate a healthy lifestyle in old age, and this has reinforced prejudice against older disabled people. In Minkler's view, it is necessary to acknowledge the diversity of the elderly population and meet the needs of elders with all functional abilities and health conditions. Similarly, Priestley (2003) indicates that both the disabled people's movement and the 'Third Age' movement are based on adult-centred values, which emphasise the significance of independent adulthood, and this distances them from the negative image of dependence attached to older disabled people.

Several studies suggest that disabled people experience physical degeneration caused by the effect of ageing itself, as well as the long-term effects of pre-existing impairment (Ansello, 1988; Crewe, 1991; Zarb, 1993; Yorkston et al., 2010). Zarb (1993) investigates the ageing experience of people with physical impairment and finds that disabled people might experience 'premature' physical ageing. This means that the process of physical degeneration is associated with the ongoing course of the impairment, rather than with age itself. Lin and Lin's (2004) study, based in Taiwan, shows similar findings, that many disabled people aged over 50 experience physical degeneration, which is earlier than their non-disabled counterparts. Disabled people also experience the age-related diseases and general physical degeneration associated with ageing. Harrison (2006) explores the experience of women ageing with physical impairment and finds that some women experience damaging falls due



to osteoporosis. A study by Morris (1989) suggests that disabled women, just as non-disabled women, experience menopause. Those who use wheelchairs may find it difficult to manage heavy periods.

Apart from functional changes, disabled people might also experience psychological changes associated with ageing. Priestley (2003) suggests that the ageing process is commonly associated with the onset of impairment and thus impaired bodies are more likely to be seen as 'normal' in old age. This perspective explains why being disabled becomes more acceptable to some disabled people when they grow older. For instance, Scheer and Luborsky (1991) examine how cultural context influences polio survivors, and the way they interpret the functional losses associated with PPS. They find that older participants see these new symptoms as 'normal-ageing related' and this makes them feel they are much more 'normal'. Pentland et al. (1999) suggest that disabled women might develop a positive sense of self when they grow old, because they no longer feel the need to prove themselves. However, not all disabled people can easily accept the new functional losses associated with ageing, particularly those who have regained control and independence in their early years. Frick (1995) finds that some polio survivors assume that they have 'got over' polio, and this makes it more difficult for them to reconstruct their self-identity when they experience new functional losses in old age.

The existing literature shows that disabled people are afraid that they may lose their independence and experience institutionalisation when they grow old (Zarb and Oliver, 1993; Pentland et al., 1999; Chung, 2011). Disabled people might face increased expenditure associated with ageing, such as house modification, domestic support, transport and so on, and need financial support to maintain control of their lives (Zarb and Oliver, 1993; Yorkston et al., 2010). Due to increasing uncertainty about their physical condition, disabled people may worry about the availability of social services and informal support in the future. Chung (2011) investigates the experiences of people ageing with lifelong impairments in Singapore. Most worry that they may lose family support when they grow old because their parents and spouses are also ageing. This can be a particular issue for women, because women have greater longevity than men. Pentland et al. (1999) suggest that disabled women are afraid that they may not have support from their partners, since they are more likely to leave them.

As discussed above, disabled people experience physical and psychological changes associated with ageing and may need support to enable them to

maintain independence when they grow old. Nevertheless, previous studies show that existing social policy and services fail to address the needs of older disabled people (Ansello, 1988; Walker and Walker, 1998; Bigby, 2002). Walker and Walker (1998) argue that people with learning difficulties face 'double jeopardy' in service provision for disabled people and for older people. Those who experience the effects of premature ageing are too young to be entitled to social services for older people. On the other hand, services for young disabled people mainly focus on skills development and may not be suitable for older disabled people. A similar problem can be found in the services for older disabled women. Macfarlane (1994) argues that age-based social services do not recognise the continuum of needs of older disabled women. She suggests that services should allow older disabled women to continue their favoured lifestyle into old age.

Furthermore, existing social policy and social services are gender-blind and fail to respond to the needs of women ageing with lifelong impairments. As mentioned, many disabled women are caregivers in their families, but their needs of caregiving are profoundly overlooked by service providers (section 2.2.3). When disabled women reach their middle age, like non-disabled women, they are expected to care for their adult children, ageing parents or ill spouses. Quinn and Walsh (1995) find that many midlife disabled women experience physical degeneration, but have to provide support for their ageing parents or sick spouses. They suggest that services providers and policy makers should provide support for these women to carry out caretaking activities.

This section has reviewed existing literature on ageing and disability. It shows that disabled people experience many challenges as they grow old, while their needs remain underrepresented in social policy and service provision. Most studies reviewed here concentrate mainly on the changes experienced by disabled people in old age, little is known about how people live with lifelong impairments over time (Zarb, 1993; Zarb and Oliver, 1993; Harrison, 2006). In terms of a life course perspective, the experience in old age cannot be fully understood without considering the impact of previous life experiences (Moody, 2000). The next section discusses the life course perspective on ageing, which provides a framework through which to examine the ageing experience of people with lifelong impairments.

### **2.3.2 The Life Course Perspective on Ageing**

From a biological perspective, ageing is a physiological degeneration in which individuals experience physical changes such as grey hair, wrinkled skin and functional degeneration (Moody, 2000). This perspective is limited in its explanation of ageing. Anstey et al. (1996) argue that it is difficult to give a standardised index to identify biological ageing, because people at the same chronological age may have different functional capacities. From a sociological perspective, ageing is a socially constructed concept which varies across cultural contexts (Pilcher, 1995; Hockey and James, 2003; Vincent, 2003). Several scholars adopt a political economy perspective to examine the social aspects of ageing (Phillipson, 1982; Arber and Ginn, 1991). Phillipson (1982: 1) argues that old age is regarded as a problem for a society characterised by inequalities in the distribution of power, income and property. In a sociocultural perspective, old age and disability share a similarity of social position. Priestley (2003) indicates that older people and disabled people both are often perceived as dependent and being excluded from the labour market. Putnam (2002) argues that gerontology should incorporate the social model perspective into the 'social model of ageing', and uses it to examine the relationship between older people and the social environment.

There is a growing body of literature suggesting that a life course perspective can offer a comprehensive understanding of old age (Hareven, 2001; Moen, 2001; Vincent, 2003). Hareven (2001) indicates that scholars and policy makers generally see old age as a distinct life stage, isolated from the rest of the life course, but this perspective cannot fully explain the experience of old age. It is important to interpret old age within a life course or historical context. The life course perspective provides a holistic view of the development of human lives. An individual's life is identified as a series of interrelated careers with life transitions and particular pattern of development (Vincent, 1995: 154).

Elder (1994) identifies four elements in the life course paradigm. The first element is 'lives and historical times', which means that people born in different historical periods are exposed to different constraints and opportunities. The second fundamental principle is 'the timing of lives'. People's lives are regulated by socially constructed age norms and by the expected timing of life transitions. The third element is 'linked lives'. This means that human lives are embedded within social relationships with family members and friends. Hareven (2001) indicates that individual choices are profoundly influenced by family and intergenerational relations. The fourth element is 'human agency'.

This means that human lives constitute a series of choices. People make their choices creatively, depending on constraints and the availability of opportunities. In Elder's view, the four elements intertwine and shape a person's life course trajectory. The life course perspective provides a framework through which to understand the associations between historical conditions, social structures and interpersonal relations and how they influence individuals to make their life choices (Elder, 1994; Giele and Elder, 1998).

Although there is a growing interest in exploring the ageing experience in terms of the life course perspective, we know little about the experience of people living with lifelong impairments and what challenges they face over time. A few studies have adopted the life course perspective to explore the experiences of people ageing with lifelong impairments (Zarb, 1993; Shah and Priestley, 2011; Harrison, 2003; Grassman et al., 2012; Grassman and Whitaker, 2013). Harrison (2003) suggests that Elder's life course paradigm is useful to examine the experiences of women ageing with lifelong impairments. Harrison indicates that disabled women have highly interdependent lives. The interpersonal relationships between disabled women and families profoundly influence these women's life choices. Several studies adopt the life course perspective to examine macro-level impacts on the lives of disabled people. Shah and Priestley (2011) adopt a biographical approach to examining how the development of disability policy in the UK shapes the life experience of disabled people over time. Grassman et al. (2012) investigate the experience of people ageing with lifelong impairments in Sweden in terms of life course perspective. The research shows that welfare reform and the development of disability politics significantly change disabled people's lives.

The life course approach emphasises the cumulative effects of earlier events on later experiences over the entire course of a life (Hareven and Masaoka, 1988; Elder, 1994). From this point of view, ageing is a lifelong process, and old age is seen as the result of all the stages that came before (Moody, 2000). Hareven (2001) suggests that the life course perspective provides an understanding of how problems, needs and patterns of adaptation of older people are shaped by their past experiences and historical conditions. For example, Pentland et al. (1999) indicate that some disabled women push themselves too hard in order to meet the social expectations of being an ideal mother and holding a job, which are physically demanding tasks. These women are more likely to experience physical degeneration caused by overuse of physical strength in earlier years. This suggests that that the ageing experience

of disabled people cannot be fully understood without considering the impacts of previous life experiences. This raises the question of how disabled women's previous experiences of living with lifelong impairments shape their lives in old age. Next, I discuss how the life course perspective can bring insights to the experiences of women ageing with lifelong impairments.

### **2.3.3 Gender, Inequality and Life Course**

Life course is gendered. Gender shapes men's and women's lifestyles in the early adult years, and it produces considerable differences in roles and inequality in relationships and resources (Moen, 2001). Arber and Evandrou (1993) argue that older people are not a heterogeneous group. The interaction between gender and class during adult life influences the experience of ageing and the meanings attached to it. Several studies have demonstrated that women experience inequalities in access to material resources during their adult years, and therefore may face economic disadvantages in old age, compared to their male counterparts (Minkler and Stone, 1985; Arber and Ginn, 1991; Vartanian and McNamara, 2002).

Pearce (1978) introduces the concept 'feminisation of poverty' to describe that women are more likely to live in poverty than men. In Pearce's view, although women's participation in the labour market has increased, women experience gender segregation and this leads to limited occupational opportunities and wage discrimination. On the other hand, existing employment policy does not improve women's lives, but institutionalises the inequalities women experience in economic activities (Pearce, 1978). As discussed previously, disabled women, like non-disabled women, experience gender segregation in occupational training programmes and employment. The existing services fail to challenge structural inequalities disabled women experience in employment. Disabled women are channelled towards less skilled, lower paid jobs (section 2.2.3).

However, Minkler and Stone (1985) suggest that the feminisation of poverty should be understood from a life course perspective. In this view, poverty among young women may lead to more economic inequalities in their old age. Vartanian and McNamara (2002) examine the factors that contribute to older women's economic status from a life course perspective. The findings show that women's economic vulnerabilities in old age can be seen as a consequence of longstanding life course characteristics combined with the

effects of age. For example, disabled women find it more difficult to find jobs than their male counterparts, and rarely have financial plans for economic security when they grow old (Pentland et al., 1999).

Previous studies show that discontinuity of paid work reduces the number of years of pension contributions, and this decreases the opportunities for women to gain access to work-based pension schemes (Minkler and Stone, 1985; Arber and Ginn, 1991). This can be a particular problem for disabled women. As mentioned previously, disabled women experience physical degeneration and may have to retire early. Harrison (2006) suggests that some disabled women retire early before they reach the statutory retirement age, or have to push themselves to stay employed as long as possible in order to meet aged-based entitlements through their work, despite the changing condition of their bodies. This makes it more difficult for disabled women to have access to work-related pension schemes. Russo and Jansen (1988) indicate that disabled women are much less likely to be covered by pension schemes and health plans than disabled men.

Furthermore, the existing literature shows that women's marital status affects their economic wellbeing in old age (Minkler and Stone, 1985; Vartanian and McNamara, 2002; Arber, 2004). Vartanian and McNamara (2002) suggest that women who are divorced, separated or never married are more likely to live in poverty than those who are married. A study by Agnihotri and Patel (2015) also shows a similar result, that disabled widows are worst off in terms of economic status. Disabled widows face multiple discrimination combined with widowhood, gender and disability, and this poses a risk to their economic wellbeing. In addition, women's marital status may influence their living arrangement choices when they grow old. Arber (2004) suggests that women who are widowed or never married are more likely to live in residential settings in old age, due to the lack of family support. A study by Harrison (2006) indicates that disabled women who are unmarried are more likely to live with their ageing parents and provide mutual support for each other.

In this section, the existing literature has shed light on the ageing experiences of disabled women. It can be seen that the disadvantages disabled women experience in earlier years influence their lives in old age. The life course perspective has been used broadly to examine the ageing experience of older women, yet we know relatively little about disabled women's lives over time. Furthermore, most of the studies reviewed about the ageing experience of disabled people were conducted in a western context. Only a few studies have

been made on this issue in Asia (Iwakuma, 2001; Prakash, 2003; Chung, 2011). Harrison (2006) suggests that further research is needed in various geographical locations to understand how women with various cultural backgrounds experience ageing with lifelong impairments.

To fill a gap in the current research, the present study adopts a life course perspective to explore the experience of women ageing with childhood-onset polio in Taiwan. This is used to explore the women's experience of living with polio in various life stages, and see how previous life events influence their subsequent life choices and shape their life trajectories. The life course perspective provides a framework through which to understand how intergenerational relations, opportunity structure and constraints influence the women's life choices across the course of their lives. It brings insights to the experiences of women ageing with lifelong impairments in Taiwan.

## **Summary**

This chapter discusses two models of disability, from a western viewpoint. The definition of disability has shifted from an individual model to a social model. The social model of disability suggests that disability is not caused by individual impairment, but by disabling environments and prejudicial attitudes that exclude disabled people from participation in society. The chapter also reviews the debates on disability and feminism, and examines the concept of multiple oppression with particular reference to disabled women. This suggests that the oppression disabled women experience is far more than the 'double disadvantage' of gender and disability. Disabled women are subject to multiple oppression related to the intersection between their multi-stigmatised identities. Furthermore, a brief overview of the research into the experience of disabled women was provided. It demonstrates that disabled women face many difficulties that restrict them from fulfilling their reproductive roles as well as other productive roles.

Existing studies on ageing and disability are discussed, which provide insights into the ageing experiences of disabled people. Moreover, the life course perspective is introduced as a framework for exploring the experiences of people growing old with lifelong impairments. It can be argued that ageing is a lifelong process, and therefore the ageing experience of disabled people cannot be understood without considering the impacts of previous life experiences. Finally, the gender inequality experienced by women is examined in terms of the life course perspective. The life course perspective brings

insights into the experiences of women ageing with lifelong impairments. The subsequent analysis is based not only on the theoretical framework discussed so far, but also on data generated by the research. The next chapter justifies my chosen methodology and data generation strategies.



## **Chapter Three**

### **Researching the Experiences of Women Ageing with Polio**

#### **Introduction**

The previous chapter reviews the existing literature related to the research topic. This chapter addresses the theoretical assumptions and methodological considerations of the study. It begins with a brief introduction to the emancipatory paradigm in disability research, and clarifies how emancipatory principles relate to the study. I discuss the strategies and methods I employ to generate data, followed by a discussion of the data analysis. Finally, my reflective account is provided.

#### **3.1 Emancipatory Disability Research**

French and Swain (1997: 65) critique traditional disability research, stating that it is oppressive to disabled people, and fails to assist them in their struggle for civil rights and full participative citizenship. For a long time, disability research was dominated by medical and healthcare academics. Rioux (1994) describes traditional disability research as 'the research into measles', which focuses on prevention and seeks cure for disease, rather than challenging the disabling social barriers experienced by disabled people. In traditional disability research, the researcher takes advantage of disabled participants, while not necessarily improving the quality of disabled people's lives (Oliver, 1992).

In the early 1990s, several researchers claimed it was imperative to establish a new emancipatory paradigm to challenge the social relations of disability research production (Oliver, 1992; Zarb, 1992; Morris, 1992; Barnes, 1992b; Stone and Priestley, 1996). Several features of emancipatory disability research have been defined explicitly. Firstly, emancipatory disability research adopts a social model of disability to examine the oppressive experiences of disabled people, which identifies disability as a result of social barriers rather than individual problems (Stone and Priestley, 1996). Morris (1992) suggests that it is important for researchers to turn the spotlight on the 'oppressors'

rather than disabled people themselves. Additionally, emancipatory disability research aims to change the social relations of research production. Researchers should recognise disabled participants as experts in their own experiences (Oliver, 1992; 1997; Stone and Priestley, 1996). More importantly, emancipatory disability research allows disabled people to take control of the research agenda:

The social relations of research production do have to be fundamentally changed, researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose (Oliver, 1992: 111).

Oliver (1997) indicates three key fundamentals of the emancipatory research paradigm, reciprocity, gain and empowerment. These fundamentals are crucial for researchers to change the social relations of research production and facilitate the process of self-empowerment of disabled people. In this way, emancipatory disability research can not only be used to produce new knowledge, it is also a part of the liberation of disabled people (French and Swain, 1997). The following sections introduce several emancipatory principles and discuss how these principles relate to this research.

### **3.1.1 Ontological and Epistemological Position**

Ontology is the starting point of all research. Ontological assumptions are concerned with what the researcher believes constitutes social reality (Blaikie, 2000: 8). As a researcher who conducts 'disability' research, I have to identify what constitutes the nature of 'disability' in the present study. Emancipatory disability research adopts the social model of disability as the ontological view of research production (Priestley, 1997). In terms of a social model perspective, there is a 'reality out there' to be investigated, namely, the social oppression of disabled people that is historically, environmentally, culturally and contextually variable (Barnes, 2003b: 11). This suggests that disability is socially constructed and varies across social contexts. The nature of disability consists of the social oppression experienced by disabled people. In the current study, I adopt a social model perspective as my ontological position. Disability is caused by the disabling environment and social attitudes rather than individual

impairment. The social model of disability serves as a lens to examine the various forms of social oppression that women with polio experience across the course of their lives.

Epistemology is concerned with the theory of knowledge, as a way of gaining knowledge of social reality (Grix, 2002). The second essential question to be answered here is: How can I know about the nature of disability? One aspect of emancipatory epistemology is that disabled people are the 'true knowers' and 'experts' in their own experiences (Stone and Priestley, 1996). Disabled people's experiences can provide rich information and bring insight to the reality of disability. The epistemological importance of personal experience is emphasised by several disabled feminists (Campling, 1979; Morris, 1989; 1996; Thomas, 1999). Thomas (1999) suggests that disabled women's stories are new ways of understanding what knowledge is and how it is produced. Similarly, Morris (1996) indicates that women's writing is a way to see how women resist and struggle against oppression. In the present study, I argue that knowledge is grounded in women's experiences of living with polio. Their experiences can be analysed in order to shed light on the social relations between disabled women and society. Furthermore, these women's experiences give us an opportunity to understand how they respond to disabling environments and prejudicial attitudes.

### **3.1.2 Surrendering 'Objectivity'**

Oliver (1992) critiques positivist research emphasising that the study of the social world should be value-free and that it distorts the experiences of disabled people and overly simplifies the relation between research and social change. Similarly, Zarb (1992) argues that traditional disability research alienates disabled people. The researcher often chooses to accept the discourse of objectivity, and this may threaten the interests of disabled people. The emancipatory research paradigm challenges the discourse of objectivity in positivist research. Emancipatory research makes no claims to objectivity through overt political commitment to the struggles of disabled people for self-empowerment (Stone and Priestley, 1996: 706). This suggests that researchers cannot be neutral and have to make their political positions clear. This is particularly important for researchers who conduct studies of oppressed groups. Barnes (1996b: 111) argues that academics and researchers cannot be neutral when researching oppression. They can only be with the oppressor or the oppressed.

As a woman with polio doing research on women with similar experiences, I cannot stand on the middle ground. My personal experiences of living with polio make me realise that disabled women face many difficulties in Taiwanese society. Moreover, my professional training with the social model of disability profoundly shapes my political position. There is no doubt that I choose to stand with women with polio and tend to examine the social oppression these women experience. I am aware that my personal experience, professional training and political position influences the process of research production (see section 3.6).

### **3.1.3 Who Gains?**

In emancipatory disability research, researchers should concern themselves with whether their research brings practical benefits for self-empowerment of disabled people and removal of social barriers (Stone and Priestley, 1996). It cannot be denied that I am the main beneficiary of the study. The research project is conducted for my doctoral degree. I may publish articles in academic journals and build my academic career. However, the study provides an opportunity for participants to review their life experiences, and some mentioned that they gained new insight into their own experiences. For example, Shu-Fen had a new interpretation of her life after retelling her story:

When I told you my story, I saw the person who I used to be. When I faced problems, I did not know how to seek help from others. If the same thing happened again, I would know how to deal with it (Shu-Fen).

Apart from the benefits for participants, the research results should be disseminated in a wider context. Barnes (1996b) states that the university system in the UK is profoundly influenced by market forces. University-based researchers are often encouraged to publish their works in 'good quality' academic journals, which represent the quality of the research. Consequently, research results are shared with other academics rather than disabled people themselves. A similar situation can be seen in Taiwan. The ministry of education launched a formal university evaluation policy in 2005 to improve the competitive strength of universities. Research performance is mainly assessed

in terms of the number of articles published in international journals, such as Science Citation Index (SCI) or Social Science Citation Index (SSCI) (Chou et al., 2013). As a result, researchers are encouraged to write articles in English in order to publish articles in these international journals. With regard to disability research, although researchers may focus on the experiences of disabled people in Taiwan, they may prefer to share the research findings with international academics rather than the local disability community.

As a PhD student, I cannot deny that publishing articles in academic journals is helpful for me in building my academic career, but I should keep in mind that the research is relevant to the oppressive experiences of women with polio in Taiwan. It is important to increase the research impact on the disability community, service providers and policy makers in Taiwan. I intend to translate the research report into Mandarin Chinese and publish it in various formats, such as magazines, newspapers and social media. A disability organisation has invited me to participate in a documentary film project on the history of polio in Taiwan, which gives me an opportunity to share my research results with practitioners in disability organisations.

### **3.1.4 Reciprocity and Empowerment**

Reciprocity is a fundamental principle of emancipatory disability research. Feminist researchers define various layers of reciprocity in the relationship between the researcher and the researched. Ribbens (1989) indicates that the first level of reciprocity is mutual exchange of information between the researcher and the researched. The researcher has to respond to questions asked by the interviewees. The second level is that researchers should take the same risk of self-exposure that they ask their respondents to. Before the interviews, I let participants know that I was willing to answer questions they had. Some respondents were interested in my experiences and asked questions about my experience of medical treatment, family life etc. I found that the participants felt more comfortable talking about their experiences if I shared my experiences with them. Nevertheless, it can be a problem if the researcher talks too much about themselves, as it might interrupt the respondents' flow of thoughts (Ribbens, 1989). I am aware that if I share my personal experiences too much, it may guide the participants to share their experiences in such a way as to meet my expectations. Thus, I did not actively share my own experiences unless the respondents asked me to do so.

Empowerment is an essential element of emancipatory disability research. Emancipatory disability research places disabled people and their concerns at the centre of the research and facilitates their self-empowerment (Oliver, 1992; Ward and Flynn, 1994). French and Swain (1997) describe empowerment as people, who are aware of the oppression they face, becoming assertive about their needs and rights, and coming together as a group. From this point of view, it is difficult to say that the study has facilitated the self-empowerment of disabled people, because the social relations of research production have not been fundamentally changed. The research topic and research methods are chosen by the researcher rather than the participants. Although participants cannot fully control the research process, some of them did indicate that they became increasingly aware of their rights. For instance, Shu-Juan's account shows that she recognised the oppression she faced and intended to take control of her own life:

I'd very much tell the whole world that I am a person, just like you. Please ask me what I want, instead of making the decision for me, as if I don't even exist. Please respect me as a person. Let me decide what I want for my life (Shu-Juan).

Some participants expressed their willingness to meet other participants. They believe their experiences are meaningful and worth sharing with other women with polio. For example, a participant mentioned that she could make a contribution to the disability community by sharing her experiences with other disabled women:

It was good to share my experiences with other women. My experiences might be useful for them to deal with similar problems. I also could learn from other women and see how they coped with their situation. Maybe one day I would face a similar situation (Mei-Zhu).

This section discusses several emancipatory principles and how they relate to this research. The research cannot be perfectly described as emancipatory disability research because it does not fully change the social relations of

research production. In order to increase the level of emancipation, I could choose appropriate research methods to generate data and make the research more inclusive. The following section discusses the data generation strategies employed in the study.

### **3.2 Data Generation Strategy**

Emancipatory research has a tendency to use qualitative data rather than quantitative data, but this does not mean that the use of qualitative data necessarily leads to the removal of disabling barriers (Stone and Priestley, 1996). Qualitative research is used to investigate subjective meaning within culture, understanding attitudes and beliefs and unravelling the dynamic constructs of culture and social traditions (Hartley and Muhit, 2003: 104). Kitchin (2000) investigates disabled people's attitudes to research methods, and finds that disabled people prefer to take part in qualitative research because it allows them to represent their experiences and opinions. This research takes a qualitative approach that gives participants an opportunity to represent their subjective experiences, using their own words.

Additionally, the study uses a life history research method to explore the life experiences of women with polio. The purpose of life history research is different from that of narrative research. Narrative research emphasises making meaning of individual's experiences, whilst life history research focuses on interpretation of personal experience in a broader context (Cole and Knowles, 2001). Life history research explores how opportunities and constraints structure people's lives, and how they respond to these opportunities and constraints creatively (Miller, 2000). It is useful to examine the social relations between women with polio and the social environment. Furthermore, life history can represent the fluidity of individual experiences, which helps explain the constantly changing nature of individuals and societal realities (Cole and Knowles, 2001). For example, Shah and Priestley (2011) adopt a biographical method to examine the impact of social changes on disabled people's lives across generations, and represent the continuous change of disabled people's lives over time. The life history methodology adopted in this thesis emphasises empirical and successional accounts of historical time, in preference to more theoretical accounts of time (Adam, 1992). Interpretation of data is not always fixed, while the participants' new empirical accounts would continuously affect past interpretation of data.

Several researchers used life history research methods to explore the life experiences of disabled people (Booth and Booth, 1994; Goodley, 1996; Atkinson, 2004). Life history research represents an insider perspective and allows marginalised groups to make their voices heard (Goodley, 1996). Disabled women's experiences have been absent from cultural representation for a long time. This research method enables disabled women to reveal their oppressive experiences and represent subjective realities. Smith and Sparkes (2008) suggest that disabled people's experiences can be used as 'counter-narratives', which provide an alternative interpretation of disability and impairment that eschew tragedy stories and challenge social oppression. In this study, life history research is used to explore how the past experiences of women with polio shape their current life. It gives the opportunity to see how participants respond to disabling environments and combat discrimination against disabled women. Following this discussing of data generation strategies, the next section provides more detail on the process of fieldwork.

### **3.3 Research Process**

The fieldwork was conducted in Taiwan and it lasted for four months, from November 2013 to February 2014. The activities during the period of fieldwork included conducting life story interviews with ten participants, making fieldwork notes and collecting relevant documents. The fieldwork consists of three phases. The first is setting the criteria to select information-rich cases; the second is developing recruitment strategies to approach potential participants; and the third is conducting the life story interviews and transcription of the data. More details are given in the following sections.

#### **3.3.1 Phase One: Sampling Frame**

Qualitative research often uses purposive sampling rather than random sampling strategies. Purposive sampling strategies are designed to select information-rich cases which provide the greatest insight into the research questions (Coyne, 1997). The research aims to explore the experiences of women ageing with childhood-onset polio. As mentioned earlier, polio can strike at any age, but it mainly affects children under five years old (WHO, 2014). The research adopts the WHO's description of polio as its sampling criteria. It includes only women who contracted polio before the age of five, and who, at the time of the interviews were aged between 50 and 60. In Taiwan the



definition of an older person is a person aged 65 or over. However, the official definition is not entirely relevant to the ageing experience of polio survivors. Many polio survivors experience functional degeneration caused by PPS in their middle years (see section 1.3). The study focuses on women aged between 50 and 60, because they may have experienced functional changes.

People born in different generations are exposed to different constraints and possibilities (Elder, 1994). Miller (2000) suggests that membership of a specific generation can be considered a structural variable of equal significance to other major structural variables, such as class or gender. The participants aged between 50 and 60 may have experienced specific historical events and social changes, and this make their experiences different from people of other generations. These participants' experiences provide an opportunity to understand how social change shapes disabled people's lives across historical periods.

Sample size is a controversial issue in qualitative research. The sample size should not be too small to achieve data saturation, or too large to undertake deep analysis (Bryman, 2012: 425). Adequacy of sample size in qualitative research is determined by several factors, including the purpose of the enquiry, the research questions, the availability of resources, and the particular research method (Patton, 1990; Sandelowski, 1995). In this study, the sample size is affected by the choice of research method and the availability of research resources. Life history research favours small numbers of individuals for extensive exploration, rather than large numbers for more superficial engagement (Cole and Knowles, 2001). This suggests that the sample size in the study should be relatively small. In addition, I consider the practical constraints in conducting fieldwork. It is difficult to conduct intensive interviews with too many participants due to time and location constraints. Atkinson (1998) indicates that the most time-consuming part of a life story interview is the transcription. Considering the availability of resources and the quality of research data required, ten participants are included in the study.

### **3.3.2 Phase Two: Participant Recruitment**

Participants are recruited from three sources, disability organisations, social networking sites, and the participants' personal networks. Ethical review was required by the review committee at the University of Leeds. The ethical approval was obtained before any participant recruitment or fieldwork

commences. The study involves the recruitment of participants through nine organisations for disabled people in Taiwan. None of these organisations requested for ethic approvals. I made contact with four disability organisations to approach potential participants by email. The Joyce-Agape Association was established by a group of polio survivors and provides employment services for disabled people. Operation de-Handicap is an organisation that provides rehabilitation consulting services for polio survivors. The Eden Social Welfare Foundation and Access for All in Taiwan provide services for people with physical impairment, which includes polio survivors.

As well as these four organisations, I contacted five rehabilitation institutions which were established for children with polio in the 1950s and 1960s. As mentioned in chapter one, most rehabilitation institutions that initially provided services for polio survivors have extended their services to people with various other impairments. Although these institutions do not currently provide services for polio survivors, they may have contact with residents who used to live there. I emailed a summary of the research and recruitment information to these disability organisations and asked for permission to share recruitment information with their service users. I was aware that these disability organisations would not necessarily guarantee access. Three were willing to share recruitment information with their service users. However, it was difficult to know how these organisations shared the recruitment information and who would receive it. Only one participant was accessed via these disability organisations.

In addition, I used Internet recruitment to approach potential participants. The strength of Internet recruitment is the potential for increasing the appropriateness of each participant (Hamilton and Bowers, 2006). I posted recruitment advertisements on three Facebook pages established by polio survivors who used to live in institutions. These Facebook pages made it easy for me to target those who have experiences of living in rehabilitation institutions. To maximise the diversity of participants, I intended to include those who had never lived in institutions. I also shared recruitment advertisements on three Facebook pages run by disability organisations. This gave me an opportunity to approach those who did not have experience of living in institutions. I received several responses to this Internet recruitment drive. Internet recruitment allows the researcher to have access to potential participants, regardless of location. For instance, a participant who lived in the United States participated in the research by way of email interview.

Eight participants were accessed through Internet recruitment, one participant through a disability organisation, and one was introduced by another participant. Table 1 shows the participant information. It shows the diversity in the participants' ages, use of assistive devices, marital status, educational attainment and employment status. The age of the participants ranged from 50 to 59 years. Seven participants currently used wheelchairs. The majority of the participants were married and full-time employed. Six were college educated, and one was uneducated. All participants were heterosexual, those with other sexual orientations are not included. I am also aware that Internet recruitment may exclude those who do not use social media and those who have difficulty accessing Internet technology. I accept that the results of the present study cannot be generalised to the entire population of women with polio in Taiwan.

**Table 1 Description of Participants**

	Name	Age	Assistive device (present)	Marital status	Educational attainment	Employment status
1	Ya-Ling	50	Electric wheelchair	Married	Secondary school	Self-employment
2	Shu-Fen	58	Electric wheelchair	Married	Primary school	Self-employment
3	Li-Hua	53	Electric wheelchair	Single	College	Self-employment
4	Yi-Jun	52	Crutches, Leg brace	Married	College	Full-time employment
5	Xiu-Zhen	50	Electric wheelchair	Married	College	Full-time employment
6	Hui-Ling	53	Electric wheelchair	Divorced	College	Full-time employment
7	Hui-Ping	59	Crutches, Lag brace	Married	College	Retirement
8	Yu-Lan	56	Manual wheelchair	Married	Uneducated	Self-employment

9	Mei-Zhu	50	None	Divorced	College	Full-time employment
10	Shu-Juan	57	Electric wheelchair, Breathing machine	Single	Postgraduate	Unemployment

### 3.3.3 Phase Three: Life History Interview

This section discusses the process of life history interview, including interview preparation and conducting interviews. The interviews were conducted using two techniques, face-to-face interviews and email interview. Nine participants were interviewed face-to-face, and one via email.

#### Planning the Interview

This research adopts a life history interview method of collecting data. The term life story and life history are interchangeable. The difference between a life story and an oral history is its emphasis and scope. An oral history focuses on a specific event, time or place, while a life history or a life story usually refers to a person's entire life (Atkinson, 1998). In the present study, each participant is invited to share their stories from birth to the present day. Life history interview is a 'guided conversation'. The researcher develops interview questions in terms of the purpose of the research and uses these questions to guide life history conversations (Cole and Knowles, 2001). I have developed an interview outline that covers several topics relating to the research questions in terms of four life stages, childhood, youth, early adulthood and middle adulthood. The questions about childhood experiences, for instance, explore the participants' experiences in medical settings and schooling.

In emancipatory disability research, research questions should locate the problem of disability in disabling societies rather than in the individuals themselves (Oliver, 1992). The interview questions are developed in terms of a social model perspective. For example, when I ask a question about participants' experiences in school, I may ask 'what barriers did you experience in school?' or 'how did those barriers restrict you from participating in activities in school?', rather than 'did you face any problems at school because of your impairment?' or 'how do you deal with these problems?' The former questions locate the problem in disabling environments, while the later questions focus on

the functional limitations of the disabled person and how they have made personal adjustments to cope with disabling environments.

Before the interviews, I sent an information sheet and consent form to each participant by email. I let them know that I was willing to meet them and gave details of the interviews. In the first meeting I explained the research purpose and the process of life story interview. Some participants were concerned about confidentiality issues. The identifying information, such as the names of participants, their significant others (e.g. parents, siblings, partners), and workplaces are pseudonymous. The data is stored in password protected files.

Participants could refuse to answer any questions that made them feel uncomfortable. They were allowed to withdraw from the research at any time. Barnes (1992b) suggests that the researcher should give disabled participants enough time to consider whether they want take part in the research. This not only gives them more control in terms of the decision to involve themselves, but also gives them time to fully consider the issues on which they are asked to comment. I let participants know that they could take more time to make their decision if they needed. Most participants completed the consent form at the first meeting. The participant who lives in the United States returned the form by email.

### **Face-to-Face Interview**

In order to gain in-depth understanding of individual lives, Atkinson (1998) suggests that the life story interview is undertaken over two or three sessions, each session lasting around one hour. In the present study, each participant was visited at least twice, except for one was visited three times. Each interview lasted from an hour to an hour and a half. In some cases, adjustments were needed due to unexpected situations in the fieldwork. For example, one interview respondent experienced PPS-related fatigue and this made it difficult to concentrate on the interview for long. To cope with this situation, the interview was divided into three sessions and each session was completed within an hour.

The places for the interviews were chosen by the participants. Some chose to do the interviews in their own homes, because this made them feel more comfortable. Others preferred to do it in public areas such as workplaces or restaurants. It was inevitable that interviews would sometimes be interrupted by noise in these public places. Some participants who used wheelchairs had no choice but to do the interview at home, because it was difficult to find an

accessible place for wheelchair users. I asked the interviewee's permission to record the interviews, so that I could concentrate on listening and taking notes. Participants were allowed to turn off the audio recorder at any time.

Although life story interview is guided by an interview outline, it is important for the researcher to be flexible and reflective during the interview (Cole and Knowles, 2001). I asked questions covering childhood to the present, but in practice participants did not always follow the sequence. Sometimes they mentioned a specific life event that may be relevant to another life event in a different life stage. I let them finish and waited for an opportunity to get them back on topic. For example, an interviewee mentioned that she studied in a special school for children with physical impairment. She then talked about how the experiences of being alone with other disabled children her attitude towards marriage. I did not interrupt her because the information showed how participants' past experiences influence their life choices later on. I waited for a pause in her speech and then got her back on topic.

It can be painful for participants to share oppressive experiences, particularly when they mention traumatic events. It is crucial that the interviewer is sensitive and responsive to the interviewee's emotional reaction during the interview. McCosker et al. (2001) suggest that the researcher should give the interviewees time to express their emotions, and acknowledge the importance of this to the well-being of the interviewees. For example, a respondent cried when she mentioned discrimination she faced in the workplace. I gave her time to deal with her emotional reaction. She was allowed to decide whether she wanted to suspend or continue with the interview. I also provided information about psychological consultation services for participants if required.

### **Email Interview**

Online interview allows participants to respond to questions at their own pace, time and location. The flexibility of online interview incorporates particular advantages for disabled people, who can participate irrespective of physical or sensory ability (Bowker and Tuffin, 2004). One participant lives in the United States. She uses a breathing machine and this makes it difficult for her to talk. In this situation, email interview is an appropriate way to generate data. The schedule of the email interview varies considerably. Some researchers send all the interview questions in one email message, while others decompose the schedule into several sections and ask questions in stages (Meho, 2006). In this study, the email interview consisted of four sections covering four life

stages, childhood, youth, early-adulthood and the present. The questions in each section were sent to the participant sequentially. The participant only needed to focus on five or six questions at one time, and this allowed her to provide more detailed information on each question.

Gathering data by email, researchers may find it difficult to recognise interviewees' attitudes and emotional reactions without visual cues. Thus, it is important for the researcher to minimise ambiguity in the meaning of the interview questions. To avoid misunderstandings between the researcher and the interviewee, I let the participant know that she could ask me questions at any time if she did not understand the interview questions. After receiving the interviewee's comments, I highlighted the words and sentences that I did not understand and asked the participant to explain in more detail. In addition, I added probing questions under the participant's comments in order to get more in-depth information.

In general, the length of data collection in email interviews is longer than in face-to-face interviews. The researcher may need more time to complete email interviews due to the delay between sending questions and receiving feedback, and clarification of possible interpretations (Bowker and Tuffin, 2004). The participant usually replied to emails within two weeks, and was allowed more time to reply if necessary. It took nearly four months altogether to gather the email interview data. Confidentiality is an important issue for online interviews. Identifying information may be disclosed if data are collected online or if they are stored on a computer connected to the internet (Meho, 2006). Therefore, once I received each email from the participant, I downloaded the attached document and then deleted the email. Each document was stored on the computer and password protected.

### **3.4 Data Transcription and Translation**

Transcription is a process that involves the transformation of oral speech to printed copy. By the time the transcript is made, the original experience has already been transformed in the act of telling itself (Sandelowski, 1994). In this study, all the interview conversations were transcribed by the researcher in Mandarin Chinese. Reading the transcript in my own language made it easier for me to understand the meaning and context of participants' accounts. The email interview data was written by the participant in English, and so did not need to be transcribed.

The choices researchers make in transcription depend on the purpose of the research and the research questions. Grounded theorists pay attention to the informational content of the data. They are interested in the meaning and perception contained in the data rather than the communication pattern (Oliver et al., 2005). This research explores the oppressive experiences of women with polio across the course of their lives. The analysis aims to explain the meanings attached to the disabled women's experiences. Therefore, I focus on the informational content of interview data, while non-verbal communication such as a 'pause' or 'laughing' were not included in the transcripts. I am aware that non-verbal communication pattern information can be used to explore interviewee's attitudes or feelings. I took field notes regarding the participant's emotional responses in the interview context.

It is important that the researcher gives the participants the opportunity to check the transcripts. By doing this, the researcher can check the interpretative validity, and also allow participants to reflect on what they have said (Vernon, 1997). However, this has a practical difficulty, as the length of the transcript could be more than a hundred pages. Vernon (1997) indicates that it could be difficult for the participants to give time and attention to reading a full draft of the research report and giving their comments. Making this demand of them may give rise to feelings of exploitation. For this reason, I provided a summary of the transcripts to the participants, and also let them know they could choose to read the full transcript if they wanted. Most participants accepted the summaries, and none requested full transcripts. Participants were allowed to add, delete or change any words in the transcripts, but most had no issues with them.

The interview data cited within the text was translated from Mandarin Chinese into English by the researcher. Twinn (1997) indicates that the researcher may face problems translating qualitative data particularly when no equivalent words exist in the target language. In some cases, it could be difficult to find equivalent English words to represent the participants' words, particularly when they used specific terms that can only be understood in Taiwanese culture. For example, a participant mentioned that her mother took her to a temple to see a 'Danggi' in order to seek a cure for her polio. A 'Danggi' is a type of spirit-medium in Taiwanese folk religion. As it is difficult to find an English word to replace the specific term 'Danggi', I did not translate the word, but provided more details to explain it. In addition, it is possible to mistranslate a word when the word contains multiple meanings. From a social model perspective, the



definitions of 'impairment' and 'disability' are different. The term 'impairment' refers to the functional limitation of individuals, while 'disability' refers to the social barriers experienced by disabled people. In Mandarin Chinese, the word '障礙' (zhang ai) can be used to describe both impairment and disability. When I translated the word 'zhang ai', it was necessary to return to the transcripts in order to understand the context of the conversation.

### **3.5 Data Analysis**

Coding is naming data segments with labels that simultaneously categorise, summarise, and account for each piece of data (Charmaz, 2006: 43). After transcribing all the interviews, I began the coding process to analyse interview transcripts. Naming broad topic areas is a starting strategy for organising data when the researcher is not sure about the idea or interpretation (Bazeley, 2013). I read and re-read transcripts several times. I then created five broad topic areas, medical treatment, education, relationships, employment, and the impact of ageing, and sorted the relevant sections into the five topics. I then started more detailed coding of each topic area.

The coding process consists of at least two phases, an initial coding and a focused coding. When researchers conduct an initial coding, they remain open to exploring how they interpret the data (Thornberg and Charmaz, 2014). I read through the transcripts and created labels that best capture the meaning of words, sentences and phrases. It is noted that the coding decisions are affected by the epistemological view, pre-existing knowledge, theory, and so on (Saldaña, 2015). I remained aware during the coding that my epistemological position might influence the data interpretation. The social model of disability affected what I coded and how I named each code. Some labels were derived from participants' own words, and others were named in terms of existing theories. For example, I used the theoretical concept of 'internalised oppression' to describe that participants make efforts to prove they could meet the social standards of being an ideal mother.

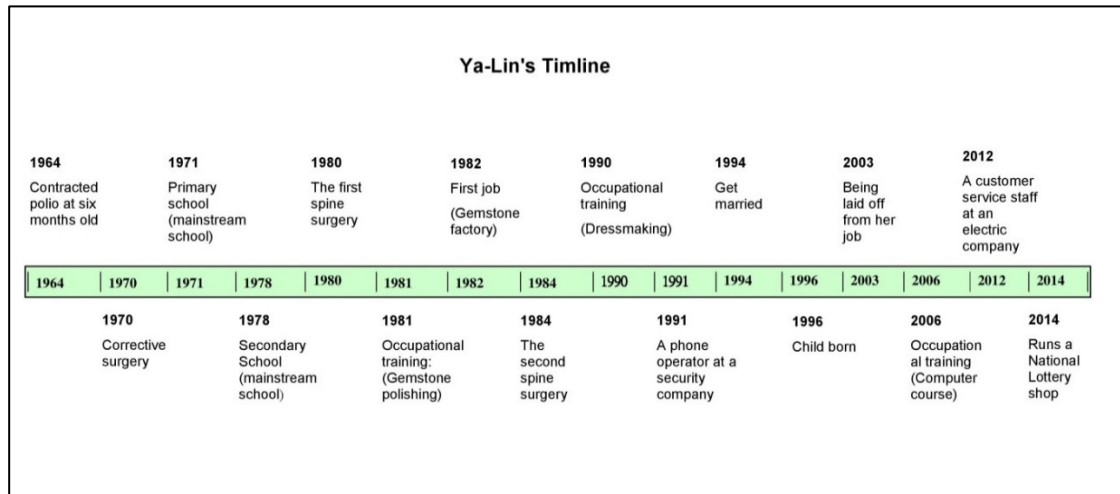
Glaser and Strauss (1967) suggest a 'constant comparative method' to sort and cluster initial codes. In this method, researchers compare data with other data from the same interview and other interviews in order to find similarities and differences (cited in Charmaz, 2006: 54). After developing a number of codes, I compared and contrasted them, in order to generate several categories. Some codes with similar characteristics were grouped together into one category. The following step was to conceptualise the relationship between the categories.

Focused coding is used to search for the most frequent or significant codes, in order to find the core categories in the data corpus (Saldaña, 2013). For instance, several categories were established to describe participants' experiences in rehabilitation institutions, including 'routine work', 'strict rules', 'reward and punishment', and 'military management'. I selected 'military management' as a core category, because it best describes participants' experiences in institutions.

Coding is not a linear process. Researchers must be sensitive to theoretical possibilities and move back and forth between the phases of coding (Thornberg and Charmaz, 2014). Some codes and categories were refined and reordered until the central concepts and main themes were defined. Sometimes several themes would emerge at the same time. In this situation, I usually returned to the research questions and decided which theme was of most significance. Memo writing is useful for the researcher to record their reflectivity of the data and identify the relations between codes and categories (Saldaña, 2013). I took analytic memos to record my observations or questions in the coding process, and this was useful in refining the codes and finding links between them.

A timeline can be used in data generation and analysis in life history research. For example, Kasnitz (2001) uses a timeline to visualise the life history events of disability activists and represent their leadership development. I created timelines to represent the life course trajectory of each participant. Each timeline detailed their significant life events from birth to the present. The timelines were checked and modified by the participants. Figure 3.2 is Ya-Lin's timeline, and shows the years she contracted polio, had her first surgery, got married, and so forth. Timelines represent the life course trajectories of the participants and also show the interaction between life events. For instance, Ya-Lin's timeline shows that she underwent three surgeries and these medical interventions may have affected her career development. Timelines can also be used to identify similarities and differences in life course trajectories between participants. Comparing the timelines of participants shows that their time of school attendance varies considerably. This raises a question of why some participants delayed school entry, while some did not. This question guided me to find out relevant information in the transcripts.

**Figure 2 Ya-Lin's Timeline**



Several meaningful themes emerged from the empirical data, which can be used to answer the research question ‘what, if any, inequalities and barriers do women with childhood-onset polio experience across the course of their lives?’ The various themes are discussed in more detail in Chapters 5 to 8. These four chapters are structured in terms of a life course sequence, and each chapter is interrelated. For example, Chapter Five focuses on participants’ experiences in childhood. Two main themes, ‘medicalisation’ and ‘exclusion from school’ are discussed. Chapter Six explores participants’ experiences in their youth with particular reference to ‘career development’ and ‘intimate relationship’. Chapter Seven focuses on participants’ experiences of employment and marriage. It is not possible to discuss these women’s experiences of employment without considering the impact of their previous experiences of education. The four chapters answer the research question ‘how do the past life do experiences of women with childhood-onset polio affect their current life?’

### **3.6 Reflective Accounts**

In qualitative research the researcher cannot be neutral and detached from the knowledge and evidence they are generating. The researcher should seek to understand their roles in the process (Mason, 1996). Reflectivity is a critical exercise for those researching oppression, particularly in order to avoid colluding in the established hegemony (Vernon, 1997: 159). As a woman with polio, doing research onto women with similar experiences, I recognise the impact of my roles on the research process. Ergun and Erdemir (2010) argue

that several social factors such as age, gender, culture and professional training significantly shape the relationship between the researcher and the informants, and therefore the researcher can only be a 'partial insider' or 'partial outsider'. Even though I am a woman with childhood-onset polio, I can only be a 'partial insider'. I share similarities as well as differences with the women I have interviewed. I have never lived in an institution, I do not have children, and my professional training is different from the participants.

It is undeniable that my role, as a disabled woman, made it easier for me to build trust with the participants. They felt secure enough to share much detailed and rich information with me. However, my role as a native researcher may affect the data gathering because of the taken-for-granted assumptions of social behaviour. This means that the native researcher and the participants make assumptions of commonalities and therefore fail to fully explain their individual experiences (Kanuha, 2000). For instance, I asked an interviewee to describe her feelings the first time she wore leg braces, and she answered 'I feel the same as you'. The participant assumed that her experience was similar to mine, so I encouraged her to explain in more detail.

Another issue associated with insider research is that the researcher may find it difficult to separate their personal experiences from the participants' experiences (Dwyer and Buckle, 2009). There is a danger that I may unconsciously connect my own experiences with the respondent's experiences. For instance, I felt angry and upset when I dealt with the data relating to intimate relationships. Tilley et al. (1996) suggest that the process of self-reflection, acknowledging emotional feeling in the data collection and analysis, is useful for the researcher. In this situation, I wrote down my emotional reaction in an analytic memo and asked myself whether this emotional response related to my personal issues. I discussed this situation with my colleagues and supervisors, and this helped me recognise the differences between my own experiences and the respondents' experiences.

Barnes (2003b) argues that in social science the researcher is not able to be truly objective. The interpretation of information varies across economic, political and cultural contexts. My values and beliefs affect my interpretations of data. As mentioned, my ontological position is based on a social model perspective, which locates the problem of disability in social structure, rather than individual impairment (section 3.1.1). However, I continue to bear in mind that I cannot impose my values and judgements on the participants, because not all participants perceive their experiences from a social model perspective. I

am not an advocate, conveying my values to the participants, instead I am a researcher, absorbing insights from their experiences.

Furthermore, my understanding of the existing literature might influence my interpretation of information. Previous studies demonstrated that disabled people lose control of their lives and their needs are profoundly ignored in institutions (Hunt, 1966; French, 1996). Although I acknowledge the negative impact of institutionalisation on disabled people, I cannot presume that participants' experiences in institutions are always negative. Some participants mentioned that they were grateful for the support they received from institutions. I cannot distort participants' interpretation of their own experiences. This does not, of course, necessarily mean that living in an institution is a favourable option for disabled people either. It is important for me to explore what factors influence the women's interpretation of their experiences in institutions.

## **Summary**

In this chapter, I discuss methodological considerations and data generation strategies. Although the research cannot be qualified as emancipatory disability research, I tend to increase the level of emancipation in the research. The social model of disability is used to identify the social barriers experienced by women with childhood-onset polio. I make my political commitment clear, that I stand with these women and examine the social oppression they face. Furthermore, I chose life history research methods to generate data. This method allows participants to have their voices heard and challenges stereotype and prejudice against disabled women. I discuss the impacts of a native researcher on data interpretation. Self-reflection is helpful to examine how my values, beliefs and professional training affect my interpretation of data. After discussing research methods in this chapter, the next chapter explores the social context in Taiwan and how it relates to the lives of women with childhood-onset polio.

## **Chapter Four**

### **Disability Policy in Taiwan since World War II**

#### **Introduction**

People born in different historical times have different experiences and are exposed to different opportunities and constraints (Elder, 1994). Over the last several decades, Taiwan's social, economic and political status has significantly changed. In the present study, all participants were born between 1955 and 1965 and are currently in their 50s and 60s. In order to gain an understanding of the experiences of women ageing with childhood-onset polio in Taiwan, this chapter provides details of the changing disability policy in Taiwan since World War II. It begins with a brief overview of Taiwan. The second section discusses social changes and the development of disability policy over time.

#### **4.1 Country Profile: Taiwan**

Taiwan, officially the Republic of China (ROC), is a leaf-shaped island of 36,000 square kilometres. The population of Taiwan is over 23.49 million, of which 50.14 per cent are female and 49.86 per cent are male (Ministry of Interior, 2016: n.p). The island is located off the south east coast of mainland Asia, across the Taiwan Strait from China. The history of Taiwan can be traced back at least 7,000 years. Austronesian people, ancestors of the island's indigenous people, are recognised as the earliest inhabitants of Taiwan. Taiwan is a favourable location for trade routes, and attracted interest from foreign countries during the maritime age. According to the colonial history of Taiwan, the island was colonised by the Dutch and then the Spanish in the early 16<sup>th</sup> century. The Dutch recruited many Han Chinese immigrants to Taiwan to engage in agricultural activities, and this led to the first wave of Chinese immigrants (Hsueh et al., 2005). In the late 16<sup>th</sup> and 17<sup>th</sup> centuries, the island was ruled by the Cheng regime and the Qing dynasty of China.

Taiwan was ceded to Japan due to China's defeat in the Sino-Japanese War in 1895 and was colonised by Japan for over fifty years (1895-1945). The government of the ROC was established in mainland China in 1912 by the

Chinese Nationalist Party, known as the 'Kuomintang' (KMT) in Chinese. The government of the ROC reclaimed Taiwan after Japan's surrender in the Second World War in 1945 (Rubinstein, 1999a; Copper, 2007). The Chinese Nationalist Party was defeated by the Communist Party of China in the Chinese Civil War in 1949. The government of the ROC fled to Taiwan after 1949, and from then on Taiwan has been governed by the ROC regime (Copper, 2007). Taiwan's industrialisation began in the late 1950s, and has successfully transformed the national economy from agriculture-oriented to industrial-oriented (Chang and Tsai, 1986). Taiwan's economic structure shifted from the industrial sector to the service sector starting around the mid-1980s, and it became a predominately commercial market in the early 2000s (Aspalter, 2001).

The population are divided into four major ethnic groups, indigenous peoples, Hakka, Fukienese, and other groups originating in mainland China. The Hakka and the Fukienese are descendants of early Han Chinese immigrants from the southeast coastal area of China. More than 95 per cent of the population are Han Chinese immigrants, and 2 per cent of the population are new immigrant residents, primarily from mainland China and Southeast Asia. Indigenous Austronesian people comprise less than 2 per cent of the total population (TAIWAN.GOV, 2016: n.p). The government officially identifies 16 tribes of indigenous peoples, and each tribe has its own language, culture and customs (Council of Indigenous People, 2014: n.p). Taiwanese traditions and customs are profoundly influenced by Chinese culture. Mandarin Chinese is the official language of Taiwan, and several dialects are used by the various groups. Taiwan has three major religions, Buddhism, Taoism and Confucianism. Christians in Taiwan exist as a minority group (Yang, 2013). Following this overview of Taiwan, the next section focuses on the development of disability policy since World War II.

## **4.2 Social Change and Disability Policy in Taiwan**

This section discusses the development of disability policy in five historical periods. In the first period 1945-1970, the post-war period, disabled people received little support from the government and most disabled people had to rely on their families. The medical treatment and education for disabled children in this period is particularly relevant to the participants' childhood experiences. In the second period, 1971-1980, the participants were moving from childhood to youth. During this period, social services for disabled people remained

absent. At the same time, Taiwan's economy was shifting from the agricultural sector to the industrial sector. The impacts of economic change on the labour market influenced the career development of the participants in their youth.

In the third period, 1981-1990, the participants were moving into their early adulthood. Several employment policies for disabled people were implemented during the 1980s. Meanwhile, the disability rights movement in Taiwan was initiated in the mid-1980s, and had a great impact on the development of disability policy. There were significant changes in the social welfare system in the fourth period, 1990-2000, which is known as the 'Golden Decade of Taiwanese Welfare' (Lin, 2012), as the government started to pay more attention to the wellbeing of disabled people. The disability rights movement led to an expansion of social services for disabled people. In the fifth period 2001-2015, Taiwan faced the challenges of an ageing population. The government established the social care system to tackle the problems associated with ageing. In the meantime, the development of disability policy was significantly influenced by the international trend for disability rights.

#### **4.2.1 The First Period: 1945-1970**

In the post-war period, the development of welfare policy was closely related to the political situation. Ku (1995) analyses the trend for social expenditure from 1950 to 1980, and finds that Taiwan's political development has a close correlation with the growth in social expenditure, particularly after political crises. As mentioned earlier, the Chinese Nationalist Party was defeated by the Chinese Communist Party in the Chinese Civil War, and fled to Taiwan in 1949. Due to the tense situation between China and Taiwan, the government declared Martial Law in 1949 to protect national security. In the martial law period (1949-1987), citizens were prohibited from mobilising collective action and expressing their opinions, and had little opportunity to influence government policy-making (Lin, 2012).

In the 1950s, the government implemented several welfare programmes that mainly benefited military servicemen, public servants and employees of state enterprises (Lin, 2012). For example, 'Servicemen Insurance' was launched in 1950, and the 'Act of Insurance for Military Personnel' was implemented in 1953. These policies aimed to consolidate the power of the ruling party and accumulate human resources for the government (Chen and Yang, 2001). Beneficiaries were given generous retirement pensions and health insurance



for their dependents. In contrast, the disadvantaged population, such as the poor, children, older people and disabled people, received little social support (Fell, 2012; Lin, 2012).

In the post-war period, the role of the state in social services for disabled people was absent. Disabled children received little support from the state and faced many difficulties in accessing medical treatment and education. The social relief system solely targeted disabled people who were poor, while the majority of disabled people had little support from the government (Tsai and Ho, 2010). The 'Social Relief Act 1945', defined disabled people as those with physical and mental impairments who did not have the capacity to work (Sha, 2005). This definition of disability was based on an individual medical perspective, which emphasised a connection between impairment and an individual's productivity. At that time, services for disabled people were mainly provided by religious groups and a few state-owned institutions. Many disabled children from poor families were abandoned by parents and lived with the poor and orphans in workhouses (Tsai and Ho, 2010).

Medical resources were limited, so not all disabled children were able to receive medical treatment. Western medicine was introduced into Taiwan by western medical missionaries in the late 19<sup>th</sup> century. During the Japanese colonial period, the Japanese initiated the professionalisation of western medicine, which became a foundation of the healthcare system of Taiwan. In the post-war period, Chinese medicine was still commonly used by people because the expense of western medicine was high (Chi, 1994). As mentioned in Chapter One, the treatment for polio was introduced by western missionaries in the late 1950s. The cost of treatment such as corrective surgery and rehabilitation therapy could be a burden for a family. Many children with polio who were economically disadvantaged could not afford the expense of rehabilitation therapy (Wai et al., 2001). Some children from poor families might receive financial support for medical treatment provided by hospitals or institutions (Sørheim-Queseth, 2013). Those from a privileged background, such military families, were able to receive financial support for medical treatment. For example, the 'Statute of Favours for Military Servicemen and their Dependents' was implemented in 1960, which gave children of military families the right to free medical treatment in public hospitals (Legislative Yuan, 1960).

In addition to medical treatment, disabled children faced many barriers that prevented them from accessing education. Despite the fact that the

government implemented six- year compulsory education, many disabled children were excluded from mainstream primary schools. According to the 'Enforcement Education Act 1944', citizens between 6 and 12 years of age received six-year of compulsory education, with the exception of children with physical impairments or severe disease (Legislative Yuan, 1944). In other words, children who were of compulsory school age had the legal obligation to attend school, but not disabled children. Lack of accessibility, including to public transportation, hindered disabled children from attending school. In the 1960s public transport remained underdeveloped, and many children with physical impairment could not go to school due to poor transportation (Huang, 2010).

Compulsory education was extended to nine years in 1968. According to the 'Enforcement Statute for Nine-year Compulsory Education 1968', children with physical and mental impairment and children classified as gifted were granted educational opportunities and received special education. This was the first time special education for disabled people was mentioned in formal legislation (Lin, 2013). In the same year, the first special school for children with physical impairment 'National Hemei Experimental School' was established to provide life skill training and vocational training for disabled children (Ministry of Education, 1990). This was the only special school for children with physical impairment in Taiwan. Due to the limited resources for special education for children with physical impairment, the majority of children with polio studied in mainstream schools. The numbers of disabled students in mainstream schools increased in the 1970s, and many of these students were children with polio (Huang, 2010). A few mainstream primary schools set up special classes for children with polio who lived in institutions. For example, the Pingtung Jen-Ai primary school established a special class for children with polio from the Pingtung Victory Home in 1953 (Sørheim-Queseth, 2013). Some children received education in institutions. The Cheng-Hsin Polio Rehabilitation Medical Centre set up an educational sector to provide primary and secondary education for residents (Yu, 2000).

#### **4.2.2 The Second Period: 1971-1980**

During the 1970s, Taiwan's economy shifted from the agricultural sector to the industrial sector. Taiwan's industrialisation began in the late 1950s. At the beginning, the government adopted the import-substitution industrialisation strategy to develop the national economy. The strategy aimed to decrease the

dependency on imported products and encourage the development of labour-intensive industries such as electricity and fertiliser (Wang, 1999). During the 1960s, the import-substitution industrialisation strategy was replaced by the export-oriented strategy. This strategy aimed to export domestic products to foreign markets, and resulted in a significant development of labour-intensive industries. For example, textiles became Taiwan's largest export product in the 1960s (Rubinstein, 1999b).

During the 1960s and 1970s, the government established several Export Processing Zones (EPZs) to encourage international corporations to establish their factories in Taiwan. The EPZ is a multi-function zone with the characteristics of a free-trade zone, a duty free zone and an industrial park (Nguyen, 2010). The government provided free trade for enterprises to import materials and equipment, and soon attracted foreign capital and local capital to establish factories in the EPZs. A large proportion of the factories in EPZs were light industries such as garments, textiles, and electronic assembly (Ping, 2015). The increase in labour-intensive industries led to a growth in the work force and a significant decline in the unemployment rate from 1965 to 1970.

Industrialisation was not restricted to urban areas. A number of small-medium enterprises (SMEs) emerged in rural areas in the 1970s. Most of these SMEs were home-based factories that supplied specific products for domestic businesses or international companies (Rubinstein, 1999b). The ideology of 'boy preference' was deeply rooted in Taiwanese culture. Traditionally, a son was obligated to continue a family's ancestral line, and had priority to inherit his parent's property. In contrast, a daughter became a member of her husband's family once she got married and was less likely to inherit her parent's property. (Wolf, 1972; Gallin, 1984). In a poor family, parents expected their young daughters to earn supplementary income for the family (Gallin, 1984). The development of industrialisation led to a greater demand for labour and created a significant number of employment opportunities for young women.

During the 1970s, many young women worked in labour-intensive industries such as textile factories or electronic processing factories (Huang, 1977; Peng, 2004). These assembly-line jobs required workers to have patience and carefulness, and were therefore perceived as suitable jobs for women (Ping, 2015). The policy 'Living Rooms as Factories' was introduced in 1974. It was designed to bring the surplus labour of communities and families, particularly housewives, into productive work. The government provided special loans for families to purchase a machine to work at home and also provided training for

housewives (Hsiung, 1996). At that time, it was common to see housewives taking components from factories and doing assembly work at home (Chen, 2016).

As mentioned in Chapter Two, industrialisation created a new mode of production which was constructed by able-bodied norms. The new factory-based work excluded many disabled people from the work force (Finkelstein, 1980; Oliver, 1990). The situation can be seen in Taiwan, where industrialisation led to increasing demand for labour, but the availability of job opportunities for disabled people remained very limited. The government paid little attention to the employment issue for disabled people before 1980. The 'Patriotism Lottery' was issued in 1950 to create a financial resource for the establishment of infrastructure (Lee and Chang, 2005). Many disabled people sold the Patriotism Lottery to earn a living. During the 1970s, nearly twenty thousand disabled people sold the Patriotism Lottery (Lin, 2012). In Taiwan, disabled women experienced more disadvantages in the labour market than disabled men. The official statistics for disabled women's labour participation rate were absent before 1980. By the end of 2014, the labour force participation rate of disabled women was 13.1 per cent, which was far less than the 24.7 per cent of disabled men (Ministry of Labour, 2014: 01). Although the development of industrialisation created job opportunities for women, not all disabled women were able to work in factories. Factory-based jobs were physically demanding, and most workplaces were not accessible (Tsai, 2001).

Disability policy remained absent before 1980. Political change during the 1970s influenced the development of welfare policy in Taiwan. In the late 1970s, the ruling KMT party faced a diplomatic crisis. The United States ended relations with Taiwan and normalised their relation with China in 1979. In the meantime, domestic political forces challenged the ruling authorities (Chen and Yang, 2001). Under these circumstances, the KMT government enacted three pieces of welfare legislation in 1980 in order to consolidate its political position, the 'Social Assistance Act', the 'Welfare Act for the Aged', and the 'Welfare Act for Disabled People'. This was the first time that the government addressed issues related to disabled people in Taiwan. However, the legislation was regarded as a mere formality, and did not respond to the actual needs of disabled people (Lin, 2012). Firstly, the legislation used an individual medical perspective to identify disability. Disability was defined as a problem caused by the functional losses of individuals, rather than social barriers (Hsieh, 1996). In addition, the Act introduced a 'quota system' to encourage enterprises to

employ disabled people. Enterprises that hired disabled people in excess of three percent of the workforce would be rewarded; however what reward would be provided, remained unspecified (Tsai and Ho, 2010). The government did not provide appropriate budgets or staff for the implementation of the Act. This legislation was subject to criticism from many disability organisations and further influenced the development of the disability rights movement in the mid-1980s (Chang and Tsai, 1986).

#### **4.2.3 The Third Period: 1981-1990**

Taiwan's economy shifted from labour-intensive industry to skill-intensive industry in the 1980s. The oil crisis that occurred in 1975 greatly affected labour-intensive industries that had high energy consumption. To cope with the situation, the government encouraged the development of 'strategic industry', characterised by 'low energy consumption, high technological intensity, and high added value', such as the electronics industry and the computer industry (Rubinstein, 1999b: 374). The quick development of the technology industry led to an increased demand for educated workers and professionals. The government developed specialised education and vocational training programmes in order to improve the quality of human resources (Rubinstein, 1999b; Lin, 2012).

The 'Vocational Training Act', which was implemented in 1983, aimed to advance work skills and promote employment for nationals. According to the Act, the central competent authority would provide vocational training for disabled people to improve their work knowledge and skills (Legislative Yuan, 1983). Vocational training programmes for disabled people were delivered by vocational training centres, disability charities or healthcare organisations. In the beginning, most of the training programmes were based on a self-employed approach, such as massage, shoe-repair, watch-repair and stamp-making (Tsai and Ho, 2010). These programmes made an assumption that disabled people were low-competitive and had difficulties engaging in the mainstream labour market. Even today we see people with polio running clock-repair shops to earn a living (Kang, 2008).

In addition, some vocational training programmes focused on specific groups and did not recognise the different needs of people with different impairments. For example, most massage training courses were provided for people with visual impairment. According to the 'Welfare Act for Disabled People', no-one

other than people with visual impairment were allowed to be engaged in massage, with the exemption of medical and nursing professionals, who could use massage as a medical treatment (Legislative Yuan, 1980). This regulation had a far-reaching impact on the employment of people with visual impairment. Li (2003) investigated the occupations of people with visual impairment, and found that the largest proportion of participants was engaged in the massage business. This had the effect of excluding people with visual impairment from the mainstream labour market. Some vocational training programmes were based on culturally constructed gender roles. Women were encouraged to participate in training courses considered appropriated for women, such as hairdressing, sewing and cleaning. These training programmes were criticised for their low commercial value in the labour market (Chen, 2009).

The political situation became uncertain in the mid-1980s. The KMT government faced challenges from growing political opposition. The Democratic Progressive Party (DPP) was established in 1986 and pushed Taiwan towards a two-party system (Copper, 2007). Meanwhile, the lifting of martial law in 1987 was a significant achievement of Taiwanese democratisation. After the termination of martial law, citizens were allowed to organise civil groups and this led to the formation of many pressure groups. These changes in the political situation affected the development of the disability rights movement in Taiwan remarkably (Hsiao, 2001). The development of the disability rights movements in Taiwan was different from its development in a western context. The British disability rights movement was initiated in the late 1970s. Disabled activists were dissatisfied with organisations run by non-disabled professionals, and establish organisations by themselves in order to regain control of their lives (Oliver, 2009). In this context, the British disability rights movement could be recognised as a 'disabled people's movement', led by disabled activists, and with organisations run by disabled people (Oliver, 1990). In Taiwan, the disability rights movement was initially launched by various groups of parents of children with learning difficulties. Most disability organisations were established by parents of disabled children, religious groups, social work professionals and special education professionals (Hsiao, 2001; Chang, 2007).

The 'Fang-Quia Incident', which occurred in 1983, is regarded as the starting point of the disability rights movement in Taiwan. A disability organisation established a day centre for children with learning difficulties in the Fang-Quia community, and it faced strong opposition from local residents (Chang, 2007). Parents of the disabled children submitted a petition to the government and

called for the rights of disabled children to education. Special education professionals engaged in the campaign and introduced progressive ideas to address disability rights issues (Chang, 2007). From 1987 to 1990, several campaigns were launched by disability organisations to demand equal rights for disabled people in employment, education and accessibility (Chang and Yen, 2011). The League of Welfare Organisations for the Disabled was established in 1990, and played a crucial role in the development of disability policy in Taiwan.

The campaign ended with the amendment of the 'Welfare Act for Disabled People' in 1990. In the 1990 revision of the Act, the number of disability categories increased from seven to eleven. Four extra categories, 'losing function of primary organs', 'facial disfigurement', 'unconscious chronic and senile dementia', and 'autism' were included (Legislative Yuan, 1990). These disability categories were identified by individual's functional limitation, which was based on the individual medical model. In the 1990 revision, the quota system became a compulsory policy. Public sectors and private enterprises were required to employ disabled people at a specific percentage (Lin, 2012). Although the disability rights movement was led by parents of disabled children and professionals rather than disabled people themselves, it opened the door for further discussion of disability rights issues.

#### **4.2.4 The Fourth Period: 1991-2000**

The development of welfare policy took a big step forward in the 1990s, which was known as the 'Golden Decade of Social Welfare' in Taiwan (Lin, 2012). National Health Insurance was launched in 1995. By the end of 1995, the insurance covered nearly 92 per cent of the total population (Chiang, 1997: 225). Disabled people acquired subsidies for insurance premiums based on severity of impairment, and also registration fees for each outpatient visit (Ministry of Health and Welfare, 2015). In addition, several employment policies for disabled people were implemented during this period. The 'Employment Service Act' was launched in 1993 to promote employment of nationals. The Act not only targeted middle aged people, but also included women in poor economic conditions, people from low income families, indigenous people, and disabled people (Legislative Yuan, 1993). The Act tackled discrimination against disabled people in employment and aimed to ensure the equal right of disabled people to employment (Wu, 2005).

Following the 'Employment Service Act 1993', several employment schemes were introduced to ensure the employment security of disabled people. The 'Civil Service Special Examinations for Disabled People' was launched in 1996, which aimed to create job opportunities in the public sector for disabled people (Ministry of Examination, 1996). The 'Public Welfare Lottery Scheme' was implemented in 1999 to provide job opportunities for the disadvantaged population. Three populations were permitted to run a lottery shop, disabled people, indigenous people and single parents with low-income (Legislative Yuan, 1999a). However, although the 'Public Welfare Lottery Scheme' provided job opportunities for many disabled people, they received little support from trade unions to protect labour rights and interests (Chen, 2007).

During the 1990s, the development of disability policy saw significant progress. In 1997, the 'Welfare Act of Disabled People' was amended to the 'Physically and Mentally Disabled Citizens Protection Act'. The categories of disability were extended from 11 to 14, and now included people with mental impairment (Legislative Yuan, 1997). Tsai and Ho (2010) suggest that the 1997 revision was affected by the social model of disability. Firstly, the Act aims to protect the legal rights, interests and livelihoods of disabled people, and secure their opportunity to participate in social life. In addition, the government established the 'Committee of the Protection of Physically and Mentally Disabled Citizens'. The members of the committee included disabled people as no less than one-third of the committee members. This means that disabled people were able to participate in the discussion about disability rights issues.

The 1997 revision affected the development of service provision for disabled people in several important areas of life, including medical treatment and rehabilitation, education support, promotion of employment, welfare services and so on (Legislative Yuan, 1997). For instance, the 'Regulations on Subsidisation for Medical Treatment and Auxiliary Appliances for Disabled People' was implemented in 1999. The subsidy scheme was particularly important for people with mobility difficulties. Disabled people became eligible for a subsidy to purchase assistive devices and adaptive vehicles (Legislative Yuan, 1999b). In the meantime, the government introduced the paradigm of 'privatisation' to provide welfare services, and this significantly influenced service provision for disabled people (Tsai and Ho, 2010). The privatisation of welfare service has changed the relationship between the state and disability organisations. The government adopted the contracting-out model to purchase welfare services from private organisations (Chen, 1997). In doing so, the



government was able to reduce spending on welfare provision. Public agencies were often criticised for being ineffective and unresponsive in service provision, while private organisations were able to respond to the needs of service users more effectively (Chiang and Ying, 2005).

However, support and services for disabled people do not necessarily respond to the actual needs of disabled people. In order to contract with the government, private organisations were required to employ professional workers with recognised licences. This led to a professionalisation of social services for disabled people (Chou et al., 2006). In the mid-1990s, the number of disability organisations significantly increased and most were led by professionals (Chang, 2011). This suggests that service provision for disabled people was still controlled by professionals, rather than disabled people themselves. In addition, service provision for disabled people in Taiwan as being overly dependent on the identification of disability, while not responding to the actual needs of disabled people (Chou and Chu 2011). Moreover, social services for disabled people failed to recognise the impact of gender on the needs of disabled people. Lin (2006) explored the motherhood of women with physical impairment in Taiwan. The research found that disabled women received little support from formal services in childcare and had to depend on informal support to take care of their children. Wang (2011) indicates that disabled women may experience difficulties accessing maternity services, whilst their needs are overlooked by the welfare service system.

#### **4.2.5 The Fifth Period: 2001-2015**

Over the last decade, the Taiwanese government has faced challenges associated with dramatic demographic changes. Taiwan had the lowest fertility rate in the world in 2009, with 1.03 children per woman (Executive Yuan, 2010: 02). The low fertility rate resulted in a labour shortage and threatened the social security system (Lin et al., 2011). Another essential issue is population ageing. As mentioned in Chapter One, older people comprised 7 per cent of the total population in 1993, which increased to 12 per cent by 2015 (Executive Yuan, 2015a: n.p). Population ageing leads to increased demand for social care for older people. In Taiwanese culture, adult children have a moral duty to look after their ageing parents. Filial piety (xiao) remains an important value in Taiwan. Filial piety is a central concept in Confucianism, containing important ideas about how children should look after their ageing parents. It demands a

range of material and emotional actions, such as support, memorialising, attendance, respect and love (Yeh and Bedford, 2003: 215).

However, nowadays young people experience difficulties that hinder them from providing support to their ageing parents. In recent years, the number of people in atypical employment has significantly increased. Young people find it more difficult to get a full-time job and are more likely to engage in unstable, low-paid or dangerous jobs (Lin et al., 2011). In these circumstances, young people face more pressure in looking after their ageing parents. To tackle the problems associated with population ageing, the government launched the 'Ten-Year Long-Term Care Programme' in 2007. The programme provides social care services for people aged 65 or over with high support needs. As mentioned in Chapter Two, disabled people may experience premature physical ageing which leads to an early decline of physical function (Zarb, 1993). The 'Ten-Year Long-Term Care Programme' recognises the effect of premature ageing on disabled people. Disabled people aged 50 or over with support needs are eligible for long-term care services (Yen et al., 2014).

Nevertheless, existing long-term care services have been criticised as overemphasising the functional limitations of disabled people and ignoring their need for social participation. Furthermore, long-term care services are exclusively provided for disabled people aged 50 and over, and overlook the needs of disabled people of other age groups (Chang, 2009). In addition to social care services for older people, the 'National Pension Scheme' was launched in 2007 to ensure economic safety for the elderly population. Citizens aged 25-65 who were not covered by any related social insurance became eligible for the pension scheme. People need 40 qualifying years of national insurance contributions to get their full basic national pension (Huang, 2008).

Over the last decade, the development of disability policy has been profoundly influenced by the international trend for disability rights. The 'Physically and Mentally Disabled Citizens Act' was amended as the 'Persons with Disability Rights Protection Act' in 2007. Several changes were made in the 2007 revision. Firstly, the Act introduced the ICF as a framework to identify the categories of disability. As mentioned in Chapter Two, several scholars criticise the ICF as being underpinned by a medical model. It regards functional limitation as a factor preventing an individual from participating in society (Hurst, 2000; Barnes and Mercer, 2010). In Taiwan, the ICF has been criticised for overemphasising the impact of body function on the social participation of disabled people, while it fails to address environmental impacts (Chou and Chu,

2011). In addition, the 2007 revision indicates that identification of disability should be conducted by a committee composed of multi-professionals from medicine, social work, special education and employment counselling. The committee aimed to include multiple professionals to represent the diverse needs of disabled people (Chang and Yen, 2011). Nevertheless, the multi-professional committee did not change the power in the relationship between professionals and disabled people. Disabled people were excluded from participation in the process of evaluation, and the committee was still dominated by professionals, who had the power to identify the category of disability.

The international trend also affected the independent living movement in Taiwan. An organisation, the New Vitality Independent Living Association (NVILA) was established in 2007, and this is regarded as the starting point of the independent living movement in Taiwan (Chang, 2011). The NVILA was the first organisation led by disabled people in Taiwan. The organisation redefined the meaning of independence as 'disabled people have equal rights to control their lives, make choices, and take responsibility for themselves' (NVILA, 2007: n.p). The Independent Living Movement claimed that disabled people, regardless of the severity of impairment, should have appropriate support to enable them to live in the community (Chuang, 2011). Although the 'independent living service' was legalised as a formal service for disabled people in 2012, personal assistance services and peer support services remain underdeveloped in Taiwan. In addition to the independent living movement, several disability organisations came together to establish an informal group, the 'Thousand Disabilities Action Group' in 2010. The alliance initiated several street protests to call for equal rights for disabled people in transportation, education, accessible information and employment (Hsu, 2011).

The international trend for disability rights influenced Taiwan's disability legislation. The Convention on the Rights of Persons with Disabilities (CRPD) was launched by the United Nations in 2006 (United Nations, 2006). The Enforcement Act of the Convention on the Rights of Persons with Disabilities was passed in 2014. The Act provides a comprehensive protection of the rights of disabled people at a legal level. It ensures all disabled people have the right to equal participation in society, politics, the economy and culture, and promotes their individual independence and development. According to Article 3 of the Act, the government is required to establish a committee for the promotion of the rights of disabled people. The members of the committee must

include disabled people as no less than one half of the committee members (Legislative Yuan, 2014). It can be seen that the international trend for disability rights has had a great impact on the development of disability policy in Taiwan over the last decade, and has led to an increased public awareness of disability rights.

## **Summary**

The development of disability policy in Taiwan has been significantly influenced by the political, economic and social changes in the various historical periods. The role of the state in social services for disabled people was absent before 1980. In the post war period, welfare provision was strongly linked to the political interests of the ruling party. Disability was regarded as a personal issue, and families were expected to take responsibility for caring for disabled people. Due to a lack of social support, disabled children faced barriers that hindered them from having access to medical treatment and education. The first disability legislation the 'Welfare Act for Disabled People' was launched in 1980, and served as a foundation for the disability rights movement of the mid-1980s.

The disability rights movement led to the expansion of social services for disabled people during the 1990s. The 1997 revision of disability legislation profoundly influenced service provision for disabled people in several areas of life. In the meantime, the privatisation of welfare services changed the way welfare services were delivered to disabled people. Services for disabled people were mainly controlled by professionals, rather than disabled people themselves. More importantly, legislation and service provision did not recognise gender differences in the needs of disabled people. Over the last decade, the Taiwanese government established a social care system to respond to the needs of an increasing elderly population. Meanwhile, the international trend for disability rights greatly influenced the development of disability policy and changed disability politics in Taiwan. This chapter provides historical context through which to understand the participants' experiences in various periods. It shows the significant progress of disability policy and service provision for disabled people over the past six decades, which profoundly influence the participants' life experiences in various life stages. The next chapter explores the childhood experiences of the participants.

## **Chapter Five**

### **Growing Up as a Girl with Polio**

#### **Introduction**

The understanding of childhood is influenced by traditional child development theory. Child development theory assumes that children's biological, psychological and cognitive development go through several standard stages (Erikson, 1968). This approach provides a framework to define what constitutes a 'normal child'. In this view, disabled children are often perceived as 'developmentally delayed' because they do not follow the process of child development. Professionals make judgements about children's 'developmental delay' and this provides a basis for determining interventions in children's lives (Priestley, 2003). Traditional child development theory has been criticised by sociologists. The sociology of childhood emphasises that childhood experiences are affected by class, age, gender and ill health (Jenks, 1996). The concept of childhood is constructed through an interweaving of social structures, political and economic institutions, cultural, policies and interactions with adults (James and James, 2004). From the sociological perspective, children are not perceived as 'incomplete adults', but social actors with needs and rights (James et al., 1998).

In Taiwan, children are defined as a citizen aged below twelve. Social responses to disabled children are based on an individual medical model. Disabled children are usually recognised as 'abnormal' and targeted by medical professionals. As discussed in Chapter One, several hospitals and rehabilitation institutions were established during the 1960s to provide treatment for children with polio. Services for 'developmentally delayed' children were institutionalised in legislation. According to the 'Protection of Children and Youths Welfare and Rights Act', if social welfare, educational and medical institutes identify any developmentally delayed children, they must report it to the authorised municipal agencies to ensure proper services for these children (Legislative Yuan, 2003). Additionally, institutional discrimination is embodied in the education system for disabled children. As mentioned in Chapter Four, the Enforcement Education Act 1944 indicated that citizens

between 6 and 12 years of age received six-year's compulsory education, with the exception of disabled children and children with severe disease. This chapter focuses on the childhood experiences of the participants. Initially, it examines paternal reactions to their disabled children, and subsequently explores the relationships between disabled children and their parents. It then discusses the decision-making in medical intervention for children with polio and explores the participants' experiences of medical treatment. The participants' experiences in residential settings and community are also discussed. Finally, the barriers that prevent participants from accessing education are examined.

### **5.1 Parental Reactions to Children's Impairment: 'Polio as a Punishment for Sin'**

Previous studies have indicated that many children with polio are taken to hospitals as soon as polio is diagnosed, and experience sudden separation from their families (Bruno and Frick, 1991; Wilson, 1998; Wenneberg and Ahlström, 2000). However, in the present study, the majority of participants were not taken to hospitals or rehabilitation institutions for medical treatment at the very beginning. Due to a lack of information about polio, several participants mentioned that their parents were not aware that they were inflected with poliovirus. Information is defined by the British Independent Living Movement, as one of the seven needs of independent living for disabled people. Disabled people have rights of access to information that enables them to receive services and make choices (Greater Manchester Coalition of Disabled People, 2011).

In Taiwan, mass media remained underdeveloped during the 1950s, and this made it difficult for families to access information about treatment for polio. Yi-Jun mentioned that it was not difficult to know about the treatment for polio because information was often transmitted by word of mouth at that time. Most participants were taken to local medical clinics or used Chinese medicine for treatment at first. For example, Li-Hua was taken to a local medical clinic when her mother found she had fever. The first manifestations of polio are flu-like symptoms, and it is likely to be treated as flu (Howard, 2005). Li-Hua described the doctor misdiagnosing her as having the flu.

I had a high fever for several days. My mum thought I had flu and took

me to see a doctor. The doctor gave me an injection to reduce fever, but my lower limbs were paralysed subsequently (Li-Hua).

Similarly, Hui-Ling described that several children contracted polio in her village, but most of the families did not know about polio. Due to lack of knowledge about polio, parents sought various treatments for their children. As mentioned in Chapter Four, modern Western medicine was introduced into Taiwan in the late 19th century, and was professionalised during the Japanese colonial period. In the post-war period, Chinese medicine was still commonly used by people, because the expense of western medicine was high (Chi, 1994). Xiu-Zhen mentioned that she took an herbal bath every day in order to strengthen muscle function. The experience of Shu-Fen is similar. She was forced to have Chinese herbal soups, but the treatment was not effective.

My mum made a Chinese herbal soup for me every day. It tasted disgusting, so I refused to have it. My mum told me if I had it every day I could walk again, but it did not work at all for me (Shu-Fen).

In addition to medical treatment, the following examples show that parents sought help from religion, particularly when the treatment did not work for their children. Bennett et al. (1995) indicate that religion can play a vital role in the lives of parents who have disabled children. They found that some parents believe supernatural healing can help them maintain a positive outlook for their children's future. Hui-Ping was born into a Christian family. She was taken to several churches because her mother believed that god's healing power could cure her daughter.

I was taken to several churches. My mum believed those priests and sisters had extraordinary power to cure my legs. They touched my leg and prayed for me (Hui-Ping).

As mentioned in Chapter Two, the traditional model sees disability as a punishment for ancestral sin or divine retribution (Coleridge, 1993). The following example shows a cultural interpretation of disability in Taiwan's religions. Taiwan has three major religions, Buddhism, Taoism and

Confucianism. A 'Danggi' is a type of spirit medium in Taoism. Taoism is a polytheistic religion, and people believe that 'Danggis' are chosen by the gods and they can transmit gods' words to people (Chao, 2002). The role a 'Danggi' plays is communicating with the gods and answering questions from people, as well as prescribing medicine (Jordan, 1977). Hui-Ling's mother took her to visit a 'Danggi' and sought for advice for treatment.

My mum took me to a temple to see a Danggi. The Danggi told my mum that I was punished for sins in my previous incarnation, but I could get well if I became a child of god. At that time, I remembered I was a child of many different gods (Hui-Ling).

Mother blaming is common in families with disabled children. Sen and Yurtsever (2007) investigated the difficulties experienced by families with disabled children, and found that mothers are often blamed by their husbands and their husband's family after the birth of a disabled child. Hui-Ling mentioned that her mother was blamed by her father after she contracted polio. Her father perceived her impairment as her mother's fault. Hui-Ling's mother took her to see a fortune-teller in order to find an answer to her situation.

The fortune-teller told my mother that she shouldn't feel guilty because this is my fate that I became disabled (Hui-Ling).

This example shows that the interpretation of disability is underpinned by the personal tragedy theory of disability, in which disability is perceived as a terrible chance which occurs to unfortunate people (Oliver, 1986). Huang (2014) indicates that parents who have disabled children can obtain tremendous support at a psychological level when they seek help from a spiritual power. In Hui-Ling's case, the fortune-teller's interpretation might have released her mother's guilty feelings about having a disabled child. Next, I explore the relationship between the participants and their parents, which was mentioned by several participants.



## 5.2 Relationship between Parents and Disabled Children

The family's reaction to a disabled child reflects social attitudes toward disabled people, and the social meaning of disability (Ferguson, 2002). Thomas (1998) suggests that parents play a crucial role in challenging or reinforcing the stigmatising cultural meaning attached to children's impairment, which significantly influences disabled children's self-identity. In the present study, the participants' accounts show that parents' attitudes toward their disabled children are various. Several participants indicated that their parents were supportive and treated them as the same as their able-bodied siblings. For example, Li-Hua mentioned that her parents treated her as same as her non-disabled peers.

My parents knew I was different from other kids, but they did not feel shame of me or keep me at home. I was allowed to play with other kids (Li-Hua).

In contrast, three interviewees reported that their parents felt shame of them and treated them differently. As mentioned in Chapter One, some children with polio are abused by their parents when they return home from institutions. They are not allowed to use assistive devices in order to 'get normal' (Frick, 1995). A similar finding can be seen in Mei-Zhu's case. Polio affected Mei-Zhu's right leg. She can walk, but slowly. She was prohibited from using crutches because her parents expected her to be a 'normal person'.

My parents wanted me to look like a normal person. They felt shamed if someone saw me walking on crutches. I had to learn how to walk without using crutches. My right leg was smaller than my left leg, my parents asked me to do exercise in order to make my two legs look the same (Mei-Zhu).

Likewise, Xiu-Zhen was not allowed to be appear in front of visitors. She was told to stay in her room when her family had visitors.

Someone told my parents that I was punished by God because they

did wrong things in their previous lives. My parents told me I should stay in my room when visitors came. It became my automatic reaction. Without anyone telling me, I knew I should stay at my room every time when visitors came (Xiu-Zhen).

Reeve (2004) indicates that psycho-emotional disablism can be experienced by disabled people in social interaction with others. People's negative reaction to disabled people might undermine their psycho-emotional wellbeing. Xiu-Zhen's case shows that parental negative attitudes towards disabled children might affect their confidence and lead to low self-esteem. Conversely, Hui-Ping's case shows that positive parental attitudes towards their disabled children enable them to develop a positive personality.

My mum believed what the Bible said, a man born blind was neither his own sin nor his parents' sin. This is because the power of God might be displayed in him. My mum did not feel ashamed of me and treated me as same as other kids. That's why I never thought I should feel ashamed of myself (Hui-Ping).

These examples shed lights on the relationship between parents and disabled children. It can be seen that parental attitudes towards disabled children are considerably affected by socio-cultural beliefs. It can be argued that the problems of a disabled childhood are not simply caused by impairment, but are the outcomes of social relations, cultural representations and the behaviours of adults (Shakespeare and Watson, 1998). Next, I examine the participants' experiences of medical treatment.

### **5.3 The Medicalisation of Childhood**

As discussed, most participants did not separate from their families for treatment at first, and either received treatment in local medical clinics or used Chinese medicine. Eight respondents were taken to hospitals or rehabilitation institutions several years after the original onset. Most left home during the compulsory school age years. Medical treatment led to a suspension of study and delayed school entry. This section examines the factors influencing medical decisions for children with polio, and then explores the participants' experiences in medical settings.

### 5.3.1 Decision-Making in Medical Treatment

Medical opinion is an essential factor that frames the life expectations and trajectory of disabled people, even in early life stages (Shah and Priestley, 2011). The diagnosis and opinion of medical authorities had a great influence on the parents' medical decisions for their disabled children. Li-Hua's case shows that the doctor played a pivotal role in making medical assessment and determined whether she could stay in a hospital.

My mum took me to a hospital which was well known for polio treatment. The doctor told my mum that my situation was not severe so I did not need a corrective operation. I never stayed in a hospital or an institution (Li-Hua).

Conrad (1992) argues that medicalisation does not necessarily directly include medical professionals or treatments; it can occur on the conceptual level when a medical vocabulary is adopted to define the problem. On the conceptual level, few medical professionals need to be involved, and treatments are not necessarily applied (Conrad, 1992: 211). The following cases show that medical opinions are not necessarily given by medical professionals, but those who do not have a medical professional background, such as friends and neighbours. These people frequently make diagnoses, and their opinions greatly influence parents' medical decisions for their children. In Xiu-Zhen's case, a neighbour told her father that she needed corrective surgery to enable her to regain the ability of walking. Xiu-Zhen's father accepted the advice and took her to a hospital. She underwent corrective surgery and then stayed in a rehabilitation institution for several months. Similarly, Hui-Ling mentioned that a priest advised her father to take her to a hospital.

My dad respected to whatever the priest had said to him. The priest told my father that my bone was still young and it could be stretched. He urged my dad to send me to a hospital to have corrective surgery (Hui-Ling).

These interviewees' accounts show that medical opinion profoundly affected their parents' understanding of their child's impairment and influenced their medical decisions for the children, even though the opinions were not given by medical professionals. This suggests that medicalisation occurs when a problem is defined in medical terms, whether by medical professionals or people in general.

In addition to medical opinions, gender is an important factor influencing decision-making about medical treatment. Begum (1992) argues that the dominant image of women does not consider the diversity of individual's characteristics. Disabled women are often recognised as unattractive because their bodies do not meet the ideal standards of 'normal' appearance. Hui-Ling's account noted that these socially-constructed gender norms influenced her motivation to have corrective surgery. Hui-Ling wanted to wear a skirt like other able-bodied girls. In this context, medical treatment was recognised as an opportunity for her to pursue femininity.

When I saw many girls in my school wore skirts, I envied them. I wanted to wear skirts. When my father told me that I had to stay in a hospital for surgery, I did not resist it (Hui-Ling).

The influence of gender on medical decisions can also be seen in Shu-Fen's case. As mentioned in Chapter Two, disabled women are perceived as incapable of being ideal mothers because they are not able to look after their children and families (Fine and Asch, 1988). Shu-Fen's parents sought treatment for their disabled daughter in order to regain her physical capacity. They believed that someone would want to marry their disabled daughter if she was able to walk.

My parents persuaded me to have surgery. They told me if I could not walk, no one would want to marry me (Shu-Fen).

Shah and Priestley (2011) indicate that the prognosis for a disabled child not only provide a functional assessment, but also contains social opinions including predictions about adult social roles and the social value of disabled lives. In Shu-Fen's case, medical treatment was not simply related to functional

improvement, but also enabling her to fulfil her role as a woman. There is a danger that these kinds of underlying assumptions may reinforce the legitimacy of medical intervention for disabled women.

In addition to gender impact, the availability of social resources influences whether disabled children have access to medical treatment. Medical expenses for polio treatment could be a heavy burden for some families, including the cost of initial treatment and rehabilitation therapy and the necessary cost of assistive technology (Wilson, 1998). As mentioned in Chapter Four, in the post war period, welfare policy exclusively benefited military servicemen and public servants. People from these privileged backgrounds could receive generous social resources, while the disadvantaged population received little support. Vernon (1999) indicates that the multiple oppressions disabled people experience vary across contexts. The absence or presence of privileged identity can modify or exacerbate the experience of disablement (see section 2.2.2). Ya-Lin and Hui-Ping both came from military families and received free medical treatment for polio. Shu-Fen, on the other hand, came from a poor family. Medical expenses for polio treatment were a heavy burden for her family. Her mother had to work in order to make money for her treatment. Li-Hua also indicated that not every child with polio could have equal access to medical treatment, which was only provided to children with a privileged background.

I did not have any specific family background. If you were a kid from a military family, or your parents were teachers, then you had priority over other children to stay in rehabilitation institutions (Li-Hua).

However, Yu-Lan's account shows that sometimes the availability of social resources such as free treatment could be an incentive that encourages parents to consider medical treatment for their children, even though the treatment was not necessary. For example, Yu-Lan underwent corrective surgery at the age of six, and this enabled her to walk with crutches. She mentioned that her father took her to a rehabilitation institution because the services were free.

Someone told my father that a rehabilitation institution could provide free rehabilitation therapy for children from poor families. I stayed in

the institution for three months. I was doing nothing there because I did not need any treatment. I took some training courses to learn cooking and handcraft making (Yu-Lan).

These women's accounts represent the way the discourse of medicine, gender impact and the availability of social resources influenced decision-making in medical treatment for disabled children. The discussion here does not deny that medical intervention may be important for disabled children, but it shows that sometimes medical treatment might not be necessary. Davis and Watson (2000) argue that children's problems are often identified by parents and professionals, and ownership of their choice is taken away from children. These examples show that most of the participants were excluded from the decision making about their medical treatment. However, a previous study demonstrates that disabled children are able to make complex medical decisions (Alderson, 1993). The next section examines the experience of children with polio in medical settings.

### **5.3.2 Normalisation in Medical Practice: “What’s So Wonderful about Walking?”**

Seven participants in the present study underwent corrective surgery during their childhood, and two had scoliosis surgery in adulthood. Yoshida and Shanouda (2015) suggest that disabled people lose ownership of their bodies once they are placed in medical settings. They are treated as an object and regulated by various disciplinary forces in medical and rehabilitative practice. This is reflected in Hui-Ling and Shu-Juan's stories. Hui-Ling's example shows how a disabled person's body is objectified by medical professionals.

I took off my clothes. I was asked to show how I walk in front of doctors and nurses. They took a photo of me when I was crawling on the ground (Hui-Ling).

Hui-Ling also recounted her experiences of undergoing corrective surgery. She was treated as a passive object and lost control of her body.

I was waiting outside the operation room. I was so scared. A nurse said to me, 'little girl, there is nothing to be worried about, it's just like killing a pig' (Hui-Ling).

In Hui-Ling's case, the nurse used the term 'killing a pig' to describe the process of surgery. The child with polio was compared to an animal, 'killed' by a doctor. The example shows that disabled children can become powerless, with their bodies controlled by medical professionals. Shu-Juan's experience is similar. As mentioned in Chapter One, the scoliosis operation was not available in Taiwan until the 1970s. Before 1970, some hospitals undertook clinical trials for patients with scoliosis in order to develop the technology of scoliosis treatment. Shu-Juan has scoliosis caused by the effects of polio. She was selected as a candidate for experimental spine therapy. She felt she was treated as an object in a medical experiment, and experienced numerous unnecessary treatments.

I was a candidate for their experimental spine therapy. I had to sleep on a pile of sand bags at night and wear the back brace to sleep. What a torture! Regardless of all the physical therapy and back braces, nothing kept the scoliosis from worsening (Shu-Juan).

The ideology of normality was embodied in rehabilitation practice. As mentioned in Chapter Two, Oliver's (1993) article "What's so Wonderful about Walking?" indicates that walking ability has always been valued by society and becomes an essential part of personal identity. However, the pursuit of walking ability is oppressive to those who are 'not-walking' or 'near-walking'. As he describes, 'walking is rule-following behaviour... not-walking or rejecting nearly-walking as a personal choice is something different; however it threatens the power of professionals' (Oliver, 1993: 16). From a medical perspective, lack of walking ability can be a problem for people for maintaining a healthy lifestyle. For example, a previous study shows that disabled people have a higher rate of obesity than non-disabled people, particularly those who have mobility difficulties (Rimmer and Rowland, 2008).

The overemphasis on walking ability is problematic for disabled people. The pursuit of walking ability can be seen in conductive education in the UK. Conductive education was implemented during the 1980s, and aimed to teach children with mobility difficulties to walk without using assistive devices in order

to integrate to normal social settings (Oliver, 1989). In the present study, eight participants mentioned that they underwent painful rehabilitation therapy during their childhood. Mei-Zhu's parents did not allow her to use assistive devices and forced her to do exercises. She indicated that overuse of physical strength of her legs during childhood caused physical weakness she experiences in more recent years. Similarly, Hui-Ping underwent painful physical therapy in order to regain muscle strength in her impaired limbs.

After I recovered from corrective surgery, I did many painful physical therapies. The therapist stretched my leg vigorously every day, it was painful (Hui-Ping).

Illich (1976) indicates that the effectiveness of medical treatment has been exaggerated, while medical treatment itself can be a threat to health. He suggests that people should acknowledge the limits of medicine and reclaim their control over medical perception and decision-making. Several participants did mention that medical treatments enabled them to regain mobility. However, Ya-Lin's case shows that medical treatment did not necessarily improve her mobility. Ya-Lin's left hand was affected by polio and this made it difficult for her to hold crutches. She was encouraged to use crutches by her rehabilitation therapist. This example shows that the use of assistive devices did not always improve an individual's mobility, whereas it did lead to the creation of dependency for disabled people.

Even if I was wearing leg braces and using crutches, I needed help from others while standing up. My hands did not have enough strength to get myself up (Ya-Lin).

Ya-Lin's case notes that the ultimate goal of rehabilitation therapy was regaining walking ability. Even though it was difficult for Ya-Lin to walk on crutches, she was encouraged to use crutches rather than a wheelchair. Similarly, the majority of participants mentioned that they were often encouraged to use crutches to walk; none of them were encouraged to use wheelchairs. This highlights the assumption that 'walking' is a desirable trait for a human being, while not-walking is perceived as a problem. It can be seen



that the ideology of normalisation in rehabilitation practices profoundly shaped the participants' experiences in medical settings. Having discussed the experiences in medical settings, the next section focuses on participants' experiences in institutions.

## **5.4 Living Away From Home**

As mentioned in Chapter One, many children with polio were sent away from home to hospitals and underwent numerous painful surgeries in order to facilitate increased physical functioning (Saxon, 2001). Some children stayed in rehabilitation institutions for several years and experienced psychological and emotional distress (Bruno and Frick, 1991). Similar findings can be seen in the present study. Eight respondents reported that they were taken to hospitals or rehabilitation institutions a few years after the original onset. The length of stay ranged from a few months to several years. This section explores participants' experiences in residential settings during their childhood.

### **5.4.1 Losing Control of Life**

Jones and Fowles (1984: 200) analyse the literature about various kinds of institutions and indicate five common characteristics of institutional life, social stigma, loss of liberty, loss of autonomy, depersonalisation and low material standards. Several respondents mentioned that they had to follow strict schedules and completely lost control of their lives. For example, Yi-Jun lived in a rehabilitation institution for nine years. She used the term 'military camp' to describe her everyday life at the institution.

The bedtime, meal-time, shower-time were strictly regulated by the timetable. We were just like soldiers living in a military camp. I hated those daily routines (Yi-Jun).

In Taiwan, soldiers are required to fold a quilt so that it looks like a chunk of tofu, which represents the soldiers' obedience to stringent discipline (Chou, 2015). Yi-Jun and Ya-Lin indicated that they were asked to fold their quilts into pieces of tofu every morning. This created a problem for Ya-Lin. She had paralysis in her left hand and found it hard to manage the task.

The first thing we did every morning was folding the quilt like 'tofu pieces'. You had to fold a quilt neatly and preciously. It was difficult for me to manage the task. It took me a lot of time, so I was always late for breakfast (Ya-Lin).

The following examples show that the residents' lives were not only regulated by numerous strict rules, but also controlled by staff. Several participants mentioned that they were assigned work to do in institutions. For example, Hui-Ping described the residents in her institution having to weed the garden at the weekend. Three respondents indicated similar circumstances 'Wheelchair driver', which meant an older child who was assigned the task of carrying younger children using their wheelchairs. For example, Hui-Ling said that older children would take her to the restaurant using their wheelchairs. A similar situation occurred in Shu-Fen's case. She had to carry other children to the bathroom using her wheelchair.

The nurse assigned me a task. I had to bring younger kids to shower by using my wheelchair. I often carried two kids at the same time, one sat in front of me and the other one sat behind me (Shu-Fen).

Such examples show labour exploitation experienced by disabled children in institutions. These circumstances might be recognised as a form of child abuse today. Although those disabled children had functional limitations, they were recognised as resources that could be used to share the work of staff in institutions.

#### **5.4.2 Independent Culture**

As mentioned in Chapter Two, the meaning of independence was redefined by disabled people themselves in the British Independent Living Movement. They emphasise the individual having control and choice in their lives, rather than them having to perform every task for themselves (Brisenden, 1989: 8). In Taiwan, the concept of independence overly emphasises the self-reliance of disabled people, rather than adjustments to the environment. Independent culture was embodied in the participants' experiences in institutions. Several respondents, for instance, Ya-Lin, mentioned that they were told to do things on

their own. She took a number of life skills training courses such as bathing, cooking and cleaning dishes. The ideology of independence can be seen in a training called 'stand up on your own feet'. Ya-Lin was taught how to stand up without others' help.

Our ultimate goal was to learn how to stand up on our own. I had to find a way and get up by using my crutches or leaning against the wall. Once you fall, this training helps you get yourself up without other people's help (Ya-Lin).

The following cases show that independence culture had a great impact on these women's lives. For Yi-Jun and Hui-Lin, independence meant that an individual could manage every task on their own. Yi-Jun recognised herself as an 'independent person' because she could deal with many problems on her own. Hui-Ling attended 'independent skills training' in an institution. She was often told that she could not rely on the help of others. However, this made it difficult for her to seek support from other people.

When I experienced difficulties in my life, I did not know how to ask for help from others. It was hard for me to deal with all the problems by myself. I knew I should use social resource, or sought help from social workers (Hui-Ling).

This case shows that independence culture significantly influenced the women's sense of self. Some participants may have felt confident about themselves because they were able to manage a lot of things on their own. On the other hand, independence culture could have been a barrier that hindered disabled people from seeking help from others to deal with their problems. The next section discusses gender experiences in residential settings, which was raised by several interviewees.

### **5.4.3 Gendered Experiences in Institutions**

As mentioned in Chapter Two, disabled people are subject to infantilisation. Disabled people are often perceived as children, who are also assumed to

have no sexuality, so disabled people are similarly denied their sexual feelings (Shakespeare et al., 1996). The following cases show that disabled children are often treated as asexual in residential settings. Four participants mentioned that they took showers together with other residents. Hui-Ling mentioned that she had to share a bathroom with other female residents. Similarly, Shu-Juan indicated that children were bathed together by female staff.

We would sit in a line in the bathroom area, waiting to go inside the bathroom. A female staff member would pour the hot water over our head and the other scrub us with soap. After that we would be put on a big table with towels. Staff would dry us with whatever towel they had to hand (Shu-Juan).

Young disabled people are often discouraged from discussing issues related to sexuality, or are not provided with answers, as sex is not relevant to them (Shakespeare et al., 1996). This situation can be found in She-Fen's case. Shu-Fen had to share a bathroom with male residents. When children asked the staff questions about sexuality, the staff often didn't respond to the children's questions or gave vague answers. The example discussed here demonstrates that disabled children are often treated as child-like and asexual with little opportunity to engage in discussions of sexuality.

We shared a bathroom together, so everyone was naked in front of each other. Some children asked the staff why boys' and girls' bodies looked different. They told us this is because women could have a baby, but men could not. They did not tell us how men and women can have a child (Shu-Fen).

Wilkerson (2011) indicates that people with learning difficulties are commonly treated as children irrespective of their age or capability of making sexual choices. However, the situation might be different for people with physical impairment. The following examples show that age is a crucial factor influencing people's attitudes toward the sexuality of disabled children. As discussed in Chapter Two, social attitudes towards the sexuality of disabled people are contradictory. In some cases disabled people are recognised as

hypersexual and their sexual behaviours are controlled by others (Hall, 2011). For instance, Shu-Juan lived in a rehabilitation institution for nine years. She described that male and female children were not allowed to stay alone. Similarly, Yi- Jun indicated that that age influenced accommodation arrangements. Young disabled children lived in gender-mixed flats, while older children lived in single-sex flats. When the disabled children grew up, their sexual behaviours would be monitored and controlled by staff. Yi-Jun mentioned that imitate relationships were strictly forbidden in her institution, particularly for those in their teenage years.

Male and female residents were not allowed to talk or stay alone, especially those at the stage of puberty. Dating was also not allowed. Staff sometimes checked our school bags to see whether we had received any love letters (Yi-Jun).

This example shows that disabled people were not allowed to express their sexual desires and behaviours, which were perceived as 'inappropriate' or 'dangerous'. French (1996) examined the experiences of women with visual impairment in residential schools. She found that some participants lived with female peers for several years and this made it difficult for them to develop intimate relationships with males. These participants' accounts show that disabled children's sexuality was profoundly controlled by adults in residential settings and this may have restricted them from developing sexual relationships when they grew up. The next section explores the participants' community lives during their childhood.

## **5.5 Living in the Community**

In the present study, not all the participants had experiences of living in institutions. Two participants had never been in hospitals or rehabilitation facilities. As mentioned previously, most participants did not experience sudden separation from their families when they contracted polio. This means that they spent some time living with their families before they were taken to hospitals or institutions. As mentioned in Chapter One, the assistive technology industry was underdeveloped before the 1960s (Chang, 2013). Several respondents noted that lack of assistive devices restricted them from participating in

activities. Shu-Fen's accounts show that the lack of assistive devices restricted her activities and forced her to rely on her family.

It was a painful experience crawling on the ground. I always got hurt on my knees. I often stayed in my room, my mother and sister would deliver meals to me (Shu-Fen).

Apart from physical suffering, crawling on the ground can be a traumatic experience for disabled children. Shu-Fen mentioned that she felt ashamed when she was crawling. She felt she was different from other able-bodied peers. In contrast, Li-Hua had a different understanding of crawling. As mentioned earlier, traditional child development theory constructs what constitutes a 'normal child', in terms of a child's physical and cognitive development. For example, a child is expected to learn skills from a crawling position, and finally to stand and walk independently during the period from six months to two years (Quinn, 1997). In Li-Hua's case, she did not feel she was different from her able-bodied peers, because crawling was seen as 'normal' behaviour for every child.

I did not think that I was different from other children. Many children crawled on the ground as well. We all crawled on the ground since we were born (Li-Hua).

In addition, lack of public transport prevented disabled people from participating in social activities. Cavert (1998) suggests that disabled children and disabled young people experienced more structural constraints to participating in leisure activities, such as poor transportation, public attitudes and limited support services. As mentioned in Chapter Four, public transport remained underdeveloped in the early 1960s. The Taiwanese government encouraged the development of the bicycle industry, and bicycles became the main private vehicle during the 1960s (Yu et al., 2010). Shu-Fen's case shows how a lack of transportation excluded her from participation in leisure activities.

My mum went to the outdoor opera with her friends, but I could not go

with her. She could not ride a bike and could not take me there. I was crying and felt very disappointed (Shu-Fen).

However, not all participants experienced exclusion from leisure activities. Five participants noted that they received a lot of support from family and other children, and this enables them to play with other children. For example, Xiu-Zhen was able to participate in activities with support from her neighbours.

I went to many places with other children. My neighbour would hold my two legs, and I was crawling forward by my hands. I remembered we went to a river and playgrounds. I could do many things with them (Xiu-Zhen).

Mulderij (1997) indicates that flexibility is an essential element in the friendship between disabled and non-disabled children. Non-disabled children can change the game rules to enable disabled children to play games with them. In Shu-Fen's case, she was assigned a task that did not demand physical strength, and therefore she was able to play with other children.

We went to a sugarcane field. My friends went into the field to steal sugarcanes, and I sat near the entry to keep watch for them. If I saw some strangers coming, I would sing a song loudly to let them know they should leave immediately (Shu-Fen).

These participants' accounts demonstrate that the problems hindering disabled children participating in the community are not simply caused by their impairment. Positive attitudes and appropriate support enable disabled children to participate equally in the community. Next, I explore the barriers experienced by participants in school.

## **5.6 Schooling for Girls with Polio: 'Pee, Period, Physical Education'**

As discussed in Chapter Four, previous studies have shown that disabled girls are more likely to experience exclusion and inequality in education than their

male counterparts (Russo and Jansen, 1988). It is noted that disabled girls' access to education is not only affected by gender and disability, but their type of 'disability', the socioeconomic status of their families, ethnic background, physical location etc. (Rouso, 2004). In the present study, the level of education of the participants varies. One participant has a master's degree, six are college educated, two are at the level of compulsory education, and one is uneducated. The majority of participants studied in mainstream primary schools, but two attended a special secondary school for children with physical impairment. Eight participants were taken to hospitals or rehabilitation institutions for treatment during the compulsory school age years, and this led to delayed school entry and discontinuities in schooling. The discussion here focuses on the participants' experiences in primary and secondary school.

### **5.6.1 Barriers to Access to School**

Physical barriers and poor transportation can be determinant factors that hinder children with mobility difficulties from accessing education. Agnihotri and Patel (2015) indicate that girls with physical impairment are likely to be excluded from education due to a lack of accessible facilities such as ramps, accessible toilets, and also the problem of travelling for any distance. The Taiwanese government did not pay much attention to accessible environments for disabled people before 1980. The Welfare Act for Disabled People 1980 was the first legislation to tackle the issue of accessible environments for disabled people. According to the Act, local authorities were obligated to provide equipment and appropriate support for disabled people in public spaces and public buildings (Legislative Yuan, 1980). The majority of respondents reported that they experienced physical barriers in school, such as stairs, inaccessible toilets, classrooms etc.

As mentioned in Chapter Four, the Enforcement Education Act 1944 excluded children with physical impairment and severe disease from compulsory education. The Act did not protect the educational rights of disabled children, and therefore many disabled children were rejected by school at that time (Chang and Yen, 2011). In Hui-Ling's case, she was rejected by a primary school because the school did not have an accessible toilet.

I was rejected by a primary school. The headmaster told my mum that the school did not have accessible toilets for disabled students and no one could help me. A teacher persuaded the headmaster to let me



attend school. I delayed for two years to attend school (Hui-Ling).

Hui-Ling's case represented discrimination against disabled children in the educational system. Families were expected to take responsibility for looking after their disabled children, rather than schools. This created a problem for Ya-Lin. Due to the lack of accessible equipment in school, Ya-Lin had to wait for her younger sister to attend the same primary school with her. By doing so, her younger sister could help her use the toilet.

As mentioned in Chapter Two, Thomas (1999; 2004) developed a social relation approach to theorise the relationship between impairment effect and disability. In Thomas' view, impairment effect does not cause disability, but it serves as the raw material upon which disability works. The following examples show that the effects of physical barriers on disabled people vary in terms of the level of impairment. Participants who have relatively severe physical impairment may experience greater difficulties than those who have with mild or mediated physical impairment. This suggests that people with severe physical impairment are more likely to experience exclusion in school due to lack of accessible environments, and this leads to their dependence.

For example, the physical environment might not be an issue for Hui-Ping or Mei-Zhu who could walk without using assistive devices. Conversely, for those who had relatively severe levels of impairment, they might face greater problems caused by the disabling environment. For instance, lack of accessible equipment was a problem for Li-Hua. She walked on crutches and this made it difficult for her to manage steps. The experience of Ya-Lin was similar. She could not manage the long distance from her classroom to the toilet and needed to depend on her sister to take her.

The school did not make adjustments for disabled students. My classroom was on the second floor. There was a long distance from my classroom to the toilet. My sister studied in the same school as me, she carried me on her back to the toilet (Ya-Lin).

Kitchin and Law (2001) argue that the lack of provision of accessible public toilets profoundly undermines the dignity of disabled people. Squat toilets were prevalent in Asian countries such as Korea, Japan, China and Taiwan (Chang,

2014). Several participants mentioned that their schools did not have pedestal toilets and this made them difficult to use. Three participants indicated that they had to withhold urine due to lack of accessible toilets. Xiu-Zhen found it hard to ask classmates to help her use the toilet. She often withheld urine for hours in school and this caused some health problems. Similarly, Shu-Fen described how she had to withhold urine for several hours because she felt embarrassed to ask for help from others.

It was painful to withhold urine for four hours, particularly when you drank too much water in the morning. I would ask for help from my teacher take me to the toilet when I could not endure it any more (Shu-Fen).

Skär and Tam (2001) explored the relationship between disabled children and adolescents and personal assistants in school. The research indicates that most disabled children and adolescents found it difficult to ask their personal assistants to help them with intimate matters such as visits to the toilet or the shower. In Taiwan, personal assistance schemes for disabled people have just been developed over the past few years. The examples discussed above show that a lack of accessibility leads to the creation of dependency for disabled people. Most of the participants had to depend on teachers, classmates or family members to help them manage daily tasks in intimate situations, which affected their privacy and dignity.

As mentioned, public transport was underdeveloped during the 1960s. At that time, it was common to see children with mobility difficulties having to give up study due to poor transportation (Huang, 2010). Transport services for disabled students were first addressed in the Special Education Act in 1984. According to the Act, the local authority was obligated to provide transport services for disabled children to commute to school (Legislative Yuan, 1984). Five participants mentioned that they faced problems that hindered them from commuting to school. Li-Hua studied in a primary school near her home. Her mother and sister had to take her to school by carrying her on their backs. Likewise, Xiu-Zhen mentioned that her parents took her to school every day. Sometimes she had to wait for hours because her parents were busy with work.

As mentioned in Chapter Two, social class can be a factor that exacerbates and modifies the experiences of disablement (Vernon, 1999). Yeo and Moore

(2003) argue that poor families who do not have sufficient resources to support their disabled children are more likely to see their children excluded from education. The following examples demonstrate that parental economic status significantly influenced the educational opportunities available to the participants. For instance, Yu-Lan never completed any formal education. Her father was the sole breadwinner for her family and could not afford a car. Irregular shift work made it difficult for Ya-Lin's father to take her to school. In contrast, Hui-Ping's parents successfully ran small businesses. She did not have problems travelling from home to school. She chose to study in a good school far from her home.

My parents took me to school by motorcycle every day. If my parents were busy, they would ask help from employees in our factory to take me home (Hui-Ping).

In Hui-Ping's case, these employees are recognised as 'extra manpower', able to share her parents' responsibility of taking her to school. Similarly, Mei-Zhu's father was a military officer. She studied in a primary school with a good reputation. These participants' accounts show that their social class position was a privileged status that enabled them to overcome barriers to education. Next, I focus on the gendered experiences of participants in school.

### **5.6.2 Gendered Experiences of Girls with Polio in School**

Disabled women are often perceived as unattractive, because they cannot meet socially constructed standards of beauty (Fine and Asch, 1988; Begum, 1992; Shakespeare et al., 1996). Goffman (1968) indicates that a stigmatised person might adopt a 'passing' strategy to conceal their stigmatised identity in order to look as 'normal' people do. A study conducted by Campling (1979) indicates that some disabled women adopt this 'passing' strategy to hide the visible signs of their impairment. Similar findings can be seen in the present study. The following examples show that some participants were subject to dominant notions of beauty and adopted 'passing strategies' to manage their body images. In Taiwan, schools emphasise the similarity and discipline of students. Most students are required to wear uniform (Yi and Wu, 2004). For example, Shu-Fen felt embarrassed to show her impaired leg in public and

tended to hide her impaired limbs by wearing trousers. She asked permission from her teacher to wear trousers to conceal her leg. The experience of Xiu-Zhen was similar. She often wore trousers to cover her impaired leg in school. The strategy of 'passing' can also be seen in this example of Xiu-Zhen having her photograph taken.

I cared about my physical appearance very much when I was a child. When I was having a picture taken, I always removed my crutches and avoided showing my legs. This made me look like a normal person (Xiu-Zhen).

Xiu-Zhen and Shu-Fen's experiences show that they were subject to socially constructed norms of ideal body and experienced 'internalised oppression' (Mason, 1990; Reeve, 2004). They internalised the standards of the ideal body and perceived their own bodies as unattractive. As a woman with polio myself, I have a similar experience to these participants. I wore trousers to conceal my legs in school. However, hiding my impaired leg did not make me feel 'normal'. I was the only student who wore trousers in summer when all the other students wore skirts, so I still looked different from other able-bodied students. Previous studies indicate that disabled women may develop a negative sense of self when they use assistive devices (Morris, 1989; Lonsdale, 1990; Taub et al., 2003). A similar finding can be seen in Hui Ping's experience. Hui-Ping's case shows that the use of an assistive device significantly changed her body image. Leg braces were recognised as a threat to her femininity and needed to be concealed.

I used to wear skirts when I was a little girl, my mum always bought me beautiful skirts. Since I wore leg braces, I did not like to wear skirts. I felt it was ugly to show my leg braces out (Hui-Ping).

Morris (1989) investigated the experiences of women with spinal cord injury. The results found that what disabled women choose to wear depends on their assessment of whether trousers or skirts are easier for them to get in and out of a wheelchair, and also how they feel about showing their legs. In the present study, some participants mentioned that their choices of what to wear were

related to convenience. For instance, Shu-Juan described that it was easier for her to wear skirts to manage daily tasks.

I didn't have any problem with wearing skirts, it was convenient. Putting the trousers over my leg braces was so much work. It made it difficult to use to the bathroom (Shu-Juan).

However, Shu-Fen's case shows that she had to make a compromise between physical appearance and convenience when choosing what to wear. Shu-Fen often wore trousers in school, but had to wear skirts during her periods. Wearing skirts made it easier for her to manage her menstruation. However, this created a problem for her. In wintertime, she was the only student who wore a uniform skirt when all the other students wore trousers. This made her feel embarrassed because everyone would recognise that she was on her period.

I had to wear skirts during my periods, this could be easier for me to manage menstruation. But when I wore skirts in wintertime, everyone knew I was on periods. It just made me feel very embarrassed (Shu-Fen).

Previous studies have paid much attention to the menstrual management of women with learning difficulties (Grover, 2002; Atkinson et al., 2003), and a few studies explore menstrual management of women with physical impairment (Campling, 1979; Morris, 1989). Three participants mentioned that they experienced difficulties dealing with menstruation in school. In Taiwan, the first sex education scheme in compulsory education was implemented in 1968. Secondary school students were required to take a health education course (Yu, 2004). The sex education policy implied that sex education should be provided to secondary school students who experience sexual development. Nevertheless, the sex education policy failed to acknowledge the experience of disabled children who are often perceived as having 'delayed' life transitions. For example, Hui-Ling and Shu-Fen delayed school entry due to medical treatment. They experienced physical maturity earlier than their younger classmates. Hui-Ling started her period during the senior years of primary

school. She did not have knowledge of menstrual management and this made it difficult to deal with her first period. Hui-Ling's case shows that social policies were underpinned by the concept of normal course of life, and profoundly overlooked diversity in the experiences of disabled children.

Campling (1979) indicates that menstruation presents an extra problem for disabled women, particularly those who use wheelchairs or have restricted use of their hands. This suggests that impairment effects might restrict disabled women from dealing with periods. However, in some cases disabled women face problems managing their periods due to a lack of appropriate sanitary equipment and inaccessible environments. As mentioned in Chapter Two, a study by Rousso (2004) shows that lack of accessible toilets in schools can be a particular problem for disabled female students, especially when they need someone to help them deal with their period. She-Fen's school did not have accessible toilets, and thus she needed someone to help her deal with periods. She mentioned that it was difficult to find someone to help her because of social stigmas attached to menstruation. Menstruation is an unspoken secret among women in Taiwan. Menstrual blood is seen as dirty and needs to be avoided (Chiang, 2009). For example, women are not allowed to attend a temple or funeral during their periods, as it is disrespectful to god and to the deceased (Lai, 2003). The social stigma of menstruation made it more difficult for She-Fen to seek help from others.

When I asked for help from my classmate, she always avoided me. She told me her mother did not allow her to help me, because women's period blood was dirty (Shu-Fen).

Shu-Fen's accounts show that she experienced multiple oppression caused by the interaction between disability and gender (Stuart, 1993; Vernon, 1999). Lack of accessible toilets made it difficult for She-Fen to manage her periods and she needed to rely on someone for support. Meanwhile, she experienced the social stigma of menstruation, which hindered her from seeking help from others. This suggests that the multiple oppression experienced by disabled women varies according to cultural contexts. Next, I explore the participants' experiences of physical education.

### 5.6.3 Experiences of Physical Education

According to the 'Primary and Junior High School Act', primary and junior high school education is aimed at the moral, cognitive, physical, social and aesthetic development of citizens (Legislative Yuan, 1979). Physical education (PE) is a compulsory subject in primary and secondary education in Taiwan. However, educational institutions failed to recognise the needs of disabled students in physical education. Several respondents mentioned that they were excluded from PE class. Hui-Ling often stayed in the classroom because she did not need to participate in PE class. Similarly, Shu-Juan indicated that disabled students did not have PE class like her non-disabled peers in her school.

Yi-Jun and Hui-Ping's cases show that schools did not consider the needs of disabled students in PE class. They were often left alone in the classroom when other students went to PE class. They commonly mentioned that they were often assigned work to do in the classroom when other children went to PE class, which was not relevant to study. For instance, Yi-Jun had to take responsibility for watching the other students' belongings in the classroom. Similarly, Hui-Ping was asked to write a classroom diary when she stayed in the classroom.

I stayed in the classroom when everyone went to PE class. I had nothing to do, then the teacher asked me to write down everything that happened in our class. I did not know why I needed to do it (Hui-Ping).

In addition, the absence of PE class may have influenced the disabled children's academic career development. As mentioned in Chapter Two, in terms of a life course perspective, previous life events have a significant influence on subsequent life events (Hareven and Masaoka, 1988). Huang (2010) indicates that disabled students often have poor results in PE class and this undermines their potential to attend good schools when academic performance is required. For instance, Shu-Juan got low grades in PE class in senior high school, and the poor results affected her overall academic performance. She was not able to apply to a good university due to this low academic performance.

The most unfair thing was that PE was one of the required courses,

and the place for the class was not accessible. I was never able to go to the class. Yet, the teacher gave me a passing grade. That low grade dropped my average result of all the grades and greatly affected my choices of graduate school in the US (Shu-Juan).

However, three participants had positive experiences of PE class. Li-Hua studied in a mainstream primary school. She was able to play ball games with other non-disabled students. This example shows that disabled students are able to be included in PE class provided there is appropriate support.

My gymnastics teacher encouraged me to attend PE class. I enjoyed playing volleyball with my classmates. They picked up a ball for me, and then I used my crutch to hit the ball. When we played dodge ball, the teacher let me serve the ball. I did have much fun in PE (Li-Hua).

Barton (2009) argues that inclusive education does not aim to train special teachers or develop special teaching for disabled students. In contrast, good teachers in inclusive education are those who are capable of using their creative and imitative skills to meet the diversity of pupil's learning requirements. Li-Hua's teacher made adjustments to game rules in order to include disabled students in the PE class. In addition, support from non-disabled peers is a crucial factor that enables disabled students to participate in PE class (Goodwin, 2009). In Li-Hua's case, her classmates provided support for her and facilitated successful engagement in the PE class.

Although special schools are often criticised for separating disabled children from the mainstream learning environment, some disabled children have positive experiences in special schools, such as an accessible curriculum, peer support and specialist teaching (Hendey and Pascall, 2001). Xiu-Zhen's account shows that disabled students can have positive experiences of PE classes in special schools. Fitzgerald and Kirk (2009) suggest that experiences of participation in PE affect the self-identity of disabled students. Xiu-Zhen described how her participation in PE class made her feel like she was 'back to the normal world'.

I had the chance to play softball here. Although we could not run, we



went to bases by crawling. We used our crutches to touch the base. We were able to participate in different kinds of ball games, such as badminton, softball, baseball, and even races. I felt like I was back to the normal world (Xiu-Zhen).

In this section, these examples underline a variety of experiences of PE for the participants. It can be argued that the problems that restrict disabled students from attending PE class are usually caused by prejudicial attitudes and insufficient support for disabled students, rather than the impairment itself. Disabled students could be included in PE class with appropriate support.

## **Summary**

This chapter examines the barriers and inequalities experienced by women with polio during their childhood. The participants' experiences show that cultural understanding of disability stigmatised disabled children and their families, and influenced parents to develop negative attitudes toward their children. The participants experienced medicalisation during childhood. Most were taken to hospitals or rehabilitation institutions without being asked, and underwent numerous painful surgeries and therapies. Furthermore, the education system neglected the needs of children with polio. Participants experienced environmental barriers and discriminatory attitudes that hindered them from accessing education equally. The experiences of the participants in school were gendered. Some participants were subject to social standards relating to women's body image, which undermined their psycho-emotional wellbeing. Others experienced multiple oppression based on gender and disability, and found it difficult to get support in school. After exploring the childhood experiences of the participants, the next chapter focuses on their experiences in their youth.

## **Chapter Six**

### **Transition to Adulthood: Career Choice and Relationships of Young Women with Polio**

#### **Introduction**

Youth is a transitional stage between childhood and adulthood. It is a subordinated category, like childhood, in which people are perceived as incapable of making crucial decisions and in need of protection from their tendency to act impulsively (Furlong, 2012). Children and young people are perceived as incomplete adults who need to be educated in order to become 'proper' citizens, who are able to exercise their rights, duties and responsibilities in an acceptable way (Gordon and Lahelma, 2002: 4). Peer relations are important for young people. Friendship groups provide psychological support for young people and influence their behaviour and personalities (Pahl, 2000). In addition, peer relations offer an opportunity for young people to establish intimate relationships with others (Furlong, 2012).

In Taiwan, the legal definition of youth is aged between twelve and eighteen. Education is seen as the most important social value in Taiwanese society. Children's educational achievements bring honour and prestige to their families (Thornton and Lin, 1994). After graduating from secondary school, Taiwanese adolescents have to pass two highly competitive entrance examinations, the examination for senior high school and the examination for college and university (Yi, 2011). Therefore, most Taiwanese teenagers spend large amounts of time studying in school in order to successfully pass these entrance examinations. Most of them have very limited time for social life and recreational activities (Yi and Wu, 2004).

In Taiwan, young people are discouraged from developing intimate relationships. In the post-war period, dating and courtship were not common for young people. Marriage of young people was mainly arranged by the parental generation. Even though young people did date, dating was often with the specific aim of marriage (Marsh and O'Hara, 1961). For the last few decades, the transformation of marriage has been influenced by Western culture,

meaning that the importance of love, romance, dating and courtship has been emphasised by young people. However, this does not necessarily remove parents from supervision of their children's courtship activities (Thornton and Lin, 1994).

In short, youth is a period in which young people have to deal with multiple challenges to make the transition to adulthood, including the establishment of friendship, formation of intimate relationships, preparation for future career etc. Previous studies demonstrate that young disabled people face social barriers that hinder them from moving into adulthood (Morris, 1999; Beresford, 2004; Feldman, 2004; Riddell, 2009). Lin (1998) investigated the transitional experiences of young disabled people in Taiwan and found that young disabled people are less likely to find a job after leaving school compared to their non-disabled counterparts. This chapter explores the participants' experiences in their teenager years and early twenties. Firstly, it examines the factors influencing the career options of the participants, with particular reference to post-school education and vocational training. Secondly, several barriers experienced by the participants in the establishment of intimate relationships are discussed.

## **6.1 Career Choice for Young Women with Polio**

Morris (1999) indicates that social policies and service provision fail to help young disabled people move into adulthood. Many young disabled people do not have accessible information about their options, choices or possibilities for the future, and face barriers to forming friendships. A similar finding can be seen in a study conducted by Stalker (2002), which shows that young disabled people's choice of higher education is constrained by physical access, attitudinal barriers and lack of resources. Transition services, that provide support to facilitate the transition to adulthood, are important for young disabled people, including service continuity from childhood to adulthood and planning for adult life (Beresford, 2004). In Taiwan, transition services are first mentioned in the 'Physically and Mentally Disabled Citizens Protection Act 1997'. Article 42 indicates that related departments and local authorities should create career change and connection plans to provide continuous services for disabled people (Legislative Yuan, 1997). In this context, the women I interviewed, born between 1955 and 1965, received little social support to help them move into adulthood.

During the 1970s, the majority of secondary school students continued in post-school education to senior high schools or vocational high schools, with the minority of students choosing a vocational route (Rubinstein, 1999b). The participants' experiences are similar, with most continuing into post-school education. Seven participants went to senior high school or vocational high school, while two participants left school and participated in vocational training programmes, and one participant never completed primary education. The next section examines the factors influencing the participants' career choices.

### **6.1.1 Determinants of Career Choice**

Several studies indicate that family socioeconomic status significantly affects young disabled people's initial career development (Newman, 2005; Lindstrom et al., 2007). Riddell (2009) suggests that young disabled people who come from socially advantaged backgrounds are more likely to continue in higher education and have better life chance than others. As mentioned in Chapter Four, disabled people received little support from the government before 1980, as disability policy was absent. Without social support, family resources were a crucial factor affecting individuals' career choices. The following examples show how family economic status profoundly influenced the participants' career choices.

As discussed in the previous chapter, some participants could not continue with studies due to travelling problems (see section 5.6.1). Ya-Lin could not go to senior high school because her parents were not able to take her to school. She mentioned that she was encouraged to learn fortune-telling by her relatives. In Western culture, disabled people are often misrepresented as 'super cripples' who have special abilities or talents for doing specific things (Barnes, 1992a). Miles (2000) explores the meaning of disability in Chinese culture, and finds that people believe that disabled people have special talents for telling individual's fates, particularly those with visual impairment. Some disabled people are able to make a good living by fortune-telling. Similarly, in Taiwanese culture, disabled people are encouraged to be fortune-tellers, because people believe they have a talent for it. Ya-Lin described that she was encouraged to learn fortune-telling, but her parents could not afford the expense of fortune-telling training.

Some relatives encouraged me to learn fortune telling, but my parents

couldn't support me to learn it. They had five kids to feed, it was not possible to put the entire resources on me (Ya-Lin).

In Ya-Lin' case, transition services were not available, and her parents could not provide financial support for her to learn vocational skills. Consequently, she stayed at home for two years and just 'did nothing'. This made her feel worthless.

I had nothing to do after I left school. I stayed at home all day. That was the worst time in my life. My life was meaningless, I felt like I was a useless person (Ya-Lin).

Three participants however, reported that they did receive financial support from their families to continue with their education. Feldman (2004) indicates that wealthier and more highly educated parents are more likely to provide financial resource for young disabled people to pursue education. For example, Shu-Juan's parents successfully ran an estate business. Shu- Juan had severe physical impairment. Polio inflected her legs and one hand. Her parents could afford to hire a chauffeur to drive her to school. She was able to pursue her master's degree in the United States after she graduated from university. She-Juan's case shows that social class can be a privilege that modifies the experiences of disablement (Vernon, 1999). Sufficient financial support from her family enabled her to fulfil her educational aspirations.

Previous studies show that birth order is a factor affecting the educational opportunities of children (Travis and Kohli, 1995; Black et al., 2005). If there is a large gap in sibling ages, the younger children may find it easier to receive financial support for their schooling as their parents may be closer to the peak of family economy (Behrman and Taubman, 1986). Shu-Fen's case represents that the availability of family resources is not only related to the socioeconomic status of the family, but is also affected by birth order. Shu-Fen was the youngest of six children in her family. Her parents could provide financial support for her to continue with her study, because all the other children had left school.

I was the youngest child in my family. When I entered a senior high school, my brothers and sisters had left school. My parents could have more money to pay my tuition (Shu-Fen).

As mentioned in Chapter Two, negative parental attitudes towards their disabled daughters may exclude them from accessing education or vocational training (Maya Dhungana, 2006). Four informants noted that their parents' attitudes influenced their career choices. As mentioned in Chapter Four, the 'boy preference' belief is deeply rooted in Taiwanese culture. Traditionally, daughters are recognised as temporary family members who join their husbands' families after they get married, and therefore parents are often not willing to support the education of daughters (Thornton and Lin, 1994). However, in the present study, the participants' accounts did not show the impact of gender difference on education. On the contrary, some participants mentioned that their parents encouraged them to continue with study. For example, Xiu-Zhen's parents encouraged her to pursue higher education, although her family was not wealthy.

My mum was illiterate. She thought that education was very important for children. She encouraged us to get the higher academic degree. We were not rich, sometimes my parents had to borrow money to pay for my tuition fee (Xiu-Zhen).

As mentioned in the previous section, in Taiwanese culture, people believe that disabled people have special talents for fortune-telling. Such a stereotype of disabled people restricted Hui-Ling from pursuing her educational aspirations. Hui-Ling's mother did not allow her to continue with study, and expected her to be a fortune-teller. However, Hui-Ling's case shows how she developed a strategy to regain control of her life under resource constraints. Without her mother's financial support, she worked at a part time job to pay her tuition, doing quality checking of camera lenses at a local factory. In order to get this job, she negotiated with the employer by reducing her salary.

I begged the employer to offer me a job because I needed money to

pay my tuition. I told the employer I was willing to reduce my salary if he could offer me a job (Hui-Ling).

As mentioned in Chapter Two, human agency is an essential factor in shaping an individual's life course trajectory. This means that human lives are constituted of a series of choices. People are able to make their own decisions creatively under constraints (Elder, 1994). Previous studies show that disabled women are more likely to be employed in low-paid and low-skilled jobs and experience wage discrimination in employment (Baldwin and Johnson, 1995; O'Hara, 2004). In Hui-Ling's case, accepting a reduced salary might be seen as a strategy by her to get a job and this enabled her to continue with study. This example shows how a disabled woman responded to resource constraints and found a solution to regain control of her life.

As mentioned in Chapter Two, human lives are embedded within social relationships with family members and friends, throughout their course (Elder, 1994). Personal choices are profoundly affected by intergenerational relationships (Hareven, 2001). In Taiwanese society, family relationship is strictly regulated by Confucianism. One central feature of Confucianism is 'reciprocity' in social relations. This means that parents have an obligation to look after their children, and children need to return the gifts and services to their parents when they grow old (Holroyd, 2003). In this context, it is common to see disabled children being overprotected by their families, because the family has a strong obligation to look after the disabled individual (Lin et al., 2006). Shu-Fen's case represents that family ethics were a barrier to her fulfilling her vocational aspirations. Shu-Fen learned embroidery skills at an embroidery studio. She planned to run an embroidery studio of her own, but she faced strong opposition from her brother.

My brother did not allow to me to run my own business. Personal reputation was very important for him. He was afraid that people would judge him that he couldn't look after his disabled sister (Shu-Fen).

This example shows a tension between an individual's career development and the moral duty of the family. For Shu-Fen's family, taking care of a disabled child was not only for the child's wellbeing, but also for the family's reputation.

In this situation, disabled people are expected to rely on their families and this made it more difficult for them to fulfil their career aspirations.

In addition to family members, other significant adults' attitudes can influence disabled young people's career choices. As mentioned earlier, the life of Taiwanese teenagers is typically highly stressed. They spend much time in study in order to pass highly competitive entrance examinations (Yi and Wu, 2004). Several participants mentioned that they were under tremendous pressure to prepare for entry examinations during the senior years of secondary school. However, the situation was different in special schools. Xiu-Zhen and Shu-Juan studied in the same secondary school for children with physical impairment. They commonly mentioned that their teachers had low expectation of their academic performance. Xiu-Zhen mentioned that disabled students were not expected to develop their academic career. She said that academic competition was not a top priority in her school, and she did not feel pressure to pursue academic achievement.

The experience of Shu-Juan is similar. Shu-Juan's example shows that the curriculum in special schools focuses on vocational skills training rather than students' academic development. She described that she was required to attend vocational training, which was not required in mainstream school. This created a problem for Shu-Juan. She did not have time to prepare for the entrance examination, and consequently got a bad grade. As mentioned in Chapter Two, the life course approach emphasises the cumulative effects of earlier events on later experiences over the entire course of a life (Hareven and Masaoka, 1988; Elder, 1994). The poor grade in the entrance examination restricted her opportunity to attend a good senior high school.

In the special school, we were not expected to continue with our education. We were thought to be only good as an accountant, or doing other crafts, such as fixing watches. We had to take accounting and typing classes, which were not required in other secondary schools at all. The emphasis of the curriculum was on vocational training not on taking the high school exam, which resulted in my poor grade when taking the high school exam. I only got into the second best high school (Shu-Juan).



These examples demonstrate that young disabled people in special school did not have equal opportunities to fulfil their educational aspirations, compared with their non-disabled counterparts. Riddell et al. (2001) indicate that many vocational training programmes place low expectations on young disabled people, preparing them for less skilled and less marketable jobs. Shu-Juan's example shows that these vocational training courses, such as handicraft-making and watch-repairing, are for less marketable jobs. This could be problematic for disabled people because they are likely to be channelled towards less-skilled and lower-paid jobs. The following section explores the participants' experiences of subject choices in post-compulsory education.

### **6.1.2 Subject Choices in Post-School Education**

As mentioned in Chapter Four, Taiwan's industrialisation began in the late 1950s. The new industries demanded more educated workers, and this led to the development of vocational high schools during the 1970s. By the mid-1970s, the number of students in senior vocational schools exceeded the number in senior high schools. The experiences of the participants reflect this change. In the present study, six participants chose to study in senior vocational school, while only one went to senior high school (Rubinstein, 1999b). Lindstrom et al. (2012) suggest that career aspiration of young disabled women is often constrained by social norms and traditional gender role expectations for women. Peng and Xiong (2010) examine gender's impact on young people's subject choices in Taiwan. The research shows that female students have a preference for business-related subjects, such as accounting and financing. One reason is that many types of office jobs in the accounting field are perceived as suitable for women. Similar findings can be seen in the participants' experiences, which were profoundly affected by gender stereotypes. Four participants chose accounting, while one studied dress-design. Li-Hua majored in accounting, and mentioned that there were no male students in her class. Hui-Ping studied clothes design, which was a popular subject for female students.

At that time, most girls would choose to study business or home economics, such as clothing making and household management (Hui-Ping).

Lindstrom et al. (2004) explore career options of women with learning difficulties. They find that some of their participants were aware of the limitations due to their learning difficulties, and adjusted their goals for career development. The following examples show that participants' career options were also influenced by their functional limitations. In Li-Hua's case, she did not choose international trade because she assumed that she might not be able to manage to travel frequently for business. Hi-Ling's concern was similar. She chose to study statistics because it was not a physically demanding job.

I thought this job would not demand too much physical strength, I could often stay at the office and deal with figures. A financial administrator needed to go to the bank frequently. Travelling could be a problem for me (Hui-Ling).

These examples show that participants have an awareness of their functional limitations, and this might prevent them from choosing the subject they really wanted. As a woman with polio myself, I had similar experiences. I did not choose to study business management, because I thought that I could not manage business trips. Thus, I studied social work, partly because I was interested in it, but also I thought it would be easier to find a job in organisations for disabled people. It can be seen that the participants' accounts represent thinking using the individual model of disability, which focuses on the functional limitations of disabled people, rather than the barriers disabled people experience in the work environment. It cannot be denied that impairment effects may lead to restriction of activities (Thomas, 1999), but it is necessary to recognise that the problems disabled people experience in workplaces are not simply caused by impairment itself, but also by disabling environments and prejudicial attitudes (Barnes, 1992c).

The following cases show that parental attitudes and other significant adults' reactions had a great impact on the participants' subject choices. Feldman (2004) argues that parents with high socioeconomic status may provide more support for young disabled people to reach their potential, but sometimes they can be overprotective and discourage their children from taking risks. Parental protectiveness can be problematic for young disabled people, because they might not be given the opportunity to have fun, take risks or to learn from their mistakes as their able-bodied counterparts are (Stalker, 2002). Mei-Zhu's case shows that parental protectiveness hindered her from fulfilling her educational

and vocational aspirations. Mei-Zhu came from a wealth family. Her father was a military officer, and her uncle arranged a place for her in a military factory. Although Mei-Zhu was interested in radiology, she had no choice but to study electric science in order to meet the job requirements of the position. The experience of Shu-Juan was similar. Shu-Juan was a Christian, and was determined to be a counselling psychologist. However, her educational aspirations were denied by a Christian counsellor.

I decided to go into the field of counselling in my graduate study, but was quickly discouraged by a Christian counsellor. She said if I am disabled, I can't understand what the able-bodied people are experiencing. I felt that whichever way I turned, I was forced to give up (Shu-Juan).

In this section, the examples have shown that the participants' subject choices were influenced by the interaction of gender and disability. On the one hand, socially constructed gender norms constrained their subject choices, while, on the other hand, low expectation and prejudicial attitudes towards young disabled people restricted them from pursuing their educational interests. Next, I explore the interviewees' experiences in vocational training programmes.

### **6.1.3 Experiences of Vocational Training**

As mentioned in Chapter Two, disabled women, like non-disabled women, experience gender segregation in vocational training and employment (Russo and Jansen, 1988). In the present study, the women's accounts note that gender stereotyping influenced their experiences of vocational training. As mentioned in Chapter Four, Taiwan's industrialisation began in the late 1950s and led to rapid development of intensive-labour industries such as electricity, fertilisers and textiles. The development of the textile industry established a commercial supply chain, including the synthetic fibre industry, clothing material industry and garment industry (Chen, 2008). The embroidery industry expanded with the rise of the garment industry, achieving its height during the 1990s (Lin, 2014). Traditionally, embroidery is an important skill for Chinese women. 'Nvhong' is a type of Chinese folk art, based on women's needlework-related skills such as weaving, sewing, embroidery and pattern cutting. A woman who is good at needlework is recognised as a good wife (Taiwanese Women, 2010). During the 1970s and 1980s, the development of the garment

industry and embroidery industry in Taiwan created a significant number of job opportunities for women (Lai, 2012). The growth of the embroidery industry created an opportunity for some participants to learn occupational skills. Yu-Lan and Shu-Fen both mentioned that they went to private-owned embroidery studios to learn hand embroidery skills.

I learnt embroidery skills from an experienced master in an embroidery studio. The studio offered meals and accommodation for apprentices. The master employed several staff to make needlework and handicraft products (Shu-Fen).

The impact of gender can also be seen in vocation training programmes for disabled people. As mentioned in Chapter Four, vocational training services for disabled people were developed in the 1980s. These vocational training programmes were mainly provided by vocational training centres, social welfare charities or health care organisations (Tsai and Ho, 2010). Previous studies demonstrate that disabled women are more likely to enrol in training courses such as office work, childcare, tailoring or handicraft making, which are perceived as appropriated for women (Maya Dhungana, 2006; Agnihotri and Patel, 2015). Similarly, gender segregation is embodied in vocational training programmes in Taiwan. Chen (2009) argues that many vocational training programmes are affected by gender stereotyping, such as hairdressing, handicrafts, dressmaking, and cleaning. These programmes may improve women's work capacity, but most have low economic value. For instance, Ya-Lin participated in several vocational training projects run by government agencies. Ya-Lin's account noted that gender difference existed in vocational training programmes for disabled people.

I went to a vocational training centre that only opened for female trainees. I met my husband in a training centre. He was doing the electric class, and I took the sewing class (Ya-Lin).

In addition to the impact of gender, vocational training programmes failed to recognise the needs of people with different levels of impairment. People with

certain types of impairment were only given access to certain types of training based on their functional condition. For example, it was common to see that people with mobility impairment learn computer skills because they can sit (International Labour Office, 2013). In the past, most training programmes in Taiwan were provided for people with physical impairment, particularly those who walked with crutches, while the needs of people with sensory impairment were often overlooked by service providers (Hou, 2011). Such stereotypical thinking could be seen in many vocational training programmes, which offered courses such as sewing, clock repair, shoe repair and stamp making (Tsai and Ho, 2010). These training programmes all demand physical ability of hands. In this situation, those who had severe impairment were more likely to be excluded from vocational training services. For example, Ya-Lin did not have much physical strength in her right hand. She experienced difficulties dealing with the requirements of the dressmaking programme.

I took a dressmaking training course. I did not have physical strength in my right hand, it was difficult for me to draw a circle on clothing materials. I considered taking a shoe making course, but it also demanded physical ability in the hands (Ya-Lin).

As mentioned in Chapter two, Thomas (1999) suggests that it is important to recognise the impact of impairment effects on disabled people and explore how the interaction between impairment effects and disability shapes the life experiences of disabled people. In Yan-Lin's case, it is clear to see that the vocational training programme did not acknowledge the impact of impairment effects on disabled people and failed address their needs. Having dealt with several issues related to the career choices of the participants, the next section discusses the participants' experiences in the establishment of intimate relationships.

## **6.2 The Development of Intimate Relationships**

According to Article 23 of the CRPD, disabled people have equal rights to marriage, family, parenthood and relationships (United Nations, 2006). The formation of intimate relationships is an important issue for young disabled people. Wiegerink et al. (2006) review existing literature about sexual relationships of adolescents with physical impairment and indicate several

barriers that hinder them from developing sexual relationships, including parental attitudes, peer relations, transportation and dating activities. In Taiwan, the sexual rights of disabled people are overlooked by existing disability policy and service provision. According to Article 50 of the 'Persons with Disabilities Protection Act 1997', municipal and county competent authorities must provide marital and reproductive health counselling for disabled people to improve their social participation chances. However, existing services solely concentrate on sex education and the genetic health of disabled people, while their needs relating to intimate relationships, parental education, and relationship and marriage counselling remain underrepresented (Liang, 2015). In the present study, the majority of participants mentioned that they experienced difficulties in the establishment of intimate relationships. More detail is given in the following sections.

### **6.2.1 Social Exclusion and Friendship**

As mentioned, peer relations are important for young people. Peer relations offer opportunities for young people to establish intimate relationships with others (Furlong, 2012). The majority of interviewees mentioned that their friends were supportive and helpful. Three participants indicated that they were excluded by their female peers and found it hard to maintain friendships. Physical appearance and relationships are common topics for young girls to talk about, while disabled girls are often excluded from such 'girl talk' (Prilleltensky, 2003). Campling (1979) indicates that clothing can be a particular issue for disabled women. Many disabled women may have difficulty finding clothes that can meet their needs, because some clothes are complicated and difficult to put on. Ya-Lin's case shows that the limitation of clothing choices made it difficult for her to join in the conversation with her female peers.

It was hard to me to find a common topic with my friends... I did not have too much choice of my clothes. I couldn't buy any clothes that fit. I usually picked up bigger size clothes so they could cover my body without being pulled up by the crutches. Those clothes were hideous (Ya-Lin).

Stalker (2002) indicates that young disabled people are often denied access to the settings where their non-disabled peers spend their free time, such as clubs and fast food outlets, due to poor transportation and prejudicial attitudes. Similar findings can be seen in the current study. Two participants mentioned that they could not go out with their friends due to a lack of equipment and inaccessible transportation. Adaptive scooters are a common form of vehicle used by disabled people in Taiwan. As mentioned in Chapter Four, the 'Regulations on Subsidisation for Medical Treatment and Auxiliary Appliances for Disabled People' was implemented in 1999. Disabled people receive subsidies for assistive devices and modified vehicles based on their economic conditions (Legislative Yuan, 1999b). Before the mobility scheme, disabled people received little transport support from the government. Ya-Lin described how she had to rely on her family to take her out, and this made it difficult to go out with her friends. In Taiwan group dating was a very common activity for young people that helped them meet their potential partners during the 1980s and 1990s. A group of male students and a group of female students in the same school or from different schools would organise a day out (Feng, 2016). Shu-Fen mentioned that she was often excluded from group dating activities due to a lack of appropriate vehicles and accessible transportation, and this reduced the opportunity for her to meet potential partners.

It was not easy for me to establish intimate relationships. My classmates were keen to participate in group dating activities. They usually went out with other male students by scooter or sometimes by bus. I could not join them, I was always being left out (Shu-Fen).

Yi-Jun's parents bought her an adaptive scooter and this enabled her to participate in many activities. Yi-Jun volunteered in several disability charities and attended some training courses. She made many friends and some were interested in her. Apart from the physical barriers, the following example shows how young disabled people experienced prejudice in specific social settings. In Western culture, night clubs are venues for young people to make friends and meet potential partners. Western culture significantly influenced Taiwanese young people's recreational habits during the 1980s. The number of dancing clubs such as disco clubs and music houses significantly increased in the 1980s in urban areas. In romantic films of the 80s, it was common to see well-

dressed young people met their partners in fashionable night clubs (Huang, 2009). Li-Hua went to a disco club with her friends. This case shows that such places were mainly created for able-bodied people. She described an embarrassing experience when someone invited her to dance.

When everyone was dancing in the pool I stood there, with my crutches aside, it is hard to tell I am disabled. A guy came and asked me to dance, but I rejected him. Then he went to ask my friend for the reason. He found the crutches next to me. He did not ask further and left (Li-Hua).

Shakespeare et al. (1996) indicate that people often assume that disabled people will 'stick with their own kind', which means that disabled people would form relationships with other disabled people. They argue that the reason is that disabled people face difficulties in establishing intimate relationships with non-disabled people. For example, disabled people and older people are more likely to be excluded from mainstream leisure activities due to environmental barriers and prejudicial attitudes. Consequently, disabled people usually participate in segregated recreation and this makes it more difficult to develop relationships with their non-disabled peers (Barnes, 1991). The examples discussed above demonstrate that the participants were less likely to have access to social activities, compared to their able-bodied counterparts. Due to social exclusion, several informants reported that they met their partners in specific activities for disabled people, such as vocational training programmes, institutions or recreational activities for disabled people, and most of their partners were also disabled.

In the present study, six women married disabled men, two women married able-bodied men, and two women never married. Five participants mentioned that they met their partners in vocational training programmes, one met her husband in a rehabilitation institution, and two met their partners in general social settings such as school or the workplace. For instance, Yu-Lan met her partner in a calligraphy class for disabled people. Similarly, Xiu-Zhen mentioned that she participated in some dating events for disabled people run by disability charities.



I attended group dating for disabled people. They asked us to play some games such as sharing one apple with another guy. I feel so uncomfortable about the games and of course I did not match with anyone during that time (Xiu-Zhen).

The assumption that disabled people 'should stick with their own kind' was embodied in blind dating customs in Taiwan. As mentioned previously, courtship and dating were not common for young people in the past. Marriage of young people was mainly arranged by their parental generation (Marsh and O'Hara, 1961). In Chinese culture, the purpose of marriage was to form strong social networks between families. The bride and groom were usually from families of comparable class, wealth, socioeconomic status and so on (Chu and Yu, 2010). In the process of blind dating, parents or professional matchmakers would carry out complex negotiations and look for suitable partners for their children (Thornton and Lin, 1994). The following cases illustrate how the assumption that disabled people should marry other disabled people affects participants' experiences of blind dating. Hui-Ping described that the matchmaker introduced several men to her, but most were disabled men. Some had severe physical impairment, and some had learning difficulties. The experience of Xiu-Zhen is similar. Xiu-Zhen's parents worried about her marriage and sought help from a matchmaker to look for a potential partner for her. The matchmaker introduced a man who was also disabled.

My mom told the matchmaker about my age, job and also that I had physical impairment. Then the matchmaker suggested someone who lived nearby who had a similar physical condition to me (Xiu-Zhen).

These examples show that disabled women had limited opportunity to choose their partners due to the social prejudice against disabled people. The matchmakers had an assumption that disabled people were inferior to able-bodied people, and so they must only marry other disabled people. This assumption can still be seen in Taiwan nowadays. A survey by a disability charity showed that 53 percent of non-disabled respondents believed that disabled people were more likely to establish relationships with other disabled people, while only 38 percent of disabled respondents agree with this assumption (Eden Social Welfare Foundation, 2015: n.p).

The participants' accounts show that they did not have equal opportunities to participate in social activities as their non-disabled counterparts, due to physical barriers and prejudicial attitudes. Most of the participants met their partners in specific settings for disabled people. It is necessary to mention that the discussion here does not imply that all the participants preferred to date able-bodied partners. Some of the participants did prefer to choose disabled partners (see section 6.2.3). Next, I discuss the attitudinal barriers experienced by the participants when they developed intimate relationships.

### **6.2.2 Attitudinal Barriers to Intimate Relationships**

As mentioned in Chapter Two, previous studies have shown that disabled women are often discouraged by their parents from developing relationships (Fine and Asch, 1981; Shakespeare et al., 1996). Similar findings are shown in the present study, as four of the respondents noted that their parents did not expect them to get married or have children. A study by Rousso (1988) found that some parents do not expect their disabled daughters to marry. Parents tend to offer their disabled daughters property, because they believe that would enable them to catch a man. The experiences of the participants in this study were different. Three respondents mentioned that their parents did not expect them to get married, and bought properties for them. Their parents assumed that no one would marry their disabled daughters, and thus they needed to offer their children a place to stay in the future. For instance, Li-Hua's parents did not expect her to get married and bought a house for her in her teenage years. Similarly, Shu-Fen came from a wealth family, and her parents tried to convince her not to get married by buying her a property.

My parents and brothers tried to persuade me not to get married. They told me that nobody would really want to marry me. My parents bought an apartment for me, so I could have a place to stay when I grew older (Shu-Fen).

As mentioned in Chapter Four, the ideology of 'boy preferences' is deeply rooted in Taiwanese culture. Traditionally, a son is obligated to continue a family's ancestral line, and has priority to inherit his parent's property (Gallin,

1984). A daughter receives dowries on marriage, but she cannot inherit her parents' property in equal measure with her brothers (Chen, 2000).

However, these examples show that having a disabled daughter might challenge this traditional belief. Disabled daughters are allowed to inherit property just like their male siblings. In Shu-Fen's case, she was able to inherit her parents' property in equal measure with her male siblings. Similarly, Li-Hua mentioned that she was the only daughter who could inherit her parent's property. Ingstad and Whyte (1995) argue that being disabled could be recognised as a political privilege, entitling one to financial support and a series of welfare services. This means that once a person is officially defined as a disabled person, she/he is able to access material resources and services. These women's accounts show that being disabled is not always negative in the specific context. On the contrary, it could be a privileged status that enabled the women to have access to family resources.

Yu-Lan mentioned that her parents did not expect her to get married, but the situation was different from the examples above. Yu-Lan's parents did not offer her property, but arranged for someone to look after her. In the past, Taiwanese people adopted a child for various purposes. If a family did not have a son, they may adopt a male child in order to continue the family line. Couples who did not have children and may adopted a child to look after them when they grew old (Chen, 2010). Yu-Lan's mother did not expect Yu-Lan to get married and worried that no one could look after her. Thus, Yu-Lan's mother persuaded her to adopt a child, and expected the child to look after her when she grew old.

My mum thought I could not have a happy marriage. Some people introduced men to me, but my mum always rejected them. People believe in bringing up children for their old age. My mum persuaded me to adopt a child. When the child grew up, he could take care of me (Yu-Lan).

White and White (1993) indicate that that people with physical impairment face prejudicial attitudes when they apply for adoption, because they are often perceived as incapable of parenting skills. As mentioned in Chapter Two,

disabled women are often stereotyped as 'unfit' for ideal motherhood and this assumption hinders them from becoming mothers (Grue and Lærum, 2002; Lewiecki-Wilson and Cellio, 2011). Yu-Lan mentioned that the adoption was not successful, because she was regarded as incapable of raising a child.

We contacted a couple who would like to place out their child, but they finally chose the other family. I did not have any advantages compared with them. I was a disabled women. I understood why the couple preferred to send their child to a 'normal family' (Yu-Lan).

These examples demonstrate that family itself could be a barrier preventing disabled women from establishing intimate relationships. In addition to parental attitudes, several interviewees indicated that they faced disapproval of their union from their partner's family, and this made it difficult to maintain a lasting relationship. As mentioned, in the past, the marriage of young people was mainly arranged by parents. Although young people have gained more control of their relationships and marriages over the last decades, courtship activities are still under the supervision of parents (Thornton and Lin, 1994). For instance. Yi-Jun was questioned by her partner's parents about whether she could have a child and manage a household.

In addition to the role of wife and mother, Taiwanese women are expected to be good daughters-in-law. Social expectations of being a good daughter-in-law have a great influence on Taiwanese women's lives. Traditional folk songs often portray a good daughter-in-law as a hard working woman, who has an obligation to take care of her parents-in-law (Horng, 2007). Chao and Roth (2000) investigated the experiences of Taiwanese women who provided care for their ageing parents-in-law, and found that most respondents agreed that taking care of parents-in-law was a way to display filial piety. Shu-Fen mentioned that her boyfriend's father was against their relationship because she was not qualified to be a 'good daughter-in-law'.

My boyfriend's parents knew I walked with crutches. They thought I was not capable to take care of them. His parents strongly disagreed with our marriage (Shu-Fen).

Similarly, Li-Hui met her partner in a vocational training course. She faced strong opposition from her partner's mother because she was disabled. As mentioned in Chapter Two, Reeve (2004) argues that the psycho-emotional dimension of disablism can be manifested in internalised oppression. This means that disabled people internalise the social prejudice held by the dominant group, and this makes them feel of lesser value or worthless. Li-Hua experienced internalised oppression and this undermined her self-esteem in relationships. She made a great effort to prove that she was capable of looking after a family just as a non-disabled women would. She ran a small restaurant to prove that she could manage things by herself and did not rely on others.

I ran a small restaurant on my own. I just wanted to prove myself to his mother, that I was able to make money and support my family. I could do everything like a non-disabled woman did. I had to be tough (Li-Hua).

Although Li-Hua made a great effort to prove herself to her boyfriend's mother, she could not maintain their relationship. As discussed in Chapter Two, disabled men can 'escape' from the negative roles of being a disabled person by reinforcing their male characteristics, whereas disabled women are less likely to have such options, because traditional women's roles are perceived as dependent and passive, which are similar to the perceptions of disabled people (Fine and Asch, 1981). For example, Wilson (2004) indicates that men with polio are often encouraged to 'fight polio like a man'. The culture value of masculine traits such as strength and toughness, often play a part in the struggle to recover muscle function. Men with polio can reconstruct a sense of manhood when physical and psychological recovery is achieved.

However, the situation is different for disabled women. As discussed in the previous chapter, in Taiwan independent culture highlights the self-reliance of individuals. Disabled people are often told to do things on their own (see section 5.4.2). In Taiwan's patriarchal culture, women are perceived as inferior to men. According to Confucianism, a Chinese woman should follow the doctrine of the 'three obediences and four virtues'. The 'three obediences' are that women should obey their father in childhood, rely on

their husband after marriage, and depend on their son after their husband's death. The 'four virtues' refer to good appearance and manner, ability in domestic work, language and self-respect (Chan and Leong, 1994: 273). In this context, being 'tough' and 'independent' might not be favourable personality traits for women. Li-Hua made a great effort to challenge such negative stereotypes of disabled people by showing her self-reliance and economic independence. However, these characteristics contradict traditional women's roles and could be seen as a threat to a husband's authority. Li-Hua mentioned that her boyfriend's mother was still against their union, because she was 'too capable' of doing everything.

My boyfriend's mother said to me 'I did not want my son to marry a disabled woman liked you, you were 'too capable'. Her words hurt me very much. We finally ended our relationship (Li-Hua).

Li-Hua's case represents that she experienced multiple oppression based on both gender and disability, and this made it more difficult for her to establish intimate relationships. As a disabled person, she was perceived as dependent and passive, but in order to combat discrimination against disabled people, Li-Hua had to be tough and show that she was capable of managing every task. However, as a woman, she was expected to be obedient to her husband. Li-Hua's case shows a contraction between her dual identities of being a woman, and a disabled person.

The following examples show that the situation could be different when disabled women come from advantaged social backgrounds. As mentioned in Chapter Two, disabled people who come from the higher social class are more likely to have access to material resources that enable them to reduce the effects of their disabling environment (Vernon, 1999). Shu-Fen mentioned that her boyfriend's father was against their marriage because she was disabled, but he changed his attitude and approved their marriage when he knew Shu-Fen came from a wealthy family.

He did not allow my boyfriend to marry me because I was disabled. He then changed his attitude toward me once he knew my family was wealthy. He even consistently called to check on me, moreover agreed

our marriage (Shu-Fen).

This example shows how a complex interaction between various forms of oppression based on gender, disability and social class shaped Shu-Fen's experience of intimate relationships. Her economically advantaged background reduced the effects of barriers she experience to having an intimate relationship. Having dealt with the attitudinal barriers experienced by the participants in the establishment of intimate relationships, the next section examines the factors that influenced the participants' choice of potential partners.

### **6.2.3 Choices of Potential Partners**

A study by Howland and Rintala (2001) indicates that disabled women have extremely different attitudes when they select people to date. Some insist on dating able-bodied men, whereas others believe they should date disabled men. Similarly, the participants' accounts show their different attitudes to whether their potential partners were disabled or not. Gill (1996) suggests that some disabled women prefer to form relationships with disabled partners because they might have common experiences and understandings of disability. For example, Yi-Jun preferred to date disabled men because they were more likely to empathise with her situation and respect her.

Xiu-Zhen mentioned that she never considered dating able-bodied men. As mentioned previously, the stereotypical thinking that 'disabled people stick with their own kind' exists in Taiwanese culture. Xiu-Zhen was often told that it would be difficult for her to marry an able-bodied man and this led to low self-esteem in her relationships. The example shows how a disabled woman experienced internalised oppression that hindered her from developing relationships with able-bodied people. Xiu-Zhen internalised such social prejudice and believed she should only marry a disabled man. She rejected the opportunity to develop intimate relationships with able-bodied men.

I was a volunteer in a disability charity. Some volunteers were interested in me, but I would keep my distance from them. Although they were very nice people, I never considered dating able-bodied men. I couldn't open my mind (Xiu-Zhen).

As discussed in Chapter Two, existing studies indicate that disabled women are often perceived as asexual and unattractive, and are less likely to be recognised as sexual partners (Hanna and Rogovsky, 1991; Begum, 1992). However, Xiu-Zhen's case may challenge such a negative stereotype of disabled women. It can be seen that the problem preventing her from establishing intimate relationships was not necessarily attributable to physical appearance. In her case, social prejudice created a situation of self-denial, and this made it difficult for Xiu-Zhen to establish relationships with able-bodied people.

Previous studies suggest that disabled people may prefer to find able-bodied people as partners, who can provide assistance with daily tasks (Gill, 1996; Howland and Rintala, 2001). Several participants mentioned that they would not date those who had more severe impairment. Deal (2003) argues that a hierarchy of impairments exists, in both non-disabled people's attitudes to disabled people, and between disabled people themselves, who have different attitudes toward other impairment groups. Disabled people may distance themselves from other disabled people who they perceive as at a lower level in the hierarchy of impairment. The following examples show that this hierarchy of impairment is an essential factor influencing participants' choices of potential partners. For instance, Xiu-Zhen walked with crutches. She rejected an invitation from a man with visual impairment, because she might not be able to provide physical assistance for him. Similarly, Hui-Ping walked with crutches, and rejected a man who was a wheelchair user.

My classmate introduced a man to me, he used a wheelchair. Even though he came from a wealthy family and had a good education, I did not accept him as my partner. He may face more inconveniences than I did (Hui-Ping).

In the present study, six women married disabled men. None of their husbands had more severe impairments than the participants themselves. Yu-Lan's account noted that the hierarchy of the level of impairment made it more difficult for disabled people to find a partner, particularly among those who had severe impairment.



For non-disabled people, they did not want to marry disabled people. For disabled people themselves, disabled women looked for an able-bodied man or someone with mild impairment. Similarly, a disabled man wanted to find an able-bodied woman who was able to look after him. It was difficult for us to find a partner (Yu-Lan).

A survey by Nosek et al. (2001) shows that women with communication impairment and those with more severe functional limitations are perceived to have more constraints on attracting dating partners. From the present study, it is difficult to generalise whether women with more severe impairment are less likely to establish intimate relationships according to the participants' accounts. It is worth noting that most of the participants who were married walked with crutches. One of the two participants who were not married had severe impairment. Shu-Juan was paralysed from the neck down, and used a ventilator. She had never been in a relationship, unlike the other participants. It cannot be denied that impairment effects cause restrictions for disabled people performing activities (Thomas, 1999). The discussion here does not intend to overly emphasise the significance of impairment effects on participants' experiences of intimate relationships. However, it shows how society responds to participants with various levels of impairment differently and how that influences their experiences in the establishment of intimate relationships.

Not all the participants preferred to date disabled men. Some mentioned that they used to date able-bodied men. Howland and Rintala (2001) indicate that some disabled women believe that being with disabled men would increase their own stigma. As mentioned in Chapter Two, some disabled women prefer to form relationships with able-bodied people, not only because they can receive physical assistance from their able-bodied partners, but also because their non-disabled partners enable them to connect with 'the world of normal people' (Morris, 1991: 36). A similar situation can be seen in Hui-Ling's case. Hui-Ling preferred to date able-bodied men. Her first boyfriend was a polio survivor, who was the only disabled person she dated. She felt embarrassed to go out with her disabled partner and tended to conceal their relationship in front of her friends.

I did not let my friends know that I was dating a disabled man. We

usually met somewhere far from our town. Sometimes he drove me home from school, but I did not let him get out of the car. Only a few of my friends knew my boyfriend was a disabled person (Hui-Ling).

Morris (1989) explores the lives of women with spinal cord injury. Some disabled women report that the negative image of disability makes it more difficult to be with other disabled people in public. Hui-Ling's case showed that she had a negative view of disability, and this made her distance herself from other disabled people in public in order to avoid stigma. Likewise, Shu-Juan never considered having relationships with disabled men. As discussed in Chapter Two, from a life course perspective, previous life events have cumulative effects on subsequent events (Moody, 2000). Shu-Juan had severe impairment and experienced numerous painful treatments in hospital. She left home at the age of six, and stayed in a rehabilitation institution for nine years. Shu-Juan's case shows how previous traumatic experiences of living with polio affected her choice of future partners.

I had gone through so much hardship as a disabled person; I couldn't bear the sight of having another disabled person in my life. So the idea of marrying a disabled man never came across my mind, though some disabled girl friends had suggested that later in my life when I was in my thirties (Shu-Juan).

In this section, the participants' experiences note that public attitudes towards disabled people profoundly influenced their self-identity, and this further affected their expectations of future partners. In addition, the participants' accounts illustrate that the severity of functional limitation has a great influence on their choice of potential partners.

## **Summary**

This chapter explores the transitional experiences of the participants in their youth. The participants' accounts show two different career paths. Some continued with post-school education, while others chose a vocational route. Due to the absence of social support, their families' economic status profoundly influenced the availability of educational opportunities for the participants. The low expectations of others about young disabled people's academic ability and

gender stereotypes restricted the participants from fulfilling their educational and vocational aspirations. In addition to career choice, several barriers to the establishment of intimate relationships were reported by the participants. Some participants were excluded from peer relations and denied access to social activities, due to environmental barriers and prejudicial attitudes.

Due to exclusion, they had less opportunity to develop intimate relationships, compared with their non-disabled counterparts. Some participants were discouraged from developing intimate relationships by their parents, while others faced family disapproval of their unions. Social prejudice against disabled people profoundly influenced the participants' attitudes towards relationships and marriage. Some of the participants internalised negative views of disabled people and this influenced their expectations of future partners. Having dealt with the participants' experiences in their youth, the next chapter shifts the focus to their early adulthood.

## **Chapter Seven**

### **Work and Family Life: the Early Adulthood of Women with Polio**

#### **Introduction**

The previous chapter discussed the transitional experiences of participants in their youth, with particular reference to career options and the formation of intimate relationships. This chapter focuses on the participants' experiences in early adulthood. In Taiwan, the legal definition of an adult is a person who has attained the age of eighteen. The attainment of adulthood comprises a number of transitions, including obtaining legal rights, finishing education, obtaining full-time work, living independently, marriage and parenthood (Clark and Hirst, 1989; Westberg, 2004). Levinson (1986) conceptualises adulthood by dividing it into three age-linked phases, early adulthood (age 17-45), middle adulthood (age 45-60), and late adulthood (age 60 and over). According to Levinson's definition, early adulthood is a time of rich satisfaction in terms of love, sexuality, family life, occupational advancement, and the realisation of major life goals (Levinson, 1986: 5). Valentine (2003) argues that the conception of adulthood is not simply defined by age, because peoples' transitional experiences to adulthood vary in terms of class, race, gender and disability. This chapter focuses on two themes that emerged from the participants' accounts of early adulthood, employment and family life. The first section examines the factors influencing the availability of job opportunities for participants, and identifies the barriers and inequalities experienced by participants in employment. The second section discusses several issues related to the family lives of participants.

#### **7.1 Work Experiences of Women with Polio**

Work is a prominent marker of adulthood. The meaning of work for disabled people is similar to non-disabled people. Work not only provides financial support for individuals, but also has a great influence on personal identity and social relationships (Saunders and Nedelec, 2014). Previous studies show that disabled people experience many difficulties getting equal access to work, due

to lack of accessibility, public transport and discriminatory attitudes in workplaces (Barnes, 1991; Ravaud et al., 1992; Lindsay, 2011). Barnes (1991) argues that disabled people are more likely to experience unemployment and the period of unemployment is likely to be longer than for non-disabled people. The same study indicates that disabled people also experience underemployment, which means that they are more likely to be employed in low-paid, low-skilled jobs.

Existing studies suggest that employment policies fail to tackle the problems disabled people face in employment. Barnes and Mercer (2005) argue that existing employment policies in the UK focus solely on the supply side of the labour force, which tends to improve individual employability rather than remove the barriers experienced by disabled people to employment. Additionally, employment policies overly emphasise individuals' obligation to work and stigmatise those who cannot work (Grover and Piggott, 2013). Paid work is not the only criteria by which to evaluate an individual's value. Barnes (2012b: 480) argues that 'not all disabled people can, or should be expected to, work in the conventional labour market. To expect people with high support needs to be as productive as their non-disabled peers is one of the most oppressive aspects of modern society'. It is important to recognise the value of unpaid work. Unpaid work such as housework, childcare or voluntary work contributes not only to current household consumption, but also to social wellbeing (Miranda, 2012). As mentioned in Chapter Two, many disabled women are caregivers for their families and are involved in unpaid domestic work (Morris, 1993b; Quinn and Walsh, 1995). Many disabled people are involved in user-led disability organisations and help these organisations to develop services for disabled people (Barnes, 2012b).

In Taiwan, the labour force participation rate of disabled people is 19.7 per cent, which is far lower than the 58.4 per cent for non-disabled people (Ministry of Labour, 2014: 04). Disabled women are less likely to be employed, compared to disabled men. By the end of 2014, the labour force participation rate of disabled women was 13.1 per cent, which was far less than the 24.7 per cent for disabled men (Ministry of Labour, 2014: 01). The employment status of disabled people varies for different types of impairment. People with physical impairment are more likely to be employed than people with learning difficulties (Ministry of Interior, 2011). In the present study, four of the participants are currently employed full-time, four are self-employed, one is retired, and one is

unemployed. The next section discusses the factors affecting the employment opportunities available to participants.

### **7.1.1 Entering the Labour Market: Opportunities and Constraints**

The section examines the factors affecting the employment opportunities for the participants. Three themes emerge from the participants' accounts, informal networks, a changing labour market, and employment policy.

#### **Informal Networks**

Informal networks significantly influence the employment success of disabled people, particularly when public services are limited (Shah and Priestley, 2011). Although employment services for disabled people in Taiwan have been developed since the 1980s, the most common way disabled people find their jobs is through their informal networks. Nearly 39.76 per cent of disabled people find jobs by being 'referred by relatives and friends', followed by 23.44 per cent who create a 'home business' (Ministry of Interior, 2011: 198). In Taiwanese culture, individual behaviour and social interaction are profoundly influenced by 'quanxi' (interpersonal relationships), which is particularly important in commercial activities (Ay and Yang, 2006). A study by Hsiung (1996) shows that in Taiwan home-based factory owners prefer to hire their family members or relatives in order to have more control over their employees. Six participants reported that their family members or relatives helped them to gain employment, particularly their first job. For example, Hui-Ping used to work in her parents' factory, and then worked at a shoe factory run by her aunt. Similarly, Xiu-Zhen worked at her brother's toy factory after graduation. Xiu-Zhen's brother tended to protect her and encouraged her to work at home.

I worked at my brother's toy factory as an administrative worker... My brother wanted to protect me. He thought I would be bullied if I worked at other places (Xiu-Zhen).

Hussain et al. (2002) suggest that overprotective parents undermine their disabled children's abilities and hinder them from having control over their lives. As mentioned in the previous chapter, Mei-Zhu's parents forced her to choose a subject in which she was not interested. After she graduated from college,

she had no choice of her first job. Mei-Zhu's uncle arranged a position for her in the military sector.

My life was totally controlled by my parents. They did not care about what I wanted. After I left school, my uncle arranged a position for me in a military factory (Mei-Zhu).

In contrast, Hui-Ling and Ya-Lin did not receive support from family members or relatives, and this made it more difficult for them to find jobs. Hui-Ling found her first job by self-referral. Before that she had been rejected several times. Ya-Lin mentioned that she could not find a job after leaving school. She did not have any choice but to participate in vocational training programmes. These participants' accounts show that personal networks significantly influence the availability of job opportunities. The following section examines how changes in the labour market influenced the employment opportunities for the participants.

### **Changing Labour Market**

As discussed in Chapter Two, people born in different time periods are exposed to different constraints and opportunities (Elder, 1994). Humphries and Gordon (1992) explore the experience of disabled people in Britain from 1900 to 1950. The results show that many disabled people were recruited into full-time employment during World War II due to the large shortage of workers. In the present study, the participants' experiences note that the availability of employment opportunities for disabled people was profoundly affected by the changing labour market. As mentioned in Chapter Four, Taiwan began its industrialisation in the late 1950s and this led to rapid economic growth during the 1960s. During the 1960s and 1970s, the government established several Export Processing Zones (EPZs) to encourage international corporations to establish factories in Taiwan. A large proportion of factories in EPZs were light industries such as garments, textiles and electronic assembly.

Meanwhile, a number of small-medium enterprises (SMEs) emerged in rural areas. Most SMEs were family-run factories that provided assembled products for domestic enterprises and foreign companies (Rubinstein, 1999a). These factory assembly jobs required workers to have patience and carefulness, which are perceived as suitable for women (Ping, 2015). Thus, the development of light industry created job opportunities for young women, but

most were low-paid and low-skilled jobs (Chen, 2000). Taiwan's industrialisation provided job opportunities for the participants to some extent, but some were excluded from the workforce. Eight participants mentioned that they used to work at home-factories or at the factories in EPZs. Most worked as assembly workers, which was a low-paid and low-skilled job.

As discussed in Chapter Two, from a materialistic perspective, industrialisation established a factory-based production mode, demanding high speed and strict discipline in order to maximise productivity, and this new mode excluded disabled people from the workforce (Finkelstein, 1980; Oliver, 1990; Oliver and Barnes, 2012). A similar finding can be seen in the present study. Ya-Lin participated in a dressmaking course for disabled people. Most trainees considered working at garment factories after finishing the training course, but Ya-Lin found it hard to work at a garment factory. She did not have much physical strength in her left hand, which made it difficult to cope with high-speed, physically demanding work.

We were introduced to work at garment factories. In a garment factory, you were paid by the number of pieces you made. You had to do your work quickly in order to make more money. It was difficult for me to manage these tasks at work (Ya-Lin).

In contrast, eight participants, whose upper limbs were not affected by polio, mentioned that assembly work did not create problems for them. Mei-Zhu worked at a clock factory as a production line operator. She was able to deal with the work tasks in the clock factory, which demanded high speed and physical strength.

I worked on the production line in a clock factory. When the workers finished the previous session, they would pass the semi-finished products to me... sometimes the assembly line was going too fast, and I had to stand up to do my work. You didn't even have time to sit (Mei-Zhu).



Similarly, Yi-Jun was an assembly worker at an umbrella factory. She had good reviews of her work performance and got promoted by her employer. As mentioned in Chapter Two, from a life course perspective, previous life events have a cumulative effect on subsequent life events (Moody, 2000). Yi-Jun mentioned that her previous experience of living in an institution was helpful for her when it came to managing work tasks in the factory. She was familiar with strict regulations and routine work from the institution, and this situation was similar to the work disciplines in the factory.

I worked at an umbrella factory as an operator, and then I was promoted to a position of quality checker. I did my job well... I thought this was because I was always told to follow many disciplines when I lived in an institution. I was familiar with a routine schedule for doing things (Yi-Jun).

These examples show that the development of industrialisation in Taiwan reshaped the social relationship between disabled people and society. The new model of production created a close connection between an individual's physical capacities and productivity. In this context, the level of physical impairment significantly influenced the availability of employment opportunities for the participants. Those who had severe physical impairment were more likely to be excluded from the labour force.

Apart from the impact of industrialisation, the expansion of disability services during the 1990s created employment opportunities for participants. As mentioned in Chapter Four, the privatisation of welfare services during the 1980s led to an expansion of services for disabled people. The number of disability organisations increased remarkably during the 1990s, and most were led by professionals (Chang, 2011). Three participants mentioned that they used to work at disability organisations. Li-Hua used to work at two disability organisations and then established a disability charity herself a few years ago. Xiu-Zhen worked at an organisation for people with physical impairment. She described that staff in her workplace were friendly to disabled employees.

I sent my resume to an organisation and got a reply soon. They asked me to work the next day. Most of the staff were social workers, they

were very friendly (Xiu-Zhen).

In the section, these participants' accounts show that the changing labour market profoundly affected job availability for the participants. In the next section, I explore how employment policy for disabled people influenced employment opportunities for the respondents.

### **Employment Policy for Disabled People**

As mentioned in Chapter Four, vocational training services for disabled people have been developed since the 1980s. During the 1990s, the government paid more attention to tackling the employment issue of disabled people. According to the 'Physically and Mentally Disabled Citizens Protection Act 1997', government agencies were required to provide vocational rehabilitation services to disabled people, including vocational assessment, vocational training, employment services, job accommodation and so on (Legislative Yuan, 1997). Due to the development of computer technology in the 1990s, many vocational training centres started providing computer skills training for disabled people. By the end of 2011, computer science was the most popular vocational training programme for disabled people (Ministry of Interior, 2011). Four interviewees indicated that computer skills training courses improved their work capacity and enabled them to find jobs. For instance, Hui-Ling described how computer training programmes improved her work skills and enabled her to get a good position.

Most of my colleagues were older than me, none of them knew how to use a computer. The manager assigned some tasks to me because I had computer skills. That was why I was placed in a good position (Hui-Ling).

In addition to vocational training service, the quota system which was implemented in 1980, aimed to create employment opportunities for disabled people. The scheme became compulsory policy in 1990. Public sectors and private enterprises were obliged to employ disabled people at a specific percentage, otherwise pay a fine (Lin, 2012) (see Chapter Four). The quota scheme created job opportunities for some of the participants. Two participants

were employed in the public sector, and one worked in a private enterprise. Hirst et al. (2004) investigated the employment of disabled people in the public sector in the UK. The results show that employers in public sectors have more positive attitudes towards disabled employees. They are aware of disability legalisation and willing to make accommodation for disabled employees.

However, the situation in Taiwan is different. Cheng (2003) indicates that the quota scheme improved the employment rate of disabled people, but it did not necessarily change employer's prejudices against disabled employees. Although the quota scheme created employment opportunities for Mei-Zhu, enabling her to work in a public agency, she was dismissed from her job because of her employer's prejudicial attitude. This example shows the employer's discriminatory attitude towards disabled employees. The employer was not willing to hire Mei-Zhu as a permanent worker.

I was a contract worker at a district court... then the government launched a new policy that required all public agencies to change the work status of disabled employees from contract staff to permanent workers. The manager did not want me to stay. I was dismissed before the implementation of the new policy (Mei-Zhu).

Along with the quota scheme, 'Civil Service Special Examinations for Disabled People' were introduced in 1996, which aimed to improve the employment security of disabled people. Disabled people who passed the examination became permanent employees in the public sector (Ministry of Examination, 1996). Although Hui-Ling passed the examination, she could not find a suitable position. The case shows that the policy solely focused on the creation of job opportunities for disabled people, while it failed to address the needs of disabled people in workplaces.

I passed the examination, but I couldn't find a job in the public sector. Most jobs demanded physical strength such as workmates or cleaners. Government agencies did not have the intention to employ disabled people (Hui-Ling).

As mentioned previously, Barnes (2012b) argues that existing disability employment policies overemphasised the supply-side of the labour force, rather than improving the disabling environment in the workplace. These examples show that employment policies aimed at creating employment opportunities for disabled people did not necessarily challenge employers' negative attitudes towards them. In addition, these policies did not provide support for disabled employees in workplaces. Having discussed the factors influencing the availability of employment opportunities for participants, the following sections discuss the participants' experiences with various employment statuses, including full-time employment, self-employment and unemployment.

### **7.1.2 Barriers to Full-Time Employment**

Adams and Oldfield (2012) examined the work experiences of disabled people in the UK, and indicate that many employers and colleagues make negative assumptions about the capacities of disabled people in the workplace. In the current study, the majority of respondents experienced attitudinal barriers to employment, only a few participants indicated that their employers were helpful and supportive. Shier et al. (2009) indicate that disabled people face a dilemma of whether they should disclose their condition to employers, because employers may not believe they have sufficient work capacity because they are disabled. Li-Hua mentioned that she was often rejected by employers after she disclosed her physical impairment. She was told that she could not manage work tasks, or that the workplace was not accessible. Similarly, Hui-Ping's case shows that employers had negative attitudes towards disabled people. Although Hui-Ping had a professional accounting background, she found it difficult to find a job related to accounting. The employers held the assumption that disabled people were not qualified for such 'high-level' jobs.

I applied for an accounting assistant job, but the employer only offered me a job of assembly line worker. He thought accounting assistant was a higher level job. I was not qualified for the job because I was disabled (Hui-Ping).

A study by Hahn (1988) suggests that people with visible impairment face discrimination because their physical appearance does not fit the conventional

image of the human body. Ya-Lin's case shows that the physical appearance of disabled people was perceived as a 'problem' that hindered them from accessing work. Ya-Lin worked at a securities company as a phone operator. She was dismissed from her job because her physical appearance was recognised as a problem for the corporate image. Ironically, as a phone operator, she never interacted with customers in person.

I was sacked by my manager, because I may spoil the company image. I had worked there for several years, customers were satisfied with my services... I did not even have a chance to interact with them face to face (Ya-Lin).

Ya-Lin's case shows that she faced discrimination based on physical appearance and this made it difficult to maintain her job. Barnes (1991) argues that disabled people experience discrimination for their appearance because they cannot afford the expenses of clothes for interviews, and also the clothing industry does not recognise disabled people's needs in clothing. In Taiwan the government initiated a new employment promotion scheme in 2014. Disabled people in poor economic conditions are entitled to claim a subsidy for clothes for job interviews (Workforce Development Agency, 2014). Despite the fact that the scheme provided financial support for disabled people to buy appropriate clothes for an interview, it did not challenge negative attitudes towards disabled people in the workplace.

Previous studies suggest that disabled people are more likely to be employed in low skilled and poorly paid jobs (Barnes, 1991; Hernandez et al., 2008), and this applies equally in Taiwan. A survey by the Ministry of Interior shows that 35.84 per cent of disabled employees were 'grass-roots technical workers or manual workers', and only 10 per cent were employed as 'professionals' (Ministry of Interior, 2011:12). Several scholars indicate that disabled women are more likely to experience wage discrimination in the workplace, compared to their male counterparts (O'Hara, 2004; Pawłowska-Cypriasiak and Konarska, 2013). Hsiung (1996) investigated the management of small family factories in Taiwan, and found that the majority of female workers were employed in lower-level work and were poorly paid. In contrast, male employees were mostly doing skilled work and being paid more than female employees. The following cases represent that disabled women were likely to be employed in low-status,

low-paid jobs due to the effects of the interaction between gender stereotypes and discrimination against disabled people. Mei-Zhu used to work at a clock assembly factory. Her case shows that gender segregation existed in divisions of labour and this led to earning inequality between male and female workers.

I worked at a clock factory. Male workers were making clock movements that required some knowledge and skill with machinery. Most female workers were working on the production line (Mei-Zhu).

In addition to gender segregation, Shu-Fen's example indicates that functional limitations could be a reason for employers to reduce the salaries of disabled employees. As mentioned in the previous section, factory-work creates a close connection between individual's physical capacities and productivity. Shu-Fen mentioned that disabled people who worked at home-based factories were often paid less than their non-disabled counterparts. This shows that disabled people are often perceived as less 'productive' and thus should be paid less than non-disabled employees.

I could not manage tasks by myself. I needed help from my colleagues to finish work. The employer used it as a reason to reduce my salary. We could not argue with the employer because we may lose our jobs (Shu-Fen).

Not all participants were employed in low-paid job. Participants' incomes varied depending on their occupations. As discussed in Chapter Six, in Taiwan people believe disabled people have special talents for fortune-telling. Hui-Ling's mother expected her to be a fortune teller, but she did not accept her mother's advice at that time. Hui-Ling described how the myth had a great impact on her career options. Although she changed jobs several times, she eventually determined to be a fortune teller. She believed that she may have special talents for fortune-telling.

God gave disabled people special gifts for doing fortune-telling,

because they did not have opportunities to earn a living by doing other jobs... maybe I have supernatural power, I always could give my clients good advice (Hui-Ling).

In Chinese culture, people believe in 'feng shui' (wind and water), which means that wind and water forces are responsible for determining health, prosperity and good luck (Tam et al., 1999: 154). It is common to see business owners hire a feng shui master to help them deal with uncertainties in their business (Wang et al., 2013). In Taiwan, fortune tellers could make a good living by providing feng shui consulting services. Hui-Ling was a consultant for several companies, and this enabled her to earn a good income. Hui-Ling's case shows that cultural stereotypes profoundly influenced her career options. The stereotype of disabled people led to her choice of being a fortune-teller, which certainly provided her an opportunity to make a good living. However, it should be borne in mind that such stereotyping may also restrict disabled people from having other career options. As mentioned in Chapter Four, in Taiwan people believe that massage is suitable work for people with visual impairment. Employment policies encouraged people with visual impairment to engage in the massage business, and consequently people with visual impairment were marginalised from the mainstream labour market (Li, 2003).

In addition to prejudicial attitudes, eight respondents mentioned that they had experienced physical barriers in their workplaces, such as stairs, inaccessible toilets, inappropriate space arrangements etc. For example, Li-Hua had to deal with disabling barriers in her office, even though she worked at a disability charity. She described how the arrangement of space did not meet the needs of wheelchair users. The kitchen countertop was too high for her. The experience of Ya-Lin was similar. Her case shows that the lack of an accessible toilet can be a particular issue for disabled women during pregnancy. Gueutal and Taylor (1991) suggest that pregnant employees have to make adjustments to work loading and schedules, and need support from maternity policy and career planning. In Taiwan, pregnant employees face discrimination in the workplace. According to a national report by the Gender Equality Committee, 17 percent of women reported that they faced unequal treatment in the workplace during pregnancy, such as salary reduction, unequal parental leave arrangements, and bias in performance evaluation (Gender Equality Committee, 2013: 21).

Pregnancy affects most women's mobility, and this is particularly true for women who have mobility impairment. Some disabled women who walk prior to pregnancy find that they are more comfortable using a wheelchair during pregnancy (Rogers, 2010) (see section 7.2.1). Ya-Lin had to use a wheelchair during pregnancy to avoid the risk of falling. Due to the lack of an accessible toilet, she had to rely on her colleagues to help her use the toilet. This example shows that Ya-Lin's need was overlooked by her employer, and this led to the creation of dependency.

I needed to use a wheelchair on the fifth month of pregnancy. The toilet was not accessible, so I needed the help of my colleagues to use the toilet. Sometimes they were busy. I shared the office with other female colleagues. I did not have a choice but to use a chamber pot in my office (Ya-Lin).

In addition to physical barriers, lack of transportation and vehicles hindered the participants from accessing work. For example, Li-Hua mentioned that it was difficult for her to go out for job interviews due to lack of transportation. However, Shu-Juan studied for her master's degree in the United States. She indicated that she received mobility allowance and appropriate equipment to enable her to travel to work.

There's some financial help for people who work. You can get help to modify your vehicle, if it's used for transportation to work. They first funded my expenses in converting my car to use for my work, which gave me tremendous independence (Shu-Juan).

The examples discussed above show that disabling environments prevented the participants from having access to work, rather than their impairments. In this section, the participants' accounts demonstrate that negative attitudes towards disabled people and lack of accessibility created difficulties for them in employment. Next, I explore the participants' experiences of being self-employed.



### **7.1.3 The Experience of Self-Employment**

Pagán (2009) suggests that self-employment makes work feasible for disabled people and allows them to make adjustments in terms of functional change. However, a study by Boylan and Burchardt (2003) indicate that disabled people experience multiple barriers to setting up their own businesses. They experience difficulty in obtaining start-up capital, fear losing their benefits income, and lack access to training and advisory services. In Taiwan, employment policies tended to encourage disabled people to choose self-employment. As mentioned in Chapter Four, the policy 'Living Rooms as Factories' was introduced in 1974, which aimed to bring the surplus labour of communities and families into productive work. The government provided special loans for families to purchase machines to work at home and also provided training for housewives (Hsiung, 1996). It was common to see housewives taking components from factories and doing assembly work at home during the 1970s (Chen, 2016). In addition, the 'Public Welfare Lottery Scheme' was launched in 1999 in order to create job opportunities for disabled people. The government provided equipment for disabled people to run a lottery shop (Legislative Yuan, 1999a). Two participants reported that they used to be self-employed, and three participants are currently self-employed. Most of them ran small businesses, such as coffee shops, home-based factories, lottery shops etc.

Previous studies indicate that self-employment may be the only option for disabled people when the other options of paid work are limited (Pagán, 2009; Agnihotri and Patel, 2015). According to a national survey in Taiwan, a very high proportion of disabled people who are illiterate are self-employed (73.97 per cent) (Ministry of Interior, 2011: 203). This suggests that a low level of educational qualification could be a barrier that obstructs disabled people from entering the paid labour market, and therefore self-employment could be an option for them. The following examples show that self-employment provides job opportunities for those who have low educational attainment. For instance, Shu-Fen only completed primary education. She worked at her brother-in-law's artificial flower factory for a short period of time. The policy 'Living Rooms as Factories' provided an opportunity for her to run a small home factory. She took components from her brother-in-law's factory and hired several housewives to make artificial flowers. Similarly, Yu-Lan never completed formal education, and this made it difficult for her to find a job. She learnt hand embroidery skills in an embroidery studio and established her own business. This example

shows that lack of education created a problem for her in starting her businesses. Due to a lack of education, she did not know how to write Chinese characters correctly, and this made it difficult for her to manage embroidery work.

I did not know how to write a Chinese character with correct strokes. My needlework did not look good. Before I started my business, I took a Chinese calligraphy course to learn how to write Chinese characters correctly (Yu-Lan).

As mentioned in Chapter Two, disabled women, like non-disabled women, face challenges in managing their dual roles as a paid worker and a caregiver, and need support to enable them to balance the dual demands of work and caregiving. Self-employment can be a solution for women to deal with the dual demands of caregiving and work (Marlow, 1997). A previous study indicates that childcare is an essential factor influencing women in choosing self-employment (Connelly, 1992). Three participants mentioned that self-employment provided the flexibility that enabled them to achieve a balance between caregiving and work. For example, Shu-Fen mentioned that she could not work full time because she had to look after her child. She did assembly work at home after her first child was born. The experience of Yu-Lan was similar. Self-employment allowed her to have a manageable working schedule, and enabled her to balance caregiving and work.

I had to pick up my kid from school. Sometime my mother-in-law came to visit us, I had to prepare a meal for her. I would be better if I could work at home (Yu-Lan).

However, self-employment could pose a risk to disabled people. As mentioned, the 'Public Welfare Lottery Scheme' aimed to create employment opportunities for disabled people by running lottery shops. The following cases show that the scheme encouraged disabled people to run their own business, but it did not ensure employment stability. Lottery retailer licences were issued by the government every few years. Disabled people had to apply for the lottery

retailer license before they could run a lottery shop. Shu-Fen ran a lottery shop for ten years, but had to close the shop because she did not get a new licence.

I applied for the lottery retailer license successfully the first three times, but failed to get the new one. The lottery shop would be closed this year, I worried that it would be difficult for me to get a job (Shu-Fen).

Barnes (1992c) argues that disabled people frequently experience discontinuity of employment or stay in low-skilled jobs, and therefore have few opportunities to accumulate extensive work experience. In Taiwan, disabled people choose to run lottery shops because it does not require a specific professional background or skills (Chen, 2007). Chiang (2011) points out that the government does not provide career transition services for lottery retailers and this puts them in a risky situation. In Shu-Fen's case, we can see that disabled people are channelled into low-skilled jobs and this prevents them from accumulating valuable work experience. Shu-Fen's work experience running a lottery shop did not improve her competitiveness in the labour market, and this made it difficult for her to move into higher status occupations.

As mentioned in Chapter Two, vocational training programmes encourage disabled women to be self-employed, but they often don't receive sufficient support or equipment to initiate their own businesses (Naami et al., 2012). Ya-Lin ran a lottery shop. The government only provided the computer equipment for her, and thus she had to pay a large amount of money to rent a place and purchase equipment for the shop. She worried about the uncertainty and risk of the new business.

Some people said running a lottery shop could make a good living, but I saw some friends fail. I felt worry because I had put a lot of money to start my business (Ya-Lin).

After the interview, in December 2014, I visited Ya-Lin. She mentioned that running a lottery shop was not a profitable business. She planned to move the shop to a business district, but the rent for the new location was too high. These examples show that the employment policy did not improve the

employment of disabled people. On the contrary, it might have put disabled people at risk in employment. Having discussed the participants' experiences of self-employment, the following section discusses the issue of unemployment.

#### **7.1.4 Living without Earnings**

Employment maintenance can be difficult for some disabled people. Disabled people may leave their positions voluntarily due to functional change associated with their impairment (Riddell, 2009). Two participants left employment due to medical treatment for scoliosis, and one left a job because of the effects of PPS. As mentioned in Chapter One, the technology of scoliosis surgery was introduced to Taiwan in the early 1970s. Ya-Lin suspended a vocational training programme due to the treatment of scoliosis. Similarly, Yi-Jun decided to undergo scoliosis surgery and left her job. Shu-Juan was forced to leave employment because of the effects of PPS. As discussed in Chapter One, polio survivors may experience new functional loss caused by the PPS. The symptoms appear 30-40 years after the initial polio illness (Hollingsworth et al., 2002). Shu-Juan studied for her master's degree in the United States. After graduation she worked at a university as an English teacher. She was diagnosed with PPS in her early twenties, which is earlier than most polio survivors, and had to leave her job.

I started having pneumonia frequently... I was tired easily, I wasn't able to focus on what I was reading. The attention span was shortened because of fatigue...I was diagnosed with Post-Polio Syndrome, and advised by my doctor to quit teaching (Shu-Juan).

As mentioned previously, work not only provides financial support for individuals, but also has a great influence on personal identity and social relationships (Saunders and Nedelec, 2014). González (2009) explores the meaning of work for disabled women. The results show that work is important for disabled women to give a sense of independence, as well to expand their social relationships. Shu-Juan lived with her parents after she left her job. Leaving paid work profoundly undermined her sense of self-worth.

Having to quit working was hard. My life all of sudden was turned upside-down. I felt useless and helpless. It was hard to terminate my teaching career, as it provided me a sense of independence as well as financial support (Shu-Juan).

As mentioned, not all disabled people should be expected to enter the conventional labour market. It is imperative to change the organisation of work and reconstruct the meaning of work in terms of disabled people's perspectives (Barnes and Mercer, 2005). Iino (2012) argues that the overemphasis on the link between 'work' and 'productivity' has denied the experiences of those who cannot work. Disabled people have the right to refuse to work and demand other life possibilities. Volunteering work provides an opportunity for people to gain a sense of being needed, and also accumulate experience to enhance their employability (Rochester, 2006). A study by Trembath et al. (2010) shows that some young disabled adults do not see volunteering as a route to paid work, but recognise it as a desirable work-like alternative to employment. In Shu-Juan's case, although she did not return to paid employment, she volunteered in several disability organisations. She started doing art work and this made her feel fulfilled.

I have done quite a few types of volunteer work, such as fundraiser event organiser, art curator for disabled people... I turned to art to focus on things that are beautiful. When I'm doing artwork, I feel a sense of peace. All my life, I've been turned away from many things that I wanted to pursue. In the world of art, I can make art the way I want. It's rather fulfilling (Shu-Juan).

Barnes (2012b) indicates that many disabled people are involved in unpaid work, such as domestic caregiving or employers' personal assistants and consultants in user-led organisations, but their roles are not valued by the paid labour market. In Shu-Juan's example, she contributed her skills and knowledge, which derived from her experiences of living with polio for many years, to these meaningful activities. This case shows that paid employment is not the only criteria to define what constitutes a 'meaningful life'. According to the beliefs of the independent living movement, disabled people should have control and choice in their lives. It is crucial to acknowledge that disabled

people have the right to work, but equally have the rights to choose 'not to work' (Grover and Piggott, 2013). Having dealt with several issues related to the work experiences of participants, the following section focuses on the participants' family lives in their early adulthood.

## **7.2 Family Lives of Women with Polio**

Over the last few years, the structure of family has significantly changed in Taiwan. Traditionally, a family refers to the co-resident unit sharing a common property as well as to the larger unit including multiple single households (Thornton and Lin, 1994). Married sons are expected to live with parents, and daughters-in-law are obliged to look after parents-in-law and do household work (Hsu and Shyu, 2003). Yang et al. (2012) investigated the transition of family structure in Taiwan from 1984 to 2005. The study showed that most Taiwanese men live with their wives, children or parents for most of their lives. Due to a rapid decline in birth rates, family structure gradually shifted from a larger extended family to a smaller nuclear family in later decades. Young married couples were less likely to live with their parents. Chi and Hsin (1996) indicate that the majority of married couples in Taiwan begin married life living with the husband's parents and later move out to establish a nuclear family.

Women's roles have changed over recent decades. The rate of married women in the labour force has increased remarkably since the 1980s. Childcare responsibility has gradually shifted from parents to grandparents and childcare services (Chen, 2000). As mentioned in Chapter Two, not all disabled women have the desire to marry, be a mother or be sexual with men. However, for many disabled women, their opportunities to fulfil these traditional roles are constrained by social and cultural barriers (Fine and Asch, 1988; Begum, 1992; Lloyd, 1992). Disabled women are often discouraged from having a child and are denied access to maternity services (Thomas, 1997). Their parenting needs are overlooked in existing policies and service provision (Wates, 2002; Olsen and Clarke, 2003).

In Taiwan disabled women are less likely to establish relationships than disabled men. According to a national survey, 53 per cent of disabled men have a spouse or live with a partner, which is higher than the 41 per cent of disabled women (Ministry of Interior, 2011:79). The marriage rate of disabled people varies with different types of impairments. People with physical impairment have the highest marriage rate, at nearly 60 per cent, whilst people with learning difficulties have the lowest rate at less than 10 per cent (Ministry

of Interior, 2011: 79). In the present study, six participants were married, two were divorced, and two were never married. The majority of the participants were the main caregivers in their families. The following sections explore family life of participants, including pregnancy experiences, childcare and parenting, and the experience of being a 'good daughter-in-law'.

### **7.2.1 Pregnancy Experience: 'Hope for a Son'**

As mentioned in Chapter Two, existing studies show that many disabled women are discouraged from having children because of the myth that they are likely to pass their condition on to their children (Thomas, 1997; Gillespie-Sells et al., 1998; Prilleltensky, 2003). Kallianes and Rubenfeld (1997) suggest that the idea that impairment is always hereditary is exaggerated. In fact, a large proportion of impairment is developed later in life. Polio is not a hereditary disease. Most of the participants had rarely been questioned about hereditary risk of polio. Previous studies show that disabled women are often discouraged from having children because they are perceived as incapable of looking after their children (Grue and Lærum, 2002; Malacrida, 2009). This can be seen in Ya-Lin's case. Ya-Lin's mother-in-law assumed that she could not take care of a child and convinced her to have an abortion. She resisted the authority of her mother-in-law and decided to continue with the pregnancy.

My mother-in-law persuaded me to abort the child. She would not help me look after my child... I told my husband I would leave and never came back, if she forced me to do it (Ya-Lin).

Nevertheless, not all participants were discouraged from having children. Three informants mentioned that they were expected to have a son for their husbands' families. As discussed in Chapter Four, the cultural 'boy preference' is deeply rooted in Taiwanese culture. Traditionally, sons are able to carry the family name, and have an obligation to take care of parents when they grow old. In contrast, daughters become members of their husband's families and look after their parents-in-law (Wolf, 1972). Nowadays, Taiwanese people are still strongly influenced by traditional perceptions of 'male-lineage preservation' (Chu and Yu, 2010).

In this context, married women are under pressure to have sons for their husbands' families. A study by Coombs and Sun (1981: 1237) shows that 'boy preference' significantly affects women's fertility behaviours. According to the statistics from 1973, 54 per cent of women with three female children wanted additional births, but only 1 per cent of those with two male children did. This suggests that if a married woman did not have a boy, she was expected to keep having more children until she did have a boy. For example, Xiu-Zhen's first child was a girl. A priest advised her to have a second birth because she needed a son to look after her when she grew old. Similarly, Hui-Ling had two daughters. Her mother-in-law expected her to try for a third birth. Hui-Ling did not want more children. Her mother-in-law encouraged her husband to have a child with another woman in order to have a boy.

My mother-in-law wanted a boy to carry the family name. She tried to convince me to have third birth. She told my husband that he could have a child with other women, if I could not have a son for their family (Hui-Ling).

These examples show that disabled women have little control of their bodies. The participants experienced two forms of oppression based on gender and disability, and this profoundly undermined their reproductive autonomy. On the one hand, disabled women are discouraged from having children because they are often perceived as 'unfit' mothers, but on the other hand, in Taiwan's patriarchal society, they are forced to have sons for their husbands' families.

As mentioned in Chapter Two, previous studies show that disabled women face difficulties accessing maternity services due to the lack of accessible buildings information, and prejudicial attitudes (Thomas, 1997; Walsh-Gallagher et al., 2013). In the previous section, I discussed how disabled women need support or equipment in their workplaces during pregnancy (section 7.1.2). The following examples show that some participants experienced barriers during pregnancy, but did not receive appropriate support. Falling is a problem commonly reported by women with physical impairment during pregnancy. The risk of falls increases if someone is already a little unsteady on their feet (Post-Polio Health International, 2011). Several participants mentioned that they faced higher risk of falling due to a lack of appropriate assistive devices. Shu-Fen walked with crutches. She mentioned that she experienced several fall



accidents during pregnancy, and this might have been dangerous for the baby. Similarly, Xiu-Zhen walked with crutches during pregnancy. Xiu-Zhen's account noted that an accessible environment was important for a disabled woman during pregnancy. Lack of accessible buildings increased the risks for disabled women during pregnancy.

I walked on crutches during pregnancy. My house was not accessible. It was difficult for me to manage many steps. When I was pregnant with my second child, I moved to a house with a lift (Xiu-Zhen).

Walsh-Gallagher et al. (2013) indicate that health service professionals' hold the assumption that disabled women experience 'high risk' during pregnancy because of their impairments. Xiu-Zhen's case shows that the risk disabled women experience during pregnancy is not necessarily related to impairment itself. Lack of accessible environment may increase risk disabled women experience during pregnancy. These women's accounts show that the needs of disabled women were underrepresented in health services in Taiwan. According to the 'Shadow Report of Disabled Women's Rights 2014', disabled women are denied access to antenatal care and maternity services (The League of Welfare Organizations for the Disabled People, 2014). Next, I examine the barriers experienced by the participants in childcare and parenting.

### **7.2.2 Social Barriers to Childcare and Parenting**

As discussed in Chapter two, disabled women often face the prejudicial judgement that they are not capable of raising their own children, and experience the threatened loss of their children (Thomas, 1997). Two participants described how their family members did not expect them to take care of their children. For example, Yu-Jun's mother-in-law attempted to keep her child. She resisted the authority of her parents-in-law and persisted in looking after her child on her own. Grue and Lærum (2002) suggest that disabled women are more likely to be judged as unable to protect their children, and of putting their children in a dangerous situation. This can be seen from Xiu-Zhen's example. She indicated that her mother-in-law did not allow her to travel with her child alone. She had to lie to her mother-in-law that they had joined a tourist group.

My mother-in-law thought that I could not protect my daughter. I promised my mother-in-law that I would ensure the safety of my daughter. I told her we would join in a tourist tour. I did not let her know I travelled with my daughter alone (Xiu-Zhen).

A study by Wates (2002) indicates that the needs of disabled adults in parenting have been overlooked by service providers in the UK, and suggests that disabled people's parenting needs should be routinely covered within service provision for disabled adults. Similarly, services for disabled parents are absent in Taiwan. A survey by a disability organisation shows that 74.5 per cent of disabled women are mothers, but their parenting needs are not recognised by public policy makers or service providers (The League of Welfare Organizations for the Disabled, 2013: n.p). Due to a lack of social support, disabled mothers have to develop their own strategies to deal with problems they face in childcare. Grue and Lærum (2002) find that although functional limitations may restrict disabled mothers from performing activities of mothering, they can find creative ways to provide care for their children. Similar findings can be seen in the following examples. Ya-Lin did not have the physical strength to hold her child. She found an alternative way to provide physical care.

...I put my daughter to bed, so that I could give her milk feed... I was sitting on the floor while my kid was in the walker. My arms are not strong enough to carry her so I gripped her by her collar with my teeth and put her on the floor (Ya-Lin).

The experience of Shu-Fen is similar. It was difficult for Shu-Fen to give her child a bath because her right hand was paralysed. She found an alternative way to deal with the problem.

I had no strength in my one hand. It was not easy to hold my son when I was bathing him. I cleaned my leg first, and then put my legs in the baby bathtub. My son was able to lay upon my legs, so I could bath him easily (Shu-Fen).

Shaul et al. (1981) indicate that mothers with physical impairment find it difficult to go out alone with their children and may need environmental modification or equipment in the early years of parenting. Three respondents reported that it could be a challenge for them to take their children to hospital. They walked on crutches or used wheelchairs, and this made it difficult to hold onto a child when they went out. For example, Shu-Fen walked with crutches. It could be a problem for her to take her child to a hospital without support.

...my husband was not at home, but I had to take my child to the hospital. I could not hold my kid when I was walking on crutches. I bound the kid in front of my bosom with a long strip of cloth. I could not make it tight, so I gripped it with my teeth when I was walking (Shu-Fen).

Gitlin et al. (1998) suggest that the experience of using assistive devices is not always positive. There is a trade-off between the benefits and drawbacks of using a device, depending on the context. In Shu-Fen's case, the use of assistive devices enabled her to regain her walking ability. At the same time, it could be a barrier that restricted her from carrying out caregiving activities. The availability of appropriate assistive devices could make it easier for disabled mothers to go out with their children. However, existing policy and the assistive technology industry fails to recognise the needs of disabled parents. For instance, publicly funded agencies may fund assistive devices that can be used for medical, vocational or educational purposes, but not devices used for parenting (South Carolina Assistive Technology Program, 2015). Due to a lack of assistive device services, disabled women need to rely on the support of others to take care of their children when they go out. For example, Xiu-Zhen walked with crutches. Her mother-in-law accompanied her to take her child to the hospital.

I used crutches to walk and this made me feel it was difficult to take my son out. My mother-in-law was very supportive and helpful. When I took my son to the hospital, she always accompanied us (Xiu-Zhen).

As mentioned in Chapter Two, service providers often perceive disabled women as 'dependent' or 'helpless' and tend to do things for them, rather than enable them to manage tasks themselves (Thomas, 1997). The relationship between a disabled mother and childcare workers is complicated. Disabled women may feel that childcare workers undercut their authority as a mother (Lindgre, 2011). Xiu-Zhen's case shows that she needed help from her mother-in-law to accompany her and her child to the hospital, rather than just doing it for her. She sought help from her mother-in-law to fulfil her mother role, not to replace her mother role.

Kallianes and Rubenfeld (1997) argue that a social definition of parenting overly emphasises physical care rather than love and nurturing. This creates a problem for disabled women because they are recognised as 'unfit' mothers. Olsen and Clarke (2003) suggest that disabled parents can challenge the concept of parenting by placing greater emphasis on providing love, support and leadership, rather than physical tasks. Hui-Ping and her husband were both disabled. Hui-Ping mentioned that although she could not look after her son when he was ill, she gave him psychological support.

My son had a severe asthma attack and stayed in the hospital for a few days. I sought help from my parents to take care of him. Although we cannot provide physical care to my son, we could stay with him and comfort him (Hui-Ping).

Malacrida (2009) indicates that disabled women find it hard to resist the perception of ideal motherhood and make great efforts to meet social expectations of mothers' roles. This may consolidate the normativity of motherhood, rather than challenge common assumptions of 'a good mother'. Nevertheless, Hui-Ping's example highlights that physical care is not the only evaluation criteria of a 'good mother', as disabled mothers also provide love and support for their child. In this section, the women's accounts challenge the negative stereotype that disabled women are incapable of looking after their children. It can be argued that the problems disabled women experience in parenting are not simply caused by their functional limitations, but also by prejudicial attitudes and inadequate social support for disabled women. Next, I

discuss the availability of informal support and childcare services for participants in childcare and parenting.

### **7.2.3 Informal Support and Childcare Services**

As discussed previously, the parenting needs of disabled women have been profoundly overlooked by services for disabled people. In this context, informal support was crucial for the participants to fulfil their mothers' roles. Prilleltensky (2003) explored the experiences of mothers with physical impairment and found that husbands and family members provide a lot of assistance for disabled women in childcare. Similar findings can be seen in the current study. Five participants mentioned that they received support from family members, such as husbands, sisters-in-law or mothers-in-law, to help them look after their children. Yu-Lan described how her sister-in-law helped her son in the bath and took him to hospital. Ya-Lin and Hui-Ping indicated that their husbands were supportive, and shared childcare responsibility. As mentioned in Chapter Two, a study by Lindgre (2011) shows how a disabled mother establishes partnerships with her husband and paid assistants to care for her child. Hui-Ping's case shows that a disabled couple were able to take care of their children through mutual support. Hui-Ping walked on crutches, and her husband used a wheelchair. She described how her husband was supportive and helped her bath their child.

I couldn't take my son to the bathroom because I walked with crutches. My husband used a wheelchair, he took my son to the bathroom for me. When I finished it, my husband would come to pick him up. We did face many problems, but we could always find a solution to deal with them (Hui-Ping).

However, not all the participants were able to receive support from their families, particularly those who were divorced. Single disabled mothers are often perceived as questionable, potentially unsafe and probably unfit (O'Toole, 2002). As discussed in Chapter Two, disabled single mothers experience multiple oppression of gender, disability and singlehood, and this makes it difficult for them to get access to social resources (Cassiman, 2011). In Taiwan, divorced women have to deal with the social stigma of divorce. Traditionally, a

divorced woman disgraces her natal family. For example, a divorced woman is not allowed to reunite with her natal family during Chinese New Year because she would bring misfortune to her family (Yang, 2008). This suggests that a divorced woman loses not only the support of her husband's family, but also support from her natal family. Hui-Ling and Mei-Zhu were divorced and brought up their children alone. Hui-Ling took her two children back to her parental home after she divorced. She faced judgement from other family members and neighbours.

I took my two daughters and went back to my parents' home. I felt I was a burden to my family. My sisters-in-law showed their bad attitudes and made me feel unwelcome. I heard some gossip about me from my neighbours (Hui-Ling).

Hui-Ling decided to leave her parental home, even though she was unemployed at that time. It was difficult for her to find accommodation. She was often rejected by landlords because she was a single disabled mother. Hui-Ling's case shows that, as a single disabled woman, she experienced multiple oppression based on the intersection of disability, gender and singlehood. This made it more difficult for her to have access to material resources and social support to raise her children.

When the landlord knew I was a single disabled woman with two kids, they often refused to rent me an apartment. They thought I could not afford to pay the rent (Hui-Ling).

In addition to informal support, three participants sought help from private childcare services. The high cost of child care services created a heavy burden for them. As mentioned in Chapter Four, the state's role was absent in welfare provision for disabled people before 1980. Families had to take responsibility to look after disabled children and received little support from public services (Lin, 2012). Similarly, the government paid little attention to childcare services. In Taiwan, childcare services are mainly provided by the private sector rather than public agencies (Chen, 2000). The cost of a private nursery is nearly three

times as high as the cost of a public nursery and this can be a heavy burden for parents (Lin et al., 2011). The following cases show that disabled women had to bear heavy burdens of childcare costs. For example, Hui-Ping had two children. She was under financial pressure to pay the expenses of childcare, although her salary was higher than the other participants. Ya-Lin was a phone operator in a securities company which was a low-paid job. She mentioned that a large proportion of her salary went on the expense of child care services, while her husband's money was used to pay the cost of living. They were usually short of money at that time.

This was a difficult time for us, most of the money I earned was used to pay for the childminder, milk and diapers. My husband's salary went on the expenditure of living costs (Ya-Lin).

The high expense of childcare services can be a heavy burden for parents whether they are disabled or non-disabled. However, as mentioned previously, the majority of participants experienced barriers that hindered them from having equal access to employment, and this led to economic disadvantages (see section 7.1). Lack of access to material resources made it more difficult for them to afford the expense of childcare services. Having dealt with several issues related to motherhood, the next section discusses participants' experiences of being daughters-in-law.

#### **7.2.4 Being a 'Good Daughter-in-law'**

Taiwanese women are subject to the socially constructed obligations of a daughter-in-law. As mentioned, traditionally, parents expected their married sons to live with them, and daughters-in-law were obliged to look after parents-in-law and do household work (Hsu and Shyu, 2003). The following examples show that disabled women were often perceived as an unfit daughter-in-law. For instance, Shu-Fen lived with her parents-in-law for a short period of time. She described that her father-in-law was ashamed of having a disabled daughter-in-law and did not allow her to go out.

I lived with my parents-in-law after I got married, that was the darkest

time in my life... one day my sister came to visit me. My father-in-law did not allow me to walk my sister to the front door and asked me to stay in my room. He was afraid that someone would see me (Shu-Fen).

The experience of Hui-Ling is similar. According to Confucianism, ancestor worship is a way to represent descendants' filial piety to their ancestors. In Taiwan people believe that if they show respect to their ancestors, their ancestors bless them and keep family harmony (Chang, 2009). 'Table worship' is a ritual within families. People erect an ancestor tablet at home and worship it with food and incense (Li, 1988). The ritual of ancestor worship requires family members to kneel down in front of an ancestor tablet to express their respect to ancestors. Hui-Ling was not recognised as a 'good daughter-in-law' because she could not perform the ritual.

I couldn't kneel down and worship their ancestors. My parents-in-law thought that I would bring shame on their family and destroy their reputation. They did not allow me and my husband to visit them even after we got married (Hui-Ling).

Living with parents-in-law could be very stressful for a daughter-in-law. Gallin (1994) describes the roles of a daughter-in-law as a 'family drudge' in a Taiwanese family. A daughter-in-law is saddled with work under the close supervision and scrutiny of her mother-in-law. She has to respond to the daily needs and caters to all family members (Gallin, 1994:31). Four participants indicated that they were required to meet strict requirements of housework set by their mothers-in-law. For instance, Mei-Zhu made great efforts to do housework in order to meet her mother-in-law's high standards.

My mother-in-law wanted me to keep the house spotless. She did not allow me to use mops, so I knelt down and wiped the whole house. It was difficult for me to carry a bucket of water (Mei-Zhu).



However, the situation was different for the participants whose husbands were also disabled. The following examples show that parents-in-law had different attitudes toward their disabled daughters-in-law if their sons were disabled. For example, Hui-Ping mentioned that her parents-in-law did not expect her to do household work. Her parents-in-law felt empathy for her situation because their own son was disabled. Likewise, Xiu-Zhen mentioned that her parents-in-law did not expect her to do household work, but this led to tension in the relationship with her sisters-in-law. In a Taiwanese family, the relationship between sisters-in-law is complicated. Conflicts between sisters-in-law are attributed to unequal sharing of responsibility for housework, or caring for the parents-in-law (Li, 2010). Xiu-Zhen could not manage household work on her own. To avoid judgement from her sisters-in-law, she asked her children to do household work. Xiu-Zhen's children helped her fulfil her role of a daughter-in-law.

My children would do housework for me. My son cleaned the dining table, and my daughter wiped the floor... if I did not share housework with my sisters-in-law, I would be criticised for being irresponsible (Xiu-Zhen).

Existing studies pay much attention to disabled women's experiences of sexuality and motherhood (see section 2.2.3). However, little is known about disabled women's experiences of being daughters-in-law. These women's accounts shed light on disabled women's experiences of being daughters-in-law in a Taiwanese context. It can be seen that disabled women, like non-disabled women, are subject to culturally constructed standards of good daughters-in-law. However, they are often perceived as incapable of being a good daughter-in-law, and this made it more difficult for them to maintain good relationships with their parents-in-law and sisters-in-law. Some participants experienced internalised oppression and made a great effort to meet the social expectations of an ideal daughter-in-law. It is imperative to examine the barriers that hinder disabled women from fulfilling their roles as daughters-in-law. More importantly, it is necessary to challenge cultural assumptions of a 'good daughter-in-law', which could be recognised as a form of oppression experienced by disabled women.

## Summary

This chapter discusses the participants' experiences in early adulthood with particular reference to work and family lives. Informal networks, the changing labour market and disability employment policy significantly influenced the availability of employment opportunities for the participants. Most of the participants experienced environmental barriers and discriminatory attitudes in the workplace. The effects of the interaction of gender and disability led to income inequality for the participants. In addition to paid employment, some participants chose to become self-employed. However, policy failed to provide sufficient support for them to run their own businesses, and this may have put them at risk. The experience of unpaid work is highlighted in the discussion. Paid work is not the only way to evaluate an individual's value. Disabled people are able to engage in meaningful unpaid activities and live fulfilled lives.

The discussion of their family lives shows that the majority of participants experienced difficulties in fulfilling their roles as women due to a lack of social support and discriminatory attitudes. Some of the participants experienced discrimination generated by the intersection of gender and disability, and lost power over their reproductive autonomy. These women's accounts challenge negative stereotypes of disabled women. Most of the participants could find creative ways to look after their children. Their stories also redefine the perception of parenting, by emphasising the significance of love and company for children, rather than physical care. The participants' experiences of being 'good daughters-in-law' are explored in a Taiwanese context. Some faced judgement that they were incapable of being 'good daughters-in-law', and this led to conflict in their relationships with their husbands' families. The next chapter explores the participants' experiences in middle adulthood and their aspirations for old age.

## **Chapter Eight**

### **New Challenges of Ageing: Middle Adulthood of Women with Polio**

#### **Introduction**

In the previous chapter, I explored the participants' experiences in early adulthood. All the participants in the present study were reaching their middle age. This chapter focuses on the participants' experiences in their middle adulthood. Levinson (1986: 6) defines middle adulthood as ages 45 to 60. During this period, individuals' biological capacities are less than those of early adulthood, but are still sufficient for an energetic, personally satisfying and socially valuable life. However, the perception of middle adulthood does not fully describe the experiences of disabled people. As mentioned in Chapter One, a large proportion of disabled people in Taiwan are reaching their middle adulthood and old age. Nearly 35.79 per cent of disabled people are aged between 45 and 65, and 36.00 per cent are aged over 65 (Ministry of Interior, 2011: 02).

Disabled people experience early decline in physical function due to the effects of premature physical ageing (Zarb, 1993). Chung (2011) suggests that disabled people might face more challenges as they grow old. They not only experience the effects of ageing itself, but also the long-term impact of pre-existing impairment. Ageing is a gendered issue. Women historically live much longer than men, and are more likely than men to be widowed (Arber and Ginn, 1991). A similar trend can be seen in the disabled population in Taiwan. Approximately 29.30 per cent of older disabled women are widows, but only 7.01 percent of older disabled men are widowers (Ministry of Interior, 2011: 78). Middle-aged adults bear a heavy burden of multigenerational caregiving. They are described as a 'sandwich generation' who have had to provide assistance to their adult children and ageing parents (Boyd and Bee, 2014). Previous studies have shown that midlife disabled women are the main caregivers for their ageing family members, but they may experience difficulty in carrying out caregiving activities due to functional decline (Quinn and Walsh, 1995; Harrison, 2006). This chapter explores the participants' experiences in middle adulthood.

Three themes emerge from the respondents' accounts, changes in physical function, challenges in caregiving and concerns about the future.

### **8.1 Changes in Physical Function: 'Premature Physical Ageing'**

As mentioned in Chapter Two, existing studies suggest that disabled people experience physical degeneration caused by the long-term effects of pre-existing impairment, as well as the effect of ageing itself (Ansello, 1988; Crewe, 1991; Yorkston et al., 2010). Zarb (1993) notes that many disabled people experience 'premature' physical ageing, which means the process of physical degeneration associated with their impairment rather than with age itself. A study by Lin and Lin (2004) shows that in Taiwan many disabled people aged over 50 experience physical degeneration. Three interviewees reported that they had experienced functional degeneration in recent years. For example, Yi-Jun, aged 53, experienced a rapid decline in her physical strength. She mentioned that some of her friends experienced the effects of PPS in their early forties. Likewise, Mei-Zhu at the age of 53, mentioned that she had experienced the effects of premature physical ageing.

I experienced functional degeneration earlier than my same-aged friends... I am now 53, but my physical condition declined just like people aged 70 (Mei-Zhu).

The causes of PPS have not yet been precisely identified. One explanation is that PPS is a process of premature ageing caused by overwork of the remaining motor neurons (Howard, 2005). Pentland et al. (1999) indicate that disabled women make great efforts to be 'good mothers', and hold down jobs, which are usually physically demanding tasks. As a result, they might experience physical degeneration associated with overuse of physical strength in early years. Three interviewees reported that overuse of physical strength in their early years led to functional degeneration. For example, Li-Hua used to walk on crutches. She lived in an apartment which was not accessible. Li-Hua had to climb many steps every day and this caused shoulder pain. She was not able to walk on crutches and started using a wheelchair a few years ago. The experience of Shu-Fen is similar. She had to deal with physical barriers at her home and workplace. Overuse of physical strength in her early years led to a rapid functional decline.

My house and workplaces were not accessible, so I had to manage many steps every day. I thought it was just like an exercise, it was good for my health. But I was wrong. I was diagnosed with PPS a few years ago. I lost physical strength of my unaffected leg because I walked too much. (Shu-Fen).

Abberley (1987) argues that impairment may not be simply caused by biological factors, but can be attributed to social factors such as occupational injury, industrial pollution, war and conflict. Seekins et al. (1994) suggest that disabled people may acquire additional impairments caused by environmental factors, such as lack of accessibility or assistive devices. The previous chapters show that the participants have to deal with physical barriers in schools and workplaces. These examples discussed above show that functional decline experienced by disabled people is not simply caused by physiological factors, but could be a consequence of the effects of environmental barriers.

In addition to the effects of physical premature ageing, several informants reported that they experienced functional losses associated with ageing itself such as vision loss, memory loss, menopause, and osteoporosis. Midlife women have to deal with menopause symptoms, such as hot flushes, irregular menstrual periods and sleep disruption (Boyd and Bee, 2014). Existing studies have not paid much attention to disabled women's experiences of menopause (Campling, 1979; Morris, 1989). A study by Roller (2004) indicates that women with severe PPS symptoms may experience more menopausal problems. In the present study, most participants mentioned that they experienced menopause symptoms which were similar to their non-disabled counterparts. As discussed in Chapter Five, some participants found it difficult to manage their menstruation and needed support from others (see section 5.6.2). Xiu-Zhen had a positive attitude to menopause and saw it as a relief.

It was inconvenient for me to manage menstruation. I wish I could stop it earlier. Menopause was good for me because I did not need to deal with menstruation anymore (Xiu-Zhen).

Women who use wheelchairs face practical difficulties managing heavy periods during menopause (Morris, 1989). Li-Hua is a wheelchair user. She experienced irregular and heavy menstruation during menopause. It was difficult for her to manage personal hygiene.

...it was not easy me to deal with heavy menstruation. It made me feel uncomfortable. I always felt filthy when I woke up in the morning (Li-Hua).

Several participants mentioned that they had to cope with ageing-related diseases. For instance, Yu-Lan mentioned that she visited the doctor more frequently in recent years for the treatment of diabetes and renal calculus. Shu-Juan was diagnosed with a cataract a few years ago, and the disease had significantly reduced her vision. Priestley (2003) indicates that older people with impairment are rarely recognised as 'disabled' because impaired bodies are more likely to be seen as 'normal' in old age. However, the normalcy of impaired bodies may create a problem for older disabled people. The ageing experiences of disabled people can be complicated, and their needs may be overlooked by service providers. The following example demonstrates that the ageing experience of disabled people could be different from non-disabled people. Disabled people experience chorionic disease associated with ageing, but their experiences might be more complicated due to the effects of pre-existing impairment. Cataracts are common eye conditions experienced by older people and can be cured by surgery. Shu-Juan underwent scoliosis surgery a few years ago. She currently depends on a breathing machine, and this made it difficult for her to have cataract surgery. The effects of pre-existing impairment prevented her from seeking treatment for her vision loss.

I was diagnosed with a rare kind of cataract, posterior cataract. I have a shadow growth that blocks my vision. It has affected my driving and reading... in my case with my being on the breathing machine, using anaesthesia was a challenge. There's nothing one could do about this (Shu-Juan).

Previous studies have shown that polio survivors experience new functional losses caused by PPS and need the support of assistive technology (Stuifbergen, 2005; Gonzalez et al., 2010). Four participants mentioned that they used to walk on crutches and recently had to start using wheelchairs, due to functional changes. As mentioned in Chapter Four, the 'Regulations on Subsidisation for Medical Treatment and Auxiliary Appliances for Disabled People' was implemented in 1999. People who have mobility difficulties are entitled to claim the subsidy for assistive devices and modified vehicles (Legislative Yuan, 1999b). Xiu-Zhen experienced acute pain in her shoulders and could not use crutches. The subsidy scheme enabled her to purchase an electric wheelchair. The government launched the 'Implementation Guidance for Job Accommodation for People with Disabilities' in 1999. It provides subsidy for disabled employees to make adjustments in their workplaces, including equipment and assistive devices (Ministry of Labour, 1999). Yi-Jun currently walks with crutches. It became more difficult for her to manage long distances in her workplace. She considered claiming the subsidy to purchase an electric wheelchair for work.

Apart from the use of assistive technology, three respondents mentioned that they used home help services to assist them in dealing with daily tasks. As mentioned in Chapter Four, the government launched the 'Ten-Year Long-Term Care Programme' in 2007. This programme provided community care services for people aged 65 and over and disabled people aged 50 or over with high support needs (Yen et al., 2014). Morris (1993b) argues that community care services in the UK overly emphasise the roles of professionals in needs assessment, whilst restricting disabled people's autonomy and independence. A similar finding can be seen in Shu-Fen case. The example shows that the home help service was dominated by service providers rather than disabled people themselves, and failed to respond to the needs of disabled people.

I asked the home care worker if she could clean the upper part of the wall, but she was not allowed to climb up because of safety issues... they were able to prepare more meals for me because they assumed that I would share my food with my children. How did they know how much food was enough for me? They were not concerned about what I actually needed (Shu-Fen).

Shu-Fen's case shows that community care services were inflexible and restricted disabled people from having choice. Barnes and Mercer (2006) suggest that the development of user-led services allows disabled people to control the services they need, whilst they are not just involved in consultations about traditional social 'care' services. In Taiwan, user-led services remain underdeveloped, social services for disabled people are mainly dominated by professionals such as social workers and special education and rehabilitation professionals. As mentioned in Chapter Two, Finkelstein (1993) terms this situation 'the administrative model of service intervention'. Although services have shifted from medical control to community-based services, most non-disabled professionals still occupy an administrative position in service provision. The participants' accounts show that the majority of participants have experienced premature physical ageing and need support to cope with their new functional losses. Although these women have experienced physical degeneration, they are expected to provide care for their ageing family members. More detail is given in the next section.

## **8.2 Caregiving for Ageing Family Members**

As mentioned in Chapter Four, in Taiwanese culture, sons have to take responsibility for looking after their aging parents. This does not necessarily mean that sons provide physical assistance for their ageing parents. A study by Lin et al. (2003) suggests that sons usually provide financial support for parents, whereas daughters are more likely than sons to provide physical assistance. Most caregiving activities are carried out by women such as wives, daughters, and daughters-in-law (Chao, 2001). In the previous chapter, we saw that most of the participants have to look after their children and their parents-in-law. Most of the participants continued their caring roles into middle age. Some provided support for their ageing parents and parents-in-law, and others provided assistance for their sick spouses.

Several participants mentioned that they experienced physical degeneration and needed help carrying out caregiving activities. For instance, Xiu-Zhen described how it was becoming more difficult for her to do housework and look after her mother-in-law. Her mother-in-law had an increased need for medical services. Xiu-Zhen would ask her son to take her mother-in-law to visit the doctor. This example shows that her family members could share caring work with her.



My children had replaced my role. My children did laundry and cleaned the house for my parents-in-law. Sometimes my husband had to accompany my mother-in-law to the hospital. My son would come with them (Xiu-Zhen).

However, not all participants had informal support to help them look after their ageing family members, particularly those who never married and those who were only children in their families. Lin et al. (2003) indicate that unmarried adult children are more likely to provide assistance for their ageing parents than those who are married, particularly never-married daughters. Harrison (2006) suggests that disabled women who are unmarried are more likely to live with their ageing parents and provide mutual support. For example, Shu-Juan had never been married and lived with her parents. Her siblings were married and lived separately. Although Shu-Juan's siblings could share caring responsibility with her, she was the main caregiver for her parents. Shu-Juan had severe impairment and needed support from her mother to complete daily living tasks. She drove an adaptive car and this enabled her to take her parents to visit the doctor.

I was busy taking care of my aging parents... I was currently taking care of paying bills... taking them to their medical appointments, taking care of the house maintenance etc. I had a sister and two brothers... they did share rides to the medical appointments. However, I still needed to arrange them because none of them knew my parents' condition, since they didn't live with us (Shu-Juan).

Morris (1993b) suggests that disabled women could perform their caring roles if they had access to transport and received appropriate support for themselves. In Shu-Juan's case, the availability of an accessible vehicle enabled her to take her parents to hospital. As mentioned in Chapter Two, no one in a modern industrial society is completely independent, we all live in a society of mutual interdependence (Oliver, 1990). Shu-Juan's case challenges the stereotype that disabled people are dependent on their families. It shows that relationships between disabled children and their ageing parents are interdependent.

Mei-Zhu was divorced, and was the only child in her family. Unlike Shu-Juan whose siblings could share caregiving responsibilities with her, Mei-Zhu found it difficult to provide assistance for her ageing parents on her own. She experienced rapid physical decline, and thus providing care for her parents made her health condition worse. This example shows that disabled women face a dilemma of fulfilment of their caring roles or maintenance of their own health.

It was difficult for me to provide care for my parents. Caregiving was physically demanding work. I had to preserve physical strength and maintain my health, because no one could look after me when I grew old (Mei-Zhu).

These examples have shown that women with polio just as non-disabled women are expected to look after their ageing family members, but they may need support to fulfil their caring roles. Quinn and Walsh (1995) argue that existing social services overlook the needs of midlife disabled women in caregiving, and suggest that policy makers and service providers should support disabled women to carry out caregiving activities. However, In Taiwan existing policies fail to recognise the needs of family caregivers and provide little support for them to look after their ageing family members.

Although the 'Ten-Year Long-Term Care Programme' was launched to provide community care services for older people, resources were misplaced by the government in the development of residential care services (Tsai, 2006). In addition, long-term care services did not effectively respond to the needs of older people and their families due to limited financial resources, shortage of care workers and unequal resource allocation (Chien et al., 2013). Home-based services for older people remained underdeveloped in Taiwan and this made it difficult for families to provide support for their ageing family members. For example, Shu-Fen's case shows that she received little social support to look after her husband. She did not have any choice but to send her husband away to a nursing home.

My husband was diagnosed with dementia five years ago. I could not look after him when his condition became worse. It was difficult for me

to stop him going out. My children had to work, my only choice was taking him to a care home (Shu-Fen).

Despite the fact that placing ageing parents in residential settings has become a new caregiving alternative for some families in recent years, this placement is regarded as a violation of traditional filial obligation by most Taiwanese people (Kao and Stuijbergen, 1999). In this situation, hiring a care worker at home is an option for a family to provide care for their ageing family members. However, the cost of a local care giver could be high, and not every family could afford it. In order to reduce the heavy burden on family caregivers, the government launched a new policy in 1992. Families could employ foreign care workers at home to provide 24 hour care services for older adults and disabled people with high support needs. Most foreign care workers are female and come from Southeast Asian countries, such as Indonesia, Vietnam, and Philippines (Cheng et al., 2014).

The policy challenged the traditional culture that adult children had a duty to provide support for their ageing parents. Lan (2002) introduced the term 'subtracting filial piety' to describe adult children in Chinese families transferring filial piety of caring for their ageing parents to non-family employees. As mentioned earlier, community-based care services remained limited in Taiwan. Therefore, a number of families employed foreign care workers to look after their ageing parents. A study by Chen and Wu (2008) indicates that approximately 15 percent of older people hired foreign care workers to provide care, which was far more than those who used institutional care or home care services, accounting for 10 per cent and 5 per cent respectively. In 2016 the number of foreign care workers in Taiwan was 230,013 (Ministry of Labour, 2016: n.p).

Although the cost of hiring a foreign worker is lower than a local care worker, the government has never provided financial support for families to hire care workers. Therefore, the cost of hiring a foreign care worker could be a burden for a family with low economic status. By the end of 2015, the average monthly wage of a citizen was 38,716 TDW (Executive Yuan, 2015b: n.p), and the monthly payment for a foreign care worker was approximately 25,000 TDW, including monthly wage, agency fee and insurance premiums (Chung, 2011). A study by Chen and Wu (2008) finds that most employers of foreign care workers were middle-class people, while those who were economically

disadvantaged could not afford it. The following cases show that the family's economic status was a determining factor influencing whether a family could hire a foreign care worker. Hui-Ping and her husband both had high paid jobs. She could afford the expense of hiring a foreign worker to look after her father-in-law.

My father-in-law suffered from a serious illness and needed intensive care. My brother-in-law did not allow us to send my father-in-law to a nursing home. We hired a foreign care worker to look after him at home until he passed away (Hui-Ping).

On the contrary, Ya-Lin and her husband ran a lottery shop, which was their sole source of income. As discussed in the previous chapter, the lottery scheme did not necessarily ensure employment security for disabled people, it may have, instead, put them at risk (see section 7.1.3). The income from a lottery shop was not always stable. Ya-Lin worried that she might not be able to afford to hire a foreign care worker to look after her mother-in-law.

My mother-in-law was 86 years old, we considered hiring a foreign care worker to look after her. Our lottery shop had just opened last year, it was not sure whether we could run it successfully (Ya-Lin).

Ya-Lin's case shows that due to the absence of the role of the state in social care services for older people, caregiving for ageing family members could be a heavy burden for those who are economically disadvantaged. In Ya-Lin's case, a large percentage of her income would have been used to pay the cost of care for her mother-in-law. This raises the question of whether Ya-Lin has the financial capacity to afford the cost of living in her own old age. This is a problem because disabled people may experience additional costs when they grow old (see section 8.3.2).

Several respondents mentioned that they found it difficult to manage housework and needed domestic assistance due to functional losses. McKeever et al. (2003) indicate that disabled mothers may experience physical barriers in their homes and have to make renovations to their houses or use

technical devices to carry out their caregiving activities. In Taiwan, house adaptation is covered by long-term care services. Older people who are aged over 65, and disabled people who are aged 50 and above with high support needs are entitled to claim a subsidy for house adaptation. The maximum grant is 100,000 TWD (approximately 2,000 GBP) (Ministry of Health and Welfare, 2007: n.p). Yu-Lan used a wheelchair. She considered using the house adaptation service to make her kitchen accessible, and enable her to prepare meals for her children.

The kitchen was not accessible for a wheelchair user. The kitchen sink was too high for me. I could not switch on the vent fan because it was high. I considered claiming improvement grants to make kitchen adaptation (Yu-Lan).

In addition to house adaption, some participants used home help services to help them do housework. As discussed in Chapter Two, disabled women are often recognised as being in need of care, rather than caregivers, and this makes it difficult for them to receive services to carry out care work or maintain their household (Morris, 1996). Similar findings can be seen in the following cases. Hui-Ping mentioned that she was not eligible for home help services because she lived with her son.

I needed home help services to help me do some housework, but I could not claim the service. The reason was that my son lived with me, and so he would help me do housework (Hui-Ping).

Zarb and Oliver (1993) suggest that inappropriate services for disabled people do not enable them to maintain their independence, whereas they can lead to the creation of dependence for disabled people. In this case, Hui-Ping was perceived as a dependent of her family, rather than a caregiver. She was denied access to home help services because service providers assumed that her son should provide support for her to do homework. The example shows that inappropriate services encouraged disabled women to depend on their family members, rather than assist them in continuing their caring roles. Swain

and French (2001) argue that the power relations between disabled people and professionals are always unequal. Professionals hold the power to define problems and the needs of disabled people, provide intervention, and evaluate the effectiveness of their solutions. Shu-Fen used home help services to clean her house, but her caregiving needs were overlooked by service providers. The case shows the needs of disabled people being defined by professionals, rather than the disabled people themselves.

Home care workers came to my place to do assessment, they asked me which chair I used to sit on. They would only clean the one I sat on. They could not clean the other one that my children often used (Shu-Fen).

Zarb and Oliver (1993) argue that older disabled people may experience multiple oppression based on the intersection between disablism, sexism and ageism. The participants' accounts show that they experienced difficulties fulfilling their caring roles due to the effects of multiple oppressions based on gender, disability and age. The participants, like non-disabled women, were expected to look after their ageing family members. Most of them experienced early losses of physical function and found it hard to carry out caregiving activities. However, existing services failed to acknowledge that they were caregivers for their ageing family members. On the one hand, the cost of social care services for older adults is high, and prevents those who are economically disadvantaged gaining access. On the other hand, services for disabled adults fail to recognise disabled women as a caregivers, and this makes it more difficult for disabled women to provide support for their ageing family members.

It is necessary to mention here that the discussion is not intended to imply that all disabled women are willing to be caregivers. As mentioned in Chapter Two, some disabled women may have no desire for marriage, childbearing or heterosexual relationships and choose non-traditional lifestyles (Fine and Asch, 1988). However, these examples discussed above challenge the negative stereotype that disabled women are passive, weak and dependent on the help of others. The majority of participants, both married and unmarried, were the main caregivers in their families, who have to look after their ageing family members. The next section turns the focus from participants' recent lives to their concerns about the future.

### **8.3 Concerns and Worries about Ageing**

As mentioned in Chapter Two, the existing literature shows that disabled people fear that they may lose their independence and experience institutionalisation when they grow old (Zarb, 1993; Pentland et al., 1999; Chung, 2011). Economic security is important for older people in order for them to maintain their quality of life. Previous studies indicate that women may experience inequalities in access to material resources in early years and this leads to economic disadvantages as they grow old (Pearce, 1978; Minkler and Stone, 1985). A study by Harrison (2006) found that many disabled women experienced early retirement due to the changing condition of their bodies. In addition to economic security, living arrangement is an important issue for older people. Lack of accessible housing and limited material resources may constrain older disabled people's choices of living arrangements (Zarb and Oliver, 1993). Arber (2004) indicates that material status has a great influence on living arrangements for older women. Those who are widowed or never married are more likely to live in residential settings. In the present study, all the participants expressed their concerns about ageing. Three themes emerged in the respondents' accounts, including independence maintenance, financial security and living arrangements in old age.

#### **8.3.1 Independence Maintenance: 'Scrambled Eggs or Fried Eggs?'**

All the participants mentioned that they were afraid of losing control and being dependent on their families when they grew old. Participants' previous experiences significantly influenced their interpretation of 'independence' in old age. As mentioned in Chapter Two, many polio survivors are encouraged by rehabilitation professionals to make efforts to regain their physical abilities in their childhood, and this makes it more difficult for them to accept new functional losses as they age (Scheer and Luborsky, 1991). The experiences of participants in the present study reflect this. As discussed in Chapter Five, most of the participants underwent numerous surgeries and painful rehabilitation therapy during their childhood. They were encouraged to put great effort into regaining physical ability in rehabilitation practice. Those who lived in institutions were told that they had to manage every task on their own (see section 5.4.2). The majority of the participants perceived 'independence' as having the physical capacity to manage things, and therefore being 'dependent' on the help of others was unacceptable. For example, Hui-Ling mentioned that

she would rather choose suicide if one day she had to rely on the help of her children. Yu-Lan also mentioned that she would choose to end her life if she could not take care of herself.

I had put much effort to maintaining my health in my life. If one day I have a serious illness and had to depend on my children, I would choose to end my life (Yu-Lan).

These cases show that the participants' thinking is based on the personal tragedy theory of disability. Disabled people are recognised as a burden for their families and society (Oliver, 1986). As mentioned in Chapter Two, Morris (1991) indicates that the lives of disabled people are devalued by able-bodied people as 'unworthy lives'. Such judgements have rationalised the use of selective abortion and assisted suicide to control the lives of disabled people. This assumption encouraged the participants to believe that they would be better off dead. In the UK, the debate about euthanasia has been raised by disability activists who are campaigning against assistive suicide (NotDeadYetUK, 2015). Society holds the negative assumption that disabled people's lives are intolerable and they should have the right to choose to die. Campbell (2006) critiques this assumption, saying that it denies the existence of disabled people and those with so called 'terminal illnesses'. She argues that disabled people are not treated equally to non-disabled people, face exclusion from participation in society, and therefore do not have options to live with dignity and respect.

Oliver (1990) argues that the dependency of disabled people is not caused by functional limitation, but is created by inappropriate policy and economic exclusion of disabled people. Several participants mentioned that they were afraid they would become 'burdens' on their families when they grew old. The following examples show that the concept of a 'burden' is socially constructed. Existing policies in Taiwan fail to respond to the needs of older people and their families, and this has led to the dependency of older people. As mentioned in the previous section, the cost of social care for older people is high, so not every family can afford it. However, the younger generation may face more challenges in taking care of their ageing parents. According to a survey on the caregiving experiences of middle-aged people in Asia, the middle-aged generation is less likely to receive support from their children when they grow



old. Rapidly falling fertility rates mean that there are fewer children to share caring responsibilities for ageing parents (Economist Intelligence Unit, 2010).

In the present study, most of the participants who were married had two children, and one participant had only one child. Yu-Lan had only one son, and said that her son might not be able to afford the cost of care service for her and her husband. She and her husband considered living in a care home if one day they needed the support of others.

I did not expect my son to look after us. It was difficult for him to bear such a heavy burden. We may move into a care home someday when we need help (Yu-Lan).

As mentioned in Chapter Four, Taiwanese young people are more likely to live in poverty, and these economic conditions make it difficult for them to look after their ageing parents. The number of young people in atypical employment has increased since 2000. It is more difficult for young people to get a full-time job and they are more likely to engage in unstable, low-paid or dangerous jobs (Lin et al., 2011). Hui-Ling mentioned that her financial capacity is much better than her children. She did not expect her children to look after her when she grew old. Similarly, Shu-Fen's example noted that the younger generation might not be able to look after their ageing parents, although they would like to exercise some degree of filial piety.

Today, many young people are criticised for being unfilial to their parents, but this is because they do not have enough money to support their parents, they cannot even afford their living cost (Shu-Fen).

These examples show that the concept of 'dependence' is socially constructed (Hockey and James, 1993). Social care services for older people cannot effectively respond to the needs of older people and their families. In addition, changing family structures and economic conditions make it difficult for young people to look after their ageing parents. It can be seen that older people are

presented as a 'burden', which is attributed to changing social conditions and policy failure, rather than functional limitations.

For some participants, independence means they have control and choice of their lives when they grow old. Grassman et al. (2012) adopted a life course perspective to examine the life experience of disabled people in Sweden. The results show that welfare reform and the development of disability politics significantly influenced disabled people's lives. The following examples show how the independent living movement in Taiwan affected the participants' interpretation of independence in old age. As mentioned in Chapter Four, the meaning of independence has been redefined by disabled people themselves through the independent living movement in Taiwan. 'Independence' means that individuals have the capacity to make choices and have control over their lives (NVILA, 2007). Li-Hua was involved in advocacy work of the independent living movement. She mentioned that she would like to live in her own home, and choose what life she wanted to live when she grew old. Similarly, Mei-Zhu was a volunteer in a disability organisation and participated in training programmes for personal assistants. Mei-Zhu's case shows that independence does not mean that people have the ability to manage every task. She hoped that she could receive sufficient support to enable her to have control and choice of her life when she grew old.

I wished I could choose how I want to live my life. I might employ a personal assistant to cook for me. I could choose what I wanted to eat, scrambled eggs or fried eggs, or fried with some spring onions (Mei-Zhu).

These women's accounts show that all the participants were concerned about maintaining independence in old age. However, the meaning of 'independence' could be different for different participants. Most saw 'independence' as self-reliance, and expressed their fear of being 'dependent' on their families. The development of disability politics has reframed the meaning of independence in Taiwan. Some participants recognised that control and choice was important for them in later life. The next section focuses on financial security in old age.

### 8.3.2 Financial Security

A previous study suggests that disabled people face extra costs in maintaining an acceptable quality of life (Smith et al., 2004). Zarb and Oliver (1993) indicate that older disabled people may experience increased expenditure associated with ageing, such as household maintenance, domestic support, personal assistance, transport and so on. Several interviewees indicated that they faced additional costs associated with their increased need for medical services and accessible housing. As mentioned in Chapter Four, the 'National Health Insurance Scheme' was launched in 1995. Disabled people became eligible to receive an additional subsidy for general medical visits (Chiang, 1997). Two participants mentioned that they visited physical therapists more frequently for treatment of PPS. For instance, Hui-Ping experienced muscular pain and needed intensive physical therapy. The cost of physical therapy was mostly covered by the National Health Insurance.

I did physical therapy twice a week. Disabled people did not need to pay the registration fee for their first visit. Non-disabled people had to pay one hundred dollars for return visits, but we only needed to pay fifty dollars (Hui-Ping).

In addition to the cost of medical treatment, three respondents who used wheelchairs had an increased need for accessible housing. The cost of housing adaptation is high and can be a burden for disabled people. Barnes and Mercer (2010) criticise housing policy in the UK, saying that it fails to recognise disabled people's needs for housing. The improvement grant policy did not appropriately respond to high expenditure on house modification for disabled people. A similar situation can be seen in Taiwan. Yu-Lan for example, had to use a wheelchair. She considered making structural adaptations to her house, but the cost of the major adaptation was estimated at one million TWD. As mentioned, the maximum grant for house adaptation was 100,000 TWD (approximately 2,000 GBP), which was far below the cost Yu-Lan had to pay.

I wanted to restructure the rooms of the building, it would make a big change to my home. The expense of house modification may cost more than one million, I could not afford it (Yu-Lan).

Lack of accessible housing created a problem for Yu-Lan. During the interview, Yu-Lan had just come out of hospital for the treatment of diabetes. She was weak and could not manage the steps to her bedroom. There was no spare bedroom on the ground floor. She did not have any choice but to sleep in the kitchen. Yu-Lan mentioned that she might consider living in a care home if she could not make house adaptations. This case shows how the lack of an accessible house may lead to institutionalisation for older disabled people. Likewise, Hui-Ling, as a wheelchair user, planned to live with her daughter who worked in another city. However, it was difficult for her to find accessible accommodation. Most dwellings were not accessible, and the cost of accessible accommodation was very high.

I was not easy to find a suitable accommodation. Most of the buildings did not have accessible entry or lack of accessible parking. Some accommodations were accessible, but usually the rent was too high (Hui-Ling).

Personal savings and pensions are important sources of financial security for people to maintain quality of life in old age. As mentioned in Chapter Two, Russo and Jansen (1988) indicate that disabled women are much less likely to be covered by pension schemes and health plans than disabled men. Prakash (2003) notes that disabled women experience exclusion in relationships and employment in early years and this may lead to disadvantages in old age. In Taiwan, the official retirement age is 65. Disabled people are more likely to retire early than non-disabled people. According to the 'People with Disabilities Rights Protection Act', the central authorities in charge of labour must recognise the impact of premature ageing on disabled employee, and establish a mechanism of early retirement for disabled employees to ensure their quality of life after they leave work (Legislative Yuan, 2007). A survey has shown that the average retirement age of disabled employees is 52.8, while for non-disabled employees it is 60.7 (Ministry of Labour, 2011: 02).

The following cases show that not all participants have equal access to pension schemes. The participants' financial conditions were related to their previous employment statuses and incomes. This was a factor influencing the

participants' options for early retirement. For example, Yu-Lan ran a small business successfully. She mentioned that she chose to retire early due to physical degeneration. She had a good financial condition and this enabled her to enjoy leisure activities after retirement. In contrast, three participants described how they were not able to retire early because they needed regular income to maintain a living. As discussed in Chapter Two, Harrison (2006) says that some disabled women have to push themselves to stay employed as long as possible in order to receive aged-based entitlements through their work, despite the changing condition of their bodies. Denton et al. (2013) indicate that disabled people are more likely to retire involuntarily than non-disabled people due to health problems. Those who retire involuntarily have significantly lower incomes than those who retire voluntarily. Yu-Lan never considered early retirement. She has no choice but to stay in employment, even though she has experienced functional decline in recent years.

I wished I could stay at my job as long as I could. If I left my job, I would not have enough money for retirement. I had experienced physical weakness, but I still could work (Yu-Lan).

The example suggests that although early retirement can be an option for disabled people, not all disabled people are allowed to make their own choice, particularly those who are economically disadvantaged. As mentioned, the majority of the participants had experienced the effects of premature ageing and this made it difficult for them to manage daily tasks and work (see section 8.1). This raises the question of whether existing policies and service provision can provide adequate support and career options for disabled employees who experience the effects of ageing, and enable them to choose early retirement or maintain their jobs. A study by Pagán (2012) shows that older disabled people are more likely to work part-time than their non-disabled counterparts and suggests that policy makers should create more part-time jobs for older disabled people. The flexibility of part-time employment enables older disabled people to have greater choice and smooth work-retirement transitions. However, in Taiwan the issue of early retirement of disabled people has not been addressed either in academic discussions or policy making.

It is noted that the concept of retirement may not fully describe the experience of disabled people, since many disabled people are excluded from the paid

labour market (Priestley, 2003). Holland (2000: 29) indicates that many people with learning difficulties are excluded from paid work. Without work or its equivalent there can be 'no retirement'. As discussed in the previous chapter, Shu-Juan left her job and did not return to paid employment due to the effects of PPS (see section 7.1.4). Shu-Juan lived with her parents in the United States. She received financial support from her parents and statutory benefits to maintain her life. This example shows that disabled people who are excluded from paid employment in their early years are more likely to experience economic disadvantages and uncertainties when they grow old.

I got some financial help from the government, but the amount is too small for someone to live comfortably... I sold some work such as paintings, sculptures and ceramic work at the exhibits, but not enough to support me financially (Shu-Juan).

In Taiwan, the existing benefits system does not provide sufficient financial support for disabled people to live their lives. Most welfare benefits for disabled people are means-tested and solely provide for disabled people with low-incomes (Legislative Yuan, 2012). As mentioned in Chapter Two, the Taiwanese government launched 'National Pension Insurance' in 2007, which aimed to ensure the basic economic safety of citizens aged 25-65 who were not covered by any related social insurance. People need 40 qualifying years of national insurance contributions to get their full basic national pension (Huang, 2008). Wang et al. (2007) criticises the National Pension Insurance, saying it cannot protect the economic security of the disadvantaged population, since many people cannot even afford to pay the insurance premium. In addition, several welfare benefits schemes have been suspended since the implementation of the national pension scheme, including disability living allowance. This puts disabled people at great risk of financial hardship (Huang, 2008). In the present study, the majority of participants were not eligible to claim disability benefits, and only two of the participant received statutory benefits.

The examples discussed above show that the participants face an increased cost of living to maintain the quality of life when they grow old. Some participants experienced inequality in employment in early years and this made it difficult to gain access to pension schemes. However, existing policies do not

provide enough financial support for disabled people to ensure economic security as they grow old. Those who are economically disadvantaged in adult life may experience more economic hardship and uncertainty in old age. The next section discusses the participants' living arrangements in old age.

### **8.3.3 Living Arrangements in Old Age: “We are Not Just Waiting to Die.”**

‘Ageing in place’ is a popular term in current ageing policy. A survey by the United Nations (2012) emphasises that social policies should encourage communities and families to develop support systems which enable older people to receive appropriate services to facilitate ageing in place. Wiles et al. (2012) indicate that older people prefer to live in their own homes where they feel connected to other people and secure in a familiar environment. In Taiwanese culture, home is not only a place to live, but also a place to die. Traditionally, Taiwanese people believe that dying at home benefits not only the deceased, but also the wellbeing of living descendants (Tang, 2000). Although the number of older people living at home has decreased over the last decade, the majority of older people prefer to stay in their homes (Hsueh, 2008). Living arrangements of older people have changed in recent decades. Older people may consider neighbouring living arrangements with their married children. This means that married children do not live with their parents, but live close to their parents. By doing this, married children can maintain their privacy, and their parents have the support of their children living nearby (Tseng et al., 2006). This is shown by the current study. The majority of the interviewees said they would prefer to live in their own homes when they grew old. For those who are married, most did not expect to live with their married adult children but preferred to live with their spouse alone. Some mentioned that they would like a neighbouring living arrangement with their married children.

Previous studies demonstrate that individuals' financial capacities significantly influence the availability of services and living arrangements in later life (Arber and Ginn, 1991; Chen and Chen, 2012). Similarly, the following examples show that the participants' material statuses influence their options for living arrangements in old age. In Taiwan, residential care services are provided by both the public and private sectors. Publicly owned nursing homes are funded by the government or local councils, and their cost is relatively lower than privately run nursing homes (Wu, 2007). Ya-Lin was afraid of being a burden to

her children. She considered living in a publicly owned care home with her husband when she grew old, because the cost of a publicly run care home was much more affordable. Li-Hua had never married and lived alone. She mentioned that she might not have enough money to support herself at home. Living in a publicly run institution could be her final choice. She described how it might not be a good thing to 'live too long', if she could not maintain an acceptable quality of life.

If I did not have enough savings for retirement, I might register as a low-income household and stay in a public institution. This is my plan for the worst. It might not be a good thing to live too long (Li-Hua).

These examples show that those who are economically disadvantaged are more likely to experience institutionalisation in later life. Mei-Zhu's case was different. DaVanzo and Chan (1994) suggests that older people who are financially independent are less likely to live with their children. Their greater access to material resources may enable them to 'purchase privacy'. This can be seen in Me-Zhu's example. As discussed in the previous chapter, Mei-Zhu made a good living as a fortune-teller (see section 7.1.2). Me-Zhu was a single mother of two children. She mentioned that she preferred to live alone as it enabled her to maintain her privacy. She planned to buy a three-story property, and each of them could live on different floors. She was able to afford the cost of social care services and this gave her more options for living arrangements in old age.

I might employ a foreign care worker to look after me at home, or move into a private care home which provides good quality services for older people (Mei-Zhu).

In addition to material conditions, marital status was an essential factor influencing the living arrangements of the participants in old age. As mentioned in Chapter Two, Arber (2004) suggests that women who are widowed or never-married are more likely to live in residential settings in old age than those who are married. Living alone was a key issue, mentioned by several participants.



The number of people living alone has significantly increased in Taiwan. In general, the prevalence of one-person households in Asia is lower than in Europe and North America, but the more economically developed countries in East Asia such as Japan, South Korea and Taiwan have higher proportions of one-person households (Yeung and Cheung, 2015). In Taiwan, the percentage of older people living alone has increased from 6.49 per cent in 1991 to 9.94 per cent in 2005 (Hsueh, 2008: 52).

In the present study, some of the participants who were divorced or never-married had lived alone for many years. Victor et al. (2000) look at the interrelationships between loneliness, social isolation and living alone, and find that people who live alone feel isolated, compared with their peer groups who live with partners. Li-Hua was never married and lived on her own for many years. Li-Hua expressed her feelings of loneliness from living on her own. Her siblings were married and lived separately. She worried that one day she may die alone at home, and nobody would notice it. In addition to psychological distress, Hui-Ling's case shows that living alone was a problem for her, particularly when she needed support. Hui-Ling was divorced and lived on her own. She underwent eye surgery and this made it difficult to manage her wheelchair.

I underwent cataract surgery last year. My eyesight was not fully restored. I found it hard managing my wheelchair. I always got hurt at home. When you are old, you need a partner who lives with you and gives you support (Hui-Ling).

Living arrangements could be a particular issue for those with high support needs. Shu-Juan was never married and lived with her parents. She had severe impairment and needed support from her mother to help her with daily tasks. She worried that she might lose that support when her parents passed away. This example shows that people with high support needs may face more uncertainties surrounding their living arrangements when they grow old.

Being single made it very uncertain who I will have to live with, as it's apparent that when my parents pass away, I'd need some kind of care.

My mom helps me with housework, cooking, and setting up things for shower, changing my breathing machine tubes, etc. It would be very hard for me to have to live with other people and pay their expenses (Shu-Juan).

Solo living is not only an issue for those who never married or are divorced, but also for those who become widows. As mentioned in Chapter One, women are more likely to be widowed than men. At the end of 2011, approximately 29.30 per cent of older disabled women were widows, but only 7.01 percent of older disabled men were widowers (Ministry of Interior, 2011: 78). Several participants mentioned that they did not expect their children to look after them when they grew old. They may choose to live alone or live in residential settings when their partner passed away. Two participants indicated that they did not want to live with their children, but expected their children to visit them regularly. It is worth noting that three of the participants mentioned that they would prefer to live in institutions if their husbands passed away. For example, Yu-Lan mentioned that she would like to live with other older disabled people, rather than her children. She expected the government to create accessible dwellings for older disabled people and provide supportive services for them.

We are not like other older people who could participate in many leisure activities. We need a place to stay when we are old. The place should be accessible. We could enjoy leisure activities there, such as chess games or karaoke. We are old, but we are not just waiting to die (Yu-Lan).

A study conducted by Lin et al. (2003) shows that people with physical impairment in Taiwan experience environmental barriers that hinder them from participating in leisure activities, such as lack of accessible transport, accessible building, and recreation places. Yu-Lan's case shows that the needs of older disabled people in recreation and leisure are profoundly ignored by existing services. This example shows that older disabled people are not people who have 'care needs', while they do need support that enables them to participate in leisure activities to maintain their quality of life.

Patterson et al. (1993) suggest that friendship is important for lone older people when they have lost the social contact of work and lack family support. Some older people recognise 'reciprocity' as an essential element of friendship, such as caring, physical help, and financial assistance. Arber and Ginn (1991) indicate that friendship provides an opportunity for lone older women to continue the caring role which has been socialised in them in their early years. Two participants mentioned that they would prefer to live with other older disabled people. It was important for them to have friends and provide support for each other. For example, Shu-Fen would like to live in a group home with other older disabled people when she grew old. Providing assistance to other people might make her feel needed.

The government should provide houses for older disabled people... not a big institution, but just a normal house in a community. People there could help each other. For example, blind people could push my wheelchair, and I could give directions for them (Shu-Fen).

Likewise, Li-Hua expected to live with other disabled people when she grew old. She also mentioned that older disabled people could support each other to complete their daily tasks.

We could cook together. Some plan a menu, some prepare ingredients, and others cook. It is important that we have things to do with our friends when we are old (Li-Hua).

These examples show that living in residential settings may not always be a negative thing for these participants. Living in a residential setting may provide an opportunity for them to establish friendship and peer support. In addition, these cases show that the feeling of being needed was important for the participants as they grew old. As mentioned in Chapter Two, older people and disabled people are two social categories that share common characteristics in social structure and cultural representation. They are both often perceived as unproductive or dependent (Priestley, 2003). The participants' accounts challenge such negative stereotypes about older people and disabled people. It

can be seen that older disabled women can continue their caring roles into old age. They are not always dependent on the help of others, but can provide support for others.

The examples discussed here demonstrate that most of the participants did not expect their families to provide support for them when they grew old. Conversely, they expected the government to provide accessible dwellings and supportive services for them. This suggests that the traditional Confucian belief that children are expected to look after their parents has changed. The role of the state in social support for older people has become more significant. As Yu-Lan described, the traditional belief has changed over the last decade.

In the past, we might expect to our children to take care of us when we were old. Older people lived and died at their homes. Today the situation is different, many older people live in institutions (Yu-Lan).

As mentioned in Chapter Two, Walker and Walker (1998) argue that people ageing with learning difficulties face 'double jeopardy' in age-based service provision. On the one hand, disabled people who experience the effects of premature ageing are too young to be eligible for social services for older people. On the other hand, services for young disabled adults focus on skill development, which are not appropriate for those experiencing the effects of premature ageing. Similarly, the existing policy and social services in Taiwan are mainly based on age, and fail to respond to the needs of people ageing with physical impairment. Beardshaw (1988) examines community services for people with physical impairment in the UK. The report shows that policy makers pay little attention to community services for people with physical disabilities, compared to other groups such as older people and people with mental illness. A similar situation can be found in Taiwan. Lin (2012: 481) indicates that nearly 70 per cent of residential services are provided for people with learning difficulties and people with multiple impairment. In the early 1990s, the Taiwanese government initiated 'community home' services, which aimed to develop community-based residential services for disabled people. Several 'community homes' were established by the public and voluntary sectors, but mainly for young adults with learning difficulties (Chou and Schalock, 2007).

In addition, services for older people overly emphasise the dependency of older people and focus on intensive healthcare. In recent years, several group homes have been established for older people, which are provided particularly for people with dementia who have high support needs (Kuo et al., 2012). However, these services for people with high support needs may not be suitable for the participants. The participants who experienced the effects of premature ageing may not necessarily have high demands for social care services. They may need accessible equipment and appropriate services that enable them to maintain independence and their social lives. These inappropriate services may constrain participants' options for living arrangements in old age.

## **Summary**

This chapter explores the participants' experiences in middle adulthood. The women's accounts highlight that they experienced multiple oppression based on disability, gender and age. Most participants experience early decline in physical function caused by the effects of premature physical ageing. Disabled women, just as non-disabled women, are expected to provide support for their ageing family members, while the effects of physical degeneration make it difficult for them to carry out caregiving activities. Existing services for disabled adults fail to respond to their caregiving needs, and hinder them from fulfilling their caring roles. In addition to caregiving, participants expressed their concerns and worries about ageing. Maintaining independence was a crucial issue mentioned by all the participants. Their previous experiences of rehabilitation practice and changing disability politics significantly affected their interpretation of independence in old age. Financial security was a crucial factor influencing the participants' lives in old age. Some participants faced additional costs of living associated with ageing. Lack of savings and pension benefits made it more difficult for participants to live their life comfortably as they grew old. Most of the participants expressed their concerns about living arrangements. Living alone was highlighted in the discussion. Most of the participants did not expect their families to provide support for them in old age. The role of the state in social support for older disabled people was emphasised by the participants. The next chapter summarises the research findings and discusses the insights of the research.

## **Chapter Nine**

### **Conclusion**

#### **Introduction**

This study explored the experiences of women ageing with childhood-onset polio in Taiwan, from a life course perspective. In previous chapters, I identified the barriers and inequalities experienced by the participants at various life stages, and examined the impact of previous life experiences on their present lives. In the conclusion, it is appropriate to revisit these key themes. In the first section, a summary of the empirical findings is presented in terms of the four main research questions. The second section provides a discussion of the research findings. The implications for policy and practice are considered, and finally recommendations for future research are made.

#### **9.1 Summary of Research Findings**

This section provides a summary of the research findings of the study with respect to the four main research questions.

##### **9.1.1 What, if any, inequalities and barriers do women with childhood-onset polio experience across the course of their lives?**

The fieldwork demonstrates that women with childhood-onset polio experience barriers and inequality across the course of their lives, and this hinders them from fully participating in society. The participants experienced multiple oppression, which were attributed to the complex interaction between disability, gender, class and age. The effects of multiple oppression varied depending on the context, and significantly shaped these women's lives. Medicalisation was a common theme mentioned by participants in their childhood. Most of them were taken to hospitals or rehabilitation institutions without being asked. Some participants lived in institutions for several years and this led to segregation from society. In order to regain functional abilities, they underwent numerous surgeries and painful rehabilitation therapy.

In Taiwan, social policies for disabled people were absent prior to 1980. Due to a lack of social support, most disabled people had to rely on support from their families (see Chapter Four). Not all the participants had equal access to education. Some participants were not allowed to continue with their studies due to travelling problems. In contrast, those who were economically privileged could overcome travelling problems and had access to education. This suggests that social class profoundly influenced the availability of educational opportunities for the participants. The experience of disablement is gendered. Some participants found it hard to manage menstruation due to a lack of accessible equipment in their school. The social stigma attached to menstruation made it difficult for them to seek help from others.

Youth is a transitional stage between childhood and adulthood. Preparation for future careers and the formation of intimate relationship were two themes that emerged from the participants' accounts. The participants experienced the effects of the interaction between disability and gender, and this restricted them from fulfilling their career aspirations. Some participants were discouraged from developing their academic careers because their parents and teachers had low expectations for their academic performances. Stereotyped portrayals of disabled people only being able to do specific jobs constrained the participants' career options. Gender stereotypes also influenced the participants in choosing subjects and vocational training courses which were perceived as being appropriate for women. Social class influenced the availability of educational opportunities for the participants. Similarly, family economic status profoundly affected their career options. Those who were economically disadvantaged experienced difficulties that hindered them from pursuing certain careers, while those who were economically privileged had more options for their career development.

Participants faced difficulties in establishing intimate relationships. They were denied to access to the usual recreations of young people by physical barriers and prejudicial attitudes, and this made it more difficult for them to meet potential partners. Some participants were discouraged by their parents from developing sexual relationships and this undermined their sense of self-worth. The myth that disabled people should form relationships with other disabled people restricted their choices of potential partners. Several participants met their partners through specific activities for disabled people, and most of their partners were also disabled.

Getting a job and having a family were two themes mentioned by the participants related to their early adulthood. The emergence of factory-based industry during the 1960s and 1970s provided job opportunities for several of the participants, but it also excluded those who had severe impairment from the labour force. Several employment policies for disabled people were implemented during the 1980s. These employment schemes provided job opportunities for some participants, but they did not challenge employers' negative attitudes towards disabled people. Most of the participants experienced physical barriers and prejudicial attitudes in workplaces.

Self-employment provided an opportunity for those who were excluded from the paid labour market. Some participants used self-employment as an alternative to balance the dual demands of caregiving and work. Policies and vocational training programmes did not provide sufficient support for disabled people to initiate or maintain their own businesses. On the contrary, the policies put disabled people at risk and created job instability. It is noted that not all the participants were able to do paid work. Those who were severely impaired could not meet the job requirements of a capitalist society. The experiences of those who lived without earnings demonstrate that paid work is not necessarily a criteria by which to evaluate an individual's worth. The meaning of work should be redefined in terms of disabled people's perspectives.

The majority of participants were the main caregivers in their families. They experienced difficulties that hindered them from fulfilling their roles as mothers. Existing services for disabled adults failed to respond to the disabled women's needs around childcare and parenting. However, the high cost of child care services created a heavy burden for them, particularly those who are economically disadvantaged. Those who were single disabled mothers experienced multiple oppression based on disability, gender and singlehood and this made it difficult for them to access social support and material resources to look after their children.

In mid-adulthood, most of the participants reported that they experienced an early decline in their functional abilities associated with premature ageing. They were expected to take care of their ageing family members, but it became more difficult for them to manage caregiving activities due to the effects of physical degeneration. Existing community care services saw disabled women as a people 'in care need', rather than caregivers. On the other hand, the cost of social care services for older people is high, such that not all the participants could use them to provide support for their ageing family members. This



suggests that disabled women were still expected to provide support for their families, even though they had experienced functional losses. Their needs for caregiving remained underrepresented in policy and service provision.

Participants expressed their concern about ageing. Most of them were afraid of losing control and independence in old age. The participants' past experiences of rehabilitation practices influenced their interpretations of independence. Being a 'burden' to their adult children was unacceptable for some participants. The independent living movement in Taiwan redefined the meaning of independence as having control and choice in life. The changing concept of independent also affected the participants' interpretations of independence in old age. Financial security in old age was a key issue mentioned by participants. Some faced the additional expenses of living associated with ageing. Those who were excluded from paid work or employed in low-paid work were more likely to experience financial hardship in old age. The existing welfare benefits system and the national pension scheme did not provide sufficient support to protect the financial security of older disabled people.

Material conditions had a great impact on the participants' choices of living arrangements in old age. Those who were economically disadvantaged were more likely to experience institutionalisation in old age. The issue of living alone was highlighted in several of the participants' accounts. Those who were divorced or never married had no choice but to live alone. For the participants who were married, they did not expect to live with their children when they grew older. Some participants preferred to live in residential settings when their spouses passed away. This suggests that most of the participants did not expect family members to provide support for them when they grew old. The role of the state in social services for older disabled people was emphasised by the participants. However, existing services for older people and for disabled adults fail to recognise disabled people' needs associated with ageing.

### **9.1.2 How do women with childhood-onset polio respond to the disabling environments?**

The research findings could be seen as a counter-narrative, which challenges stereotypes of disabled women in society. As discussed in Chapter Two, several scholars emphasise that studies on disabled women should not just treat them as victims, it is necessary to recognise how disabled women resist oppression and combat discrimination (Morris, 1996; Hans, 2015). The

research findings show that the participants developed strategies to cope with the barriers and inequalities they faced. Families played an important role in the participants' career choices. Some received support from their families to pursue their careers, while others were not allowed to make decisions on their own. Overprotective family members prevented the participants from fulfilling their career aspirations. Some participants resisted parental authority to regain control over their lives. They made their decisions creatively even with constrained resources (see section 6.1.2).

Disabled women, like non-disabled women, are subject to culturally constructed gender norms. Most of the participants made great efforts to meet the social standards of being a 'good mother' and a 'good daughter-in-law'. Those who never married were also expected to provide support for their ageing parents. However, a lack of support and the disabling environment hindered these disabled women from providing support for their families. Some developed alternatives ways to look after their children, or sought help from their family members to help them complete care tasks. Others tended to challenge the conception of parenting by placing greater emphasis on providing love and companionship for their children, rather than physical assistance (see section 7.2.2).

It is worth noting that one participant with severe physical impairment was the main care-giver for her ageing parents. She received appropriate support that enabled her to maintain her independence, and thus she was able to provide support for them (see section 8.2). In Taiwanese culture, women are under pressure to be a 'good daughter-in-law'. They are expected to look after her parents-in-law and do household work. The participants were often perceived as unfitting daughters-in-law, and this made it more difficult for them to establish intimate relationships. Some participants tried hard to meet the social standards of a daughter-in-law, by developing strategies to provide support to their parents-in-law.

### **9.1.3 How do the past experiences of women with childhood-onset polio affect their current life?**

The fieldwork demonstrates that participants' previous life experiences shaped their present lives. Their early childhood experiences of rehabilitation practice influenced the participants' interpretations of the meaning of 'independence'. They were told by rehabilitation professionals to put in a lot of effort to regain

the ability to walk, while none of them were encouraged to use wheelchairs. Some participants lived in rehabilitation institutions for several years. They were encouraged to manage every daily task on their own. The impact of independence culture prevented the participants from seeking help from social services when they needed support, and also made it more difficult for them to accept new functional losses as they grew old (see section 5.4.2 and section 8.3.1).

In addition, those who were excluded from education in the early years experienced greater difficulties in accessing work. The research findings show that those who were uneducated and those who had low educational qualifications were more likely to become self-employed or be employed in low-paid jobs. Moreover, they were less likely to have opportunities to accumulate extensive work experience and this hindered them from moving to higher positions (see section 7.1.3). Furthermore, the previous employment status of the participants profoundly influenced their financial security and choices of living arrangements in old age. These participants who earned a good income had greater access to material resources, and thus had more options for retirement planning and living arrangements. Conversely, those who were economically disadvantaged were less likely to choose early retirement.

Marital status also affected the participants' choices of living arrangements in old age. Those participants who were divorced or never married, some had lived on their own for several years. They faced more uncertainty in their living arrangements as they aged. Most of the participants who were married did not expect to live with their children and may choose to live in residential settings or live on their own in old age. This suggests that living alone was not just an issue for single disabled women, but also for those who were widowed (see section 8.3.3).

#### **9.1.4 What social and cultural factors influence the life experiences of women with childhood-onset polio across the course of their lives?**

Previous studies show that many disabled women are discouraged from having children because of the social prejudice against disabled women (see section 2.2.3). The research findings show that the participants' experiences of pregnancy were affected by the custom of 'boy preference'. 'Boy preference' is a custom rooted in gender inequality that is prevalent in Taiwan. Social

pressure is put on married women to have a son for their husbands' families. Some participants were expected by their parents-in-law to have additional births until they had a boy. This suggests that the disabled women not only experienced disability-based oppression, but also experienced gender-based oppression in a patriarchal society, and these two forms of oppression undermined their reproductive autonomy (see section 7.2.1).

In Taiwan family functions and behaviours are shaped by Confucian beliefs. Confucian beliefs profoundly shaped the life experiences of the participants across the course of their lives. Based on Confucianism, parents have a duty to look after their children, and adult children have to exercise filial piety by taking care of their ageing parents. This cultural assumption emphasises families' duties to take care of their disabled children. Some participants were overprotected by their parents and did not have the power to make decisions for themselves. Most of them did not have a voice in the decision-making process about seeking medical treatment in their childhood. Some did not have a choice but to accept the jobs arranged by their parents. In some cases, parents convinced their disabled daughters not to get married (see section 6.2.2).

When the participants grew up, they were expected to be caregivers in their families. Their needs of caregiving remained underrepresented and overlooked by policy and social services. Over the last few decades, the traditional belief that adult children should look after their ageing parents has changed. A low birth rate means that the younger generation cannot share caring responsibilities with their siblings. In addition, many young people are not able to afford the rising cost of social care for ageing adults (see section 8.3.1). This changing cultural norm had a great impact on the participants' lives. They were expected to provide support for their families throughout their lives, while they found it difficult to receive support from their own families when they grew old.

## **9.2 Discussion**

As discussed in Chapter Two, several studies have suggested that disabled women experience 'doubled disadvantage' associated with their dual identities of being women and being disabled (Fine and Asch, 1988; Hanna and Rogovsky, 1991). Vernon (1999) argues that the concept of 'doubled disadvantage' fails to recognise the complex interaction between various forms of oppression. In Vernon's view, people with multi-stigmatised identities experience oppression singularly, multiply and simultaneously, depending on

the context. The effects of disability on individuals can be modified or exacerbated in terms of their ethnicity, sex, sexuality, age and class (see section 2.2.2). Similarly, the research findings demonstrate that the participants experienced multiple forms of oppression depending on various contexts. The participants certainly faced difficulties caused by the interaction between gender and disability, which prevented them from establishing relationships and becoming mothers. In addition, the absence or presence of privileged status either minimised or exacerbated the effects of the barriers experienced by the participants. Social class had a great impact on the participants' experiences of disablement. It influenced the availability of education and job opportunities for them.

The research findings deepen the understanding of the complex interaction between multiple forms of oppression. In Vernon's view, being disabled is a stigmatised identity. However, the research findings show that being disabled could be seen as a 'privileged status' in particular contexts. As discussed in Chapter Six, the belief in 'boy preference' is deeply rooted in Taiwanese culture. In general, sons are able to inherit their parents' property, in preference to daughters. However, several participants mentioned that they were the only female child who was allowed to inherit their parents' property, because they were disabled. Parents did not expect their disabled daughters to get married and thus offered them property to secure their future. In this context, being disabled became what Ingstad and Whyte (1995) call a 'political privilege' that entitled those participants to family resources, and enabled them to modify the effects of gender inequality within families (see section 6.2.2). This suggests that the effect of the interaction between forms of oppression on individuals should be understood within cultural contexts.

The research findings show that the participants' impairment effects did impact peoples' responses to them. This is an area covered in the work of Thomas (1999). As mentioned in Chapter Two, Thomas (1999) introduces the concept of 'impairment effects', which refers to the restriction of activities caused by the impairment itself rather than disability. It can be seen as a medium of disability in a social relational context. In Thomas view, disabled people's lives are shaped by the interaction between impairment effects and disability. A study by Riddell (2009) shows that the 'type' of impairment influences the transitional experiences of young disabled people. Young people with cognitive difficulties are more likely to experience social stigma in the process of transition to adulthood. In the present study, the results indicate that various levels of

impairment lead to various social and cultural responses to disabled people. Participants with severe physical impairment were more likely to experience exclusion and rejection in employment and intimate relationship, as compared to those with mild or moderate physical impairment.

A life course approach emphasises the cumulative effects of earlier events on later experiences over the entire course of a life (Moody, 2000). The current study suggests that the participants' previous life events had a great impact on the subsequent events. Participants' past experiences influenced their life choices and therefore led them along different pathways. Yeo and Moore (2003) argue that early lack of support for disabled children in nutrition and education may create huge disadvantages as they grow up. Early exclusion of disabled children leads to restricted employment and job opportunities. Similar findings are shown by the current study. It can be argued that the participants' experiences of exclusion in education influenced their opportunities to access employment. The availability of material resources profoundly influenced the options they had to maintain their quality of life in old age.

Previous studies suggest that changing social conditions profoundly shape disabled people's life experiences (Shah and Priestley, 2011; Grassman et al., 2012). The present study shows how socio-economic changes and the development of disability policy shaped the participants' lives. As discussed in Chapter Four, Taiwan's economy changed profoundly, and this influenced the participants' experiences of employment. Taiwan's industrialisation during the 1960s was accompanied by increasing demand for female labours, which provided employment opportunities for some participants. However, the emergence of factory-based industry also excluded those with severe impaired from the labour force. Disability policy and social services for disabled people were absent before 1980. The participants received little support from the government during their childhood and youth, and had to rely on family. The role of the state in the social support of disabled people became more significant after the 1980s. The disability rights movement in Taiwan in the early 1980s led to an expansion of social services for disabled people. The development of disability policy and social services for disabled people remarkably affected the participants' experiences their early adulthood and mid-adulthood.

### 9.3 Implications for Policy and Practice

The research findings are based on the experiences of a specific group, and cannot be generalised to the entire population of disabled women. Some insights can be drawn from the current study to inform policy makers for disabled people and service providers in the Taiwanese context.

- Policy makers should recognise that many disabled women are caregivers, not just people in 'care need'. Disabled women not only provide support for their children, but also have to look after their ageing family members. Existing services for disabled adults should provide sufficient information, appropriate equipment, and supportive services for disabled women to carry out their caregiving activities.
- Policy makers should acknowledge that disabled women experience multiple oppression attributed to their multi-stigmatised identities. This makes it more difficult for them to have access to services that meet their complicated needs. Training should be provided for professionals and service providers to help them understand how the interaction of various forms of oppression shapes disabled women's daily experiences. Services for disabled adults should cooperate with services for other populations such as those for women, children and older people.
- Disability policy should recognise gender differences in the course of life. Policy makers should acknowledge that the needs of older disabled women may be different from those of older disabled men. Disabled women face challenges in managing their dual roles in the family and work. Policy makers should provide support for disabled women to balance their work and family life. Women historically live longer than men and face more uncertainty in economic security and living arrangement as they age. The government should recognise the needs of older disabled women who live alone. The disability benefits system and national pension schemes should be improved to protect the economic security of older disabled women.
- Current age-based policies fail to respond to the needs of disabled

people. Some disabled people may not be able to achieve a 'normal life transition'. The research findings show that the participants experienced delayed school entry, discontinuity of employment and premature physical ageing. Policy makers should recognise diversity in the life pathways of disabled people and help them to make a smooth life transition. Service provision for disabled people cannot be simply based on age. It should be flexible and tailored to meet the needs of disabled people.

- Policy makers should be aware that problems experienced by older disabled people are related to their previous life experiences. It is necessary to provide sufficient support for disabled people in their early years to enable them to have equal access to education, employment and relationships. This might reduce the disadvantages experienced by disabled people when they grow old. Service providers should adopt a life course approach to understand the ageing experiences of disabled people. They need to understand how previous life experiences influence older disabled people to identify their needs in old age.

#### **9.4 Recommendations for Future Research**

The study has shed light on the experiences of women ageing with childhood-onset polio in Taiwan. Studies of ageing and disability remain underdeveloped in Taiwan. The few previous studies that exist are based on an individual medical model, which focus on physical degeneration and 'care needs' of older disabled people. Future research should adopt the social model of disability to examine the ageing experiences of disabled people. It is necessary to pay more attention to the disabling environment experienced by older disabled people, rather than their functional limitations.

The research findings show that people with various levels of impairment experience ageing in different ways. Little is known about the relationship between levels of impairment, different forms of impairment, and cultural responses. Expanding this work further, to research on women ageing with other forms of impairment, is needed in future. The current study highlights culture as an essential factor shaping disabled women's lives. Taiwan is a multiple-ethnic country. As mentioned in Chapter Four, the government officially identifies sixteen tribes of Taiwanese aborigines, each with its own



language, culture and customs. Future studies on women ageing with lifelong impairments should include participants from various cultural backgrounds.

Moreover, all the participants in the current study were heterosexual. There is a need for studies on the ageing experience of women with other sexual orientations. Finally, the existing studies of women ageing with lifelong impairments are mostly conducted in western contexts. Future studies on the ageing experience of disabled women in eastern contexts are needed. These would provide important comparisons of the ageing experience of disabled women in western and eastern contexts. Such comparative studies may bring more insight to the experience of women ageing with lifelong impairments in a global context.

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