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# TAIWANESE MOTHERS' PERCEPTION OF TEENAGERS WITH MILD-MODERATE MENTAL RETARDATION

# A THESIS SUBMITTED TO THE GRADUATE DIVISION OF THE UNIVERSITY OF HAWAI'I IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE DEGREE OF

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### **ABSTRACT**

The purpose of this qualitative study was to investigate the perceptions of 10 Taiwanese mothers that have children with mild-moderate mental retardation as their children enter into their teenage years (13-15), with a particular focus on the issues of education, social competence, and family relationship. In addition, this study also examined whether these 10 mothers have altered their attitudes toward persons with disabilities after having children with disabilities. Through this study, the researcher found out current perceptions of Taiwanese mothers toward their young teenagers with mental retardation. The results of this study can serve as a resource that may help special education and rehabilitation services providers to gain a better understanding of the Taiwanese population when they are working with families and young teenagers from Taiwan.

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# CHAPTER 1 INTRODUCTION

### Rationale

Parental perception concerning their children with disabilities is an issue in disability studies that has long been examined (Abbott & Meredith, 1986; Blacher & Hatton, 2001; Gupta & Singhal, 2004). Researchers found that parents who hold a positive perception on their children with disabilities more effectively cope with stress, resolve conflict, assist their children with disabilities to grow, and help the family unit as a whole. On the contrary, parents who hold negative perceptions about their children with disabilities may have an adverse influence on the prognosis of their children with disabilities. These perceptions may add stress to family relationships including their marital relationship, negatively impact attitudes of children toward their siblings with disabilities, and even impact parents' own emotional stability. Parental perceptions of their children with disabilities may be influenced by various factors such as (a) the meaning of disability in the cultural context where they live; (b) the services available to support children with disabilities and their families; (c) the age of the children with disabilities, and (d) parental social and economic backgrounds (Blacher & Hatton, 2001; Huang, Rubin, and Zhang, 1998; Kang, Lovett, and Haring, 2002). In addition, parents' perceptions toward their children with disabilities often change over time due to (a) changing life circumstances; (b) the age of the child; (c) changes in community supports, and (d) increasing self-knowledge about their role as a parent of a child with a disability.

Several studies in the United States reveal that some parents believe that having a child with a disability not only helps them understand the true meaning of their lives, but also have closer family ties as well as an opportunity for personal growth (Abbott & Meredith, 1986; Bloom, 1996; Summers, Behr, and Turnbull, 1989). However, unlike the studies done in the United

States, many researchers have found that parents from the Chinese culture tend to hold a negative perception toward having a child with disability (Axelrod, 2003; Chou & Palley, 1998; Liu, 2001). For example, children in Chinese culture are expected to inherit family property and take care of their parents; therefore, children born with disabilities are seen as unable to fulfill their assigned obligations. Moreover, Chinese who believe in reincarnation tend to view people with disabilities as if they did something bad in their previous lives (Her, 1999). Therefore, some parents may consider having a child with a disability as a disgrace to the family.

As a result of the significant achievements of the disability rights movements in the United States over the last 30 years, persons with disabilities have continued to gain greater and more equal access to education, employment, and social services from which they were once excluded. For example, Section 504 of the Rehabilitation Act of 1973 and its latter-day relative the Americans with Disabilities Act of 1990 prohibit discrimination against a person with a disability by any agency receiving federal funds. The newly reauthorized Individuals with Disabilities Education Improvement Act of 2004 (IDEIA) continues to ensure a free appropriate public education which emphasizes the provision of special education and related services to all qualified children and youth with disabilities.

Persons with disabilities in Taiwan have experienced similar instances of exclusion limiting their access to public education, social services, and employment. However, since the passage of the Special Education Act of 1997 and the Protection Act for Individuals with Disabilities of 1997, persons with disabilities in Taiwan are also now protected by laws securing their rights to education, vocational rehabilitation, medical services, and employment (Special Education in Taiwan, 1998).

After the passage of the Special Education Act of 1997 and the Protection Act for Individuals with Disabilities of 1997 that protect and provide appropriate assistance for people with disabilities, children and adults with disabilities in Taiwan not only receive supports in finance, education, and vocational rehabilitation services from the government, but also have the chance to participate in social activities. As a result, Taiwanese parents of children with disabilities now have opportunities to explore and discuss disability issues with other parents of children with disabilities. However, this does not necessarily guarantee that parents of children with disabilities will alter their perceptions toward disability issues in a positive direction.

## Background

Over the last several decades, research has explored the effects associated with caring for children with disabilities on the family (Cheng & Tang, 1995; Gath, 1985; Wikler, 1981).

Although some studies indicated a decrease in marital quality and an increase in divorce rates in families of children with disabilities (Friedrich & Friedrich, 1981; Holroyd, 1974; Floyd & Zmich, 1991), other studies contradicted these findings revealing no apparent effect on the marriage of parents of children with disabilities (Risdal & Singer, 2004; Waisbren, 1980). As mentioned previously, since the inception of the disability rights movements in the 1970s, persons with disabilities have acquired more equal access to education and social welfare sources. Likewise, parents of children with disabilities continue to have greater opportunity to explore disability issues and to actively participate in disability awareness. Therefore, the disability rights movement is gradually changing the public's attitude toward disability issues, and also the perceptions of parents of children with disabilities (Blacher & Hatton, 2001; Brown, 2002).

Unlike parents in the United States, parents in Chinese dominant societies, such as Hong Kong and China, often hold negative perceptions about their children with disabilities (Huang et al., 1998; Li-Tsang, Yau, and Yuen., 2001; Wong, Wong, Martinson, Lai, Chen, & He, 2004). These negative perceptions have the power to affect the family's self-esteem, burden the family's emotional resources, interrupt the regular routine of the family, and deprive family members of personal growth opportunities. Despite an increased interest in parental perceptions of children with disabilities in Chinese dominant societies, it is surprising that very few studies (in English) have, or are being, conducted related to viewing this topic from the perspective of Taiwanese parents. The intent of this research project is to investigate and discover the present-day perceptions Taiwanese mothers have of their young teenagers with mild-moderate mental retardation regarding issues of education, social interaction, and family relationships.

In addition, since the United States is a nation of immigrants, cultural and ethnic shifts in the population will ultimately lead today's schools to become more culturally and ethnically diverse. Therefore, special education and related services providers may encounter teenagers from different cultural and ethnic backgrounds (Lynch & Hanson, 2004). The second intent of this qualitative research is to serve as a resource that may help special education and rehabilitation services providers to gain a better understanding of the Taiwanese population when they are working with families and young teenagers from Taiwan.

### **Purpose Statement**

The purpose of this qualitative study was to investigate the perceptions of 10 Taiwanese mothers that have children with mild-moderate mental retardation as their children enter into their teenage years (13-15), with a particular focus on the issues of education, social competence, and family relationship. In addition, this study wished to determine whether these 10 mothers have altered attitudes toward persons with disabilities after having children with disabilities.

Through this study, the researcher hoped to find out current perceptions of Taiwanese mothers toward their young teenagers with mental retardation.

# **Research Questions**

The specific research questions addressed included:

- 1. What perceptions do Taiwanese mothers of teenagers with mild-moderate mental retardation currently hold as to the issue of education?
- 2. What perceptions do Taiwanese mothers of teenagers with mild-moderate mental retardation currently hold as to their child's social competence?
- 3. What perceptions do Taiwanese mothers of teenagers with mild-moderate mental retardation currently hold as to the issue of family relationships?
- 4. How do Taiwanese mothers of teenagers with mild-moderate mental retardation report that their perceptions of persons with disabilities changed after having a child with a disability?

### **Definitions of Terms**

Culture: Hundreds of definitions of culture could be found in the literature, depending on which areas researchers wished to emphasize. Generally speaking, culture was broadly defined as a system of learned and shared standards for perceiving, interpreting, and behaving in interactions with others and with the environment (Jezewski, 1990). In addition, Dodd (1998) defined culture as "the holistic interrelationship of a group's identity, beliefs, values, activities, rules, customs, communication patterns and institutions" (p.36).

Social competence was a broad term used to describe a child's social effectiveness. In general, social competence referred to the social, emotional, and cognitive skills and behaviors that children need for successful social adaptation (Encyclopedia of Children's Health, no date).

More specifically, Anderson and Messick (1974) defined social competence as the ability to be effective in the realization of social goals. These social goals included having friends, being liked by peers, and engaging in effective social interaction with peers.

Perceptions were defined as the process whereby an individual recognized and attached meaning to the various forms of stimulation they received from the world around them (Royer, 2004). Since perception was influenced by a variety of factors, including the intensity and physical dimensions of the stimulus, and the individuals' past experiences, perceptions varied from one person to another.

Family relationship was defined as the state of relatedness or connection by blood, marriage or adoption. This might include parents-children, siblings, in-laws, husband-wife, etc. (The Free Dictionary Word, no date). In this study, the family relationship specifically referred to the relationship and quality of interaction among teenagers with disabilities, siblings without disabilities, parents, and grandparents.

Education in Taiwan involved studies at the preschool, elementary, junior high, senior high, college, and graduate levels (Special Education in Taiwan, R.O.C., 1999). Since the participants were limited to mothers of teenagers with mild-moderate mental retardation, education referred to the junior high school level in this study.

Community was a word that was used in different contexts and might be defined with the context. In this study, community was defined as a few hundred or a few thousand persons living within an area of a few square miles (Small Local Community, 2003).

#### **Delimitations**

This study had several delimitations. First, since this interview study focused solely on mothers' perceptions about their young teenagers with mild-moderate mental retardation relative

to issues of education, social competence, and family relationships, the fathers of those same teenagers with mild-moderate mental retardation were not interviewed. Second, since my younger brother is a 13-year-old teenager with mild mental retardation, I would like to get a better understanding of other mothers' perception about their young teenagers with mild-moderate mental retardation. Therefore, I only investigated mothers of young teenagers (ages of 13 to 15) with mild-moderate mental retardation. Mothers of teenagers with mild-moderate mental retardation who are below the age of 13 or above the age of 15 were not included. Furthermore, because I live in Taipei, I limited my interviewees to mothers residing in the city of Taipei, the capital of Taiwan, for convenience.

# CHAPTER 2 REVIEW OF RELATED LITERATURE

# Cultural Relationship Between Mainland China and Taiwan

Taiwan, an island in the western Pacific, lies east of the south-central coast of mainland China, from which it is separated by the Taiwan Strait. Taiwan comprises around 20 small islands in the Taiwan Group, and 64 islands in the Penghu (Pescadores) Group. Taiwan is estimated to be 230 miles long and 85 miles wide, with a total area of 13, 814 square miles. Comparatively, this area is similar to the combined size of the three U.S states of Massachusetts, Rhode Island, and Connecticut (Government Information Office, 2004). One of the most important resources in Taiwan is the population, which was estimated at 22.61 million in December 2003 (Government Information Office, no date). In general, Taiwan's population consists of four major ethnic groups: the Aborigines (2%), two groups of Taiwanese Chinese (84%), and Mainlander Chinese (14%).

The aboriginal population is primarily of Indonesian origin, currently divided into 12 tribes. Nowadays, most of the aboriginal population resides in the less populated areas, especially in the mountains. The two groups of Taiwanese Chinese include the early Chinese immigrants from Fujian and Kwangtung provinces in South mainland China, which in turn consist of two major ethnic groups: Fukienese and Hakkas. The Fukienese immigrated mainly from the southern part of Fukien Province in the 18th and 19th Century; while the Hakkas were primarily exiled from Kwangtung Province in the late 18<sup>th</sup> Century. After WWII, when Chinese Communists defeated Nationalist Chinese armies on the Mainland and assumed political control of China in 1949, another group of Chinese immigrants arrived in Taiwan, currently called Mainlander Chinese. Since they came from various parts of China, they are known as wai sheng jen (outside province people), or Mainlanders (Cooper, 1996; Encyclopedia of the Nations, 2005).

As a result of these combined mainland population forces, Taiwan's culture for the most part is of Chinese origin and is primarily brought by Chinese immigrants from Fukien and Kwangtung provinces, so Taiwan's society and culture are basically traditional Chinese (Cooper, 1996). Therefore, it may be said that from a cultural viewpoint, there is little difference between mainland China and Taiwan. The cultural aspects here include sharing a common language, religious practices and beliefs, and family structure and kinship based on Confucian principles (Liu, 1996).

For example, most persons in Taiwan speak Mandarin Chinese, known as *kuo yu* (meaning "national language"), a language that comes from the Beijing dialect much as American English derives from British English (Bates, 1995). It is Taiwan's official language, and is used in administration, jurisprudence, education, and in commerce. Regarding Taiwanese religion, the majority of the population in Taiwan is generally considered exlectic in their religious beliefs and practices, especially since religious freedom is guaranteed by the Constitution. Although Protestant Christianity and Catholicism can be seen around the island, the principle religions of Taiwan today are Buddhism, Taoism, and Confucianism, which were brought by early Chinese immigrants (Cooper, 1995). In summary then, it is clearly apparent that although Taiwan and mainland China remain politically separated, culturally and ethnically they remain closely connected.

# The Meaning of "Disability" in Chinese Culture

Individuals are from a specific culture, and culture means different things to different people. According to Hunt and Marshall (2002), "culture can be seen as a series of norms or tendencies that are shared, interpreted, and adapted by a group of people" (p. 79). In daily life, cultural mores and beliefs not only shape how persons view the world, but also influence their

behaviors and interactions. Thus, in any review considering concepts, perceptions, and issues related to human disability, it is important to note that one's personal sense of disability and one's personal inclination to interact with persons with disabilities is highly influenced by one's own personal culture (Hunt & Marshall, 2002; Multicultural Disability Advocacy Association, 2005).

When discussing the Chinese view of persons with disabilities and Chinese attitudes toward disability issues, the language used to describe persons with disabilities is very illuminating. First, in Chinese culture, the traditional terms for disability are *canfei* and *canji*. *Canfei* signifies "handicap" and "useless," while *canji* means "handicap" and "illness." Another term, *canji* ren, referring to "handicapped" and "sick" persons, is also common. The term *gong neng zhang ai* she, which means "individuals with disabilities," is seldom used (Liu, 2001). These terms clearly illustrate that the overall view of disability in Chinese culture, as typified in the words Chinese people use to identify persons with disabilities, is generally negative.

In addition, the underlying philosophical and spiritual frameworks of Chinese culture have been deeply influenced by Confucianism and Buddhism. Generally speaking, the majority of the Chinese population is highly superstitious, placing significant emphasis on the mystery of fate (Multicultural Disability Advocacy Association, 2005; Scadding Court Community Centre, 2005). At the same time, people in the Chinese culture deeply believe that "every life is like a link on a chain and that therefore every individual is a product of what came before them" (Multicultural Disability Advocacy Association, 2005). This belief evolves out of the Buddhist concept that maintains that individuals are influenced by deeds in their past lives which affect their present lives, known as *karma* (Deepak, 2001). Because of these reasons, some people may interpret disability as a consequence of a lack of morality or virtue in a previous life. Others may

consider disability a punishment for the wrong things and malicious deeds done by persons with a disability or their ancestors. What persons with disabilities and their families do in this current life is often perceived as paying the debts that are owed from their past lives (Dogbo, no date; Liu, 2001; Multicultural Disability Advocacy Association, 2005).

# The Contrast of Personal Attitudes Toward Mental Retardation with Other Disabilities in Chinese Culture

In the U.S., the IDEA classifies disability into 13 categories. Taiwan adds an additional disability category -Facial Deformity- that does not exist on the U. S. disability category list. As McCormick, Loeb, and Schiefelbusch (2003) explained, "The [reason] that the practice of grouping students by disability continues is that it is tied to our system for distributing state and federal funds" (p. 75). This implies that the special education a child receives is often closely tied to these disability categories. For decades researchers have examined whether individuals hold different viewpoints toward persons with different disabilities (Furnham & Pendred, 1983; Schneider & Anderson, 1980; Westebrook, Legge, and Penna, 1993). Their results illustrate that individuals perceive various disabilities in different ways. They found that individuals hold more positive attitudes toward persons with physical disabilities than persons with cognitive disabilities or mental illness.

Similar studies sharing that dominant Chinese societies—including China, Hong Kong,
Taiwan, and Singapore—perceive various disabilities in different ways have also been reported.
For instance, Wang, Chan, Thomas, Lin, & Larson (1997) summarized a series of studies done
by Fong-Chan and his colleagues regarding high school and college students' perceptions of
different disability groups in Hong Kong and Taiwan. The results of the studies demonstrated
that these students held less positive attitudes and higher levels of pessimism for persons with

disabilities, and also indicated that the students tended to accept persons with physical disabilities more easily than people with mental retardation. However, in the study examining the attitudes of American, Taiwanese, and Singaporean students toward persons with disabilities in the general context, as well as the context of dating and marriage, Chen, Brodwin, Cardoso, & Chan (2002) reported that Chinese attitudes did not differentiate between persons with mental retardation and those with psychiatric disabilities because both of these populations were supposed to be kept at home.

# The Meaning of "Disability" in Taiwanese Culture

As Lamorey (2002) pointed out, "Each culture has its own explanations for why some babies are born with disabilities, how these children are to be treated, and what responsibilities and roles are expected of family members, helpers, and other members of the society" (p. 67). Taiwan is no exception. Since Taiwanese society reflects traditional Chinese cultural views, most Taiwanese hold similar perceptions about disability to those most mainland Chinese. It has long been demonstrated that persons with disabilities are seen as a stigma that brings shame for the family. In addition, persons with disabilities are viewed as being less valued than are persons without disabilities, and are often stereotyped as dependent, isolated, depressed, and emotionally unstable (Chou & Palley, 1998; Dogbo, no date).

For example, Her (1999) stated that, "the traditional view in Taiwan is that disabled people are the way they are because they did something bad in their previous lives" (p. 36). This is consistent with Sheng's (1999) statements that "people in Taiwan [are] conditioned to interpret the presence of genetic disabilities and infectious diseases as 'retribution' for the bad behavior and moral lapses of the ancestors of the disabled, [or] even of the disabled themselves, in their own previous lives" (p. 4). Because of perceptions held by most Taiwanese, parents of children

with disabilities in Taiwan are ashamed to admit that they have a child with a disability, feeling sullied by an invisible stain and a sense of guilt.

As with mainland Chinese cultural views, persons in Taiwanese society are also very concerned about others' reactions or social expectations, known as "face-love." In Taiwan, having a child with a disability involves losing face, and is viewed as a family disgrace as well, because the disability represents a permanent and irreversible event (Chou & Palley, 1998; Kang et al., 2002). Due to Chinese cultural influence, Taiwanese families who have children with disabilities are not only likely to face challenges from their own families, but also have serious problems resulting from stigma and negative societal reactions. As a result, many persons tend to hide their children with disabilities at home or in some private institutions, instead of asking for government assistance and support.

# The Importance of Parental Perceptions Toward Their Children With Disabilities

The perceptions held by parents of children with disabilities are an issue which has gained much attention over the years. Having a child who is identified with a disability often comes as a shock, and parents are always expected to experience harmful psychological impacts (Gupta & Singhal 2004; Summer et al., 1989). Many researchers also pointed out that parents who have children with disabilities always experience feelings of guilt, shame, and embarrassment (Blacher & Hatton, 2001; Kang et al., 2002; Lamorey, 2002; Wong et al., 2004). However, if parents continually hold negative perceptions toward their children with disabilities, their attitudes will not only negatively impact the development of their children but also will increase parental stress level as well as influence their family relationships.

Several researchers also have pointed out that parents who adapt well to raising their children with disabilities may play an important role in assisting their children to learn in

academics, to help their children develop their social networks, and also interaction skills (Abbott & Meredith, 1986; Blacher & Hatton, 2001; Gupta & Singhal, 2004). Additionally, parents who hold positive perceptions toward their children with disabilities may become valuable information givers when they participate in their children's IEP meetings (Krach, 2003). Their active attitudes to support their children can also help related professionals to search for possible and appropriate sources to assist children's learning in the school. Furthermore, since the IDEA calls for family members to be integral members during the IEP meetings, parental perceptions toward their children with disabilities may positively influence service providers to assist the development of their children and to help their children to reach maximum learning outcomes (Bowe, 2000).

# Perceptions Held by Parents of Children with Disabilities in China, Hong Kong, and Taiwan

According to Summers et al. (1989) in the U.S. "Families who have a member with a disability have long been objects of pity. Society as a whole tends to view the presence of a child with a disability as an unutterable tragedy from which the family may never recover" (p. 27). This kind of phenomenon also can be seen in the Chinese culture. Generally speaking, in Chinese dominant societies, newborn children represent and continue the lives of their ancestors. Those newborn children not only represent the continuation of the families, but also have the responsibilities of carrying the family name, inheriting family property and taking care of their parents. Children born with disabilities are perceived as not having the abilities to fulfill their assigned obligations. As a result, having a child with a disability has been traditionally regarded as a disgrace to the family (Axelrod, 2003; Chou & Palley, 1998; Liu, 2001).

Due to the influence of these general population concepts, it is not surprising that parents also tend to hold negative perceptions toward their children with disabilities. For example, Wong et al. (2004) did qualitative research in relation to the experiences of parents in caring for their children with developmental disabilities in Guangzhou, China. One parent of a child with a disability acknowledged that she seldom talked to other persons regarding the conditions of her child because she was afraid of telling others that there was a problem related to the child's brain. Another parent reported it was not a good thing to have a child with a disability. A third parent said since she was afraid of being looked down upon because of the child, she never told others about the child. In addition, a study done by Huang et al. (1998) revealed that mothers felt very stressed and frustrated when taking care of their children with developmental disabilities because these children could not fulfill their family expectations. These findings demonstrate how having a child with a disability in a Chinese family is specifically and negatively impacted by the traditional Chinese cultural contexts and view.

## Perceptions Held by Parents of Children with Disabilities in the United States

Similar studies have been conducted on perceptions held by parents of children with disabilities in the United States. The interpretations of the results of studies seem to be more various, illustrating that those parents' perceptions of their children with disabilities can be either positive or negative. However, their perceptions of disabilities can change throughout the stages of their children's development. According to Taanila, Syrjala, Kokkonen, and Jarvelin (2002), "The birth of a disabled child is an event that affects all the family members and both their internal and external relationships" (p. 73). This may include maternal mental health problems, adjustment problems with siblings, marriage quality and family cohesion (Risdal & Singer,

2004). Changes in home routines, vocational life, and relationships with family may also affect parental attitudes toward their children with disabilities.

Regarding the negative perceptions held by parents of children with disabilities, Baxter, Cummins, and Yiolitis (2000) conducted a longitudinal study over seven years, which primarily compared the stress of taking care of a child with a disability to the stress of taking care of that child's youngest sibling without a disability. The results revealed that parents attributed their stress level from the child with a disability to be about double that attributed to the youngest sibling without a disability because parents thought they needed to pay more attention to the behavior of the child with a disability in public as well as attend to their level of speech, intelligence, and physical health. Moreover, Shearn and Todd (2000) did a qualitative study concerning maternal employment and their children with disabilities. Based on their research, mothers of children with disabilities have acknowledged that they felt they experienced a loss of self, because they thought the care work that they performed was particularly demanding. At the same time, those mothers of children with disabilities also reported that they have restricted employment opportunities due to a lack of usable child care and societal expectations of the appropriate role of a mother of a child with a disability. Consequently, they felt isolated and unfulfilled.

While these parental studies report only upon the adverse consequences of having children with disabilities, there are a growing number of parental studies that indicate some parents experience generally positive consequences. In a study of coping resources of families who have children with mental retardation, Abbott and Meredith (1986) found that 33 of 36 parents (88%) reported developing traditional family strengths because of having a child with a disability.

Among those parents, 55% said they had a closer and stronger family as a result of this

experience; 41% mentioned personal improvements, such as more patience, compassion, and unselfishness; and 17% said they had a greater appreciation for the small and simple things of life. Hastings and Taunt (2002) also found that parents report many positive effects of having children with disabilities. These positive effects include personal growth, expansion of tolerance for human differences, valuable life lessons learned, strengthened families, and the child as a source of joy. Research by Ellis and Hirsch (2000) and Scorgie and Sobesey (2000) revealed similar results. These findings support the conclusion of Summers et al. (1989) that "in the experience of many families who have children with disabilities, those children are not devalued objects, but active and contributing members of their families, whose presence makes a real contribution to an improved quality of life" (p. 31).

# CHAPTER 3 METHOD

### Criteria for Participants

I listed the following criteria to find, identify, and select the 10 participants for this study. Since my topic primarily focused on mothers' perceptions about their young teenagers with mild-moderate mental retardation, the first criteria was that my interview participants must be mothers of young teenagers age 13 to 15 with mild-moderate mental retardation. Next, because one of my research questions addressed their perceptions toward the issue of education, the second criterion was that participants must be mothers of teenagers with mild-moderate mental retardation who are currently enrolled in a public school. Third, participants must be birth mothers of those teenagers with mild-moderate mental retardation because the adoptive parents may be well prepared to raise a child with a disability while the birth mothers may not (Glidden, Kiphart, Willoughby, & Bush, 1993); thus, to achieve the highest quality and integrity of information, only birth mothers could qualify as the best sources of clearest perceptions of personal experiences in raising children with disabilities. Lastly, the participants must be native Taiwanese so they could have a better, or more detailed, understanding about how Taiwanese society perceives mothers who raise teenagers with disabilities.

### **Procedures**

The first step in conducting this interview study was to contact the Institutional Review Board (IRB), and to receive approval from the Committee for Human Studies at the University of Hawaii. The project was approved in the exempt category. Second, after being granted permission to conduct interviews in Taiwan by the IRB, I contacted the Parents' Association for Persons with Intellectual Disability in Taipei, my younger brother's special education tutor, and my mother who knew people who have teenagers with disabilities to find my potential interview

participants. Third, I called the potential participants and explained the purpose and objective of my study to obtain their permission for an interview. Fourth, after receiving permission from participants, I distributed the consent forms (Appendix A), in Chinese and English, to each of them via email or fax and explained the content of these forms. Fifth, I asked them to sign these forms and also informed them they had the right to withdraw from this study at any time without penalty. Sixth, I scheduled time and location with each of the participants to conduct the interviews at their convenience. I recommended they choose a place that was quiet and comfortable for interviewing. Seventh, I informed participants that the whole interview would last approximately one hour, and would be tape recorded. Eighth, I provided each of the participants a series of open-ended interview questions (Appendix B) via email or fax, so they could prepare in advance and decrease their stress level during the interview. Finally, I conducted all of the 10 interviews in Taipei, Taiwan during Spring 2006.

### **Participants and Interview Settings**

Participants whose views were represented in this paper were 10 Taiwanese mothers of teenagers with mild-moderate mental retardation. Of those participants, one was found through my mother; one was introduced by the Executive Director, Miss Mary, of Parents' Association For Persons with Intellectual Disability in Taipei; two were introduced through the interviewee who introduced by Miss Mary; and the remaining six were referred by my younger brother's special education tutor. Key information about the participants was as follows (Table 1).

Table 1. Demographics of Interview Participants

Mother	Age	Education degree	Job title & duty	Marriage Status	Family members	Primarily disability label	The Age & grade	Primarily family
l						of the child	of the Child	income resource
A	42	University.	Accountant & keep/inspect the financial accounts of the company.	Married for 14 years.	Herself, husband, one older son (13 years), and one younger son (10 years).	l .	13 years	Double income family.
В	46	Vocational school.	Accountant & keep/inspect the financial accounts of the company.	Married for 17 years. Divorced last year.	Herself and daughter (15 years old).	mild mental	15 years old/9 <sup>th</sup> grade.	Mother.
С	46	University	Housewife & take care of child, look after the family, and clean the house.	Married for 19 years.	Herself, husband, and son (15 years old).		15 years old/9 <sup>th</sup> grade.	Father.
D		High school.	Retired. Now primarily take care of the children.	Married for 27 years. Divorced 2 years ago.	Herself, older daughter (25 years old), younger son (15 years old).			Her retired pension.
E	46	Vocational school.	Interior designer & plan the choices of style, color, furnishing, etc for the inside of a house	16 years.	daughter (15 years old),	attention deficit,		Double income family.

Table 1. (Continued) Demographics of Interview Participants

Mother	Age	Education	Job title & duty	Marriage	Family members	Primarily	The Age	Primarily
	-	degree		Status		disability label	& grade	family
		_				of the child	of the	income
							Child	resource
F	45	University.	Vice manager &	Married for 19	Herself, husband, older	Cerebral Palsy		Double
			keeping the financial	years.	brother (17 years old),	and mild mental	old/8 <sup>th</sup>	income
	ĺ		accounts of the	[	younger brother (14	retardation.	grade.	family.
			company.		years old).			
G	43	High	Accountant &	Married for 20	Herself, husband, older	Scoliosis, heart	14 years	Double
_		school.	keep/inspect the	years.	son (19 years old),	deficit, and mild		income
			financial accounts of	<u> </u>	younger son (17 years	mental	grade.	family.
			the company.		old) and younger	retardation.		_
					daughter (14 years old).			
H	43	University.	Human resource	Married for 16	Herself, husband, older	Autism and mild		Double
			administrator & deal	years.	son (15 years old), and	mental	old/9 <sup>th</sup>	income
			with the administration,		younger daughter (14	retardation.	grade.	family.
			management, and		years old).			
			training of employees.					
I	48	_	. •	Married for 25	,,,	Mild mental		Double
			- U	years.	[ <b>2</b>	1	1	income
			appointment for the		21, and 19 years old),		grade.	family.
			manager in the office.		and youngest son (13			
	44				years old).			
J	41	· ·			Herself, husband, three	Moderate mental		Father.
			_	years.	daughter (who are 15,	retardation.	old/9 <sup>th</sup>	
			family, and clean the		12, 11 years old), and		grade.	
			house.		one son (14 years old).			
					<u> </u>			

After contacting with these qualified interviewees and obtaining their permissions for interviews, I distributed the consent forms and provided a list of open-ended interview questions to them via e-mail and fax. All interviews were conducted between 60 and 75 minutes. During interviews, most participants provided me with highly detailed answers to my interview questions. Except for two interview participants who asked me to stop recording due to their emotional changes, most interviews were conducted in a very relaxed and comfortable atmosphere (Table 2).

Table 2. Participants' interview

Mother	Recruitment	Date of Interview	Place of Interview	Length of Interview (mins)	Comments
A	My mother	Feb. 10	Starbucks	75	She provided me with lots of information about her son and also shared the progress of her son with me. The atmosphere of this interview changed once due to her unstable emotions regarding her teenager with disabilities.
В	Miss Mary	Feb. 12	Ling Liang Church	65	She was very talkative and we had a very in-depth conversation during the interview.
C	Mother B	Feb. 19	Ling Liang Church	60	She was very supportive during the interview. However, she asked me to stop recording when we talked about her child's future. She also left her contact information and told me I could call her if I needed other information.
D	Mother B	Feb. 19	Ling Liang Church	65	She was very talkative and provided me with detailed information about my interview questions. She also expressed optimism about being a mother of a teenager with disabilities.
Е	Miss Helen	Feb. 21	A classroom in Miss Helen's school	65	She was willing to share her viewpoints toward persons with disabilities and her experiences of being a mother of child with disabilities. The whole interview went very smoothly.

Table 2. (Continued) Participants' interview

Mother	Recruitment	Date of Interview	Place of Interview	Length of Interview (mins)	Comments
F	Miss Helen	Feb 23	A classroom in Miss Helen's school	65	She provided me with highly detailed answers to my questions, and did not hesitate to tell me about her experience of being a mother of a child with disabilities.
G	Miss Helen	Feb 27	A classroom in Miss Helen's school	65	She was very talkative during the interview and seemed to hold an optimistic attitude toward her current life. Besides, I found that she was a believer in Buddhism and she provided mw with a lot of viewpoints based on her religious beliefs.
Н	Miss Helen	Mar. 2	A classroom in Miss Helen's school	65	During the interview, she seemed to have something in mind, and did not provide very detailed information to my questions. She did not like to talk too much and she always answered my questions based on my requests.
I	Miss Helen	Mar. 8	Mother I's office	65	She itemized a lot of information about her son's stories and her personal experience of raising a child with a disability.
J	Miss Helen	Mar. 10	Mother J's home	65	She not only talked about her personal experience of being a mother of a child with a disability but discussed her daughter's interaction patterns within the family. She asked me to stop recording once when I asked her about her daughter's learning situation and interpersonal relationships in the school.

## **Data Collection**

According to Creswell (1994), "Qualitative researchers are concerned primarily with process, rather than outcome or products, [and qualitative research should focus only on] how people make sense of their lives, experiences, and their structure of the world" (p. 145). Since the purpose of this interview study was to find out 10 Taiwanese mothers' perceptions about their young teenagers with mild-moderate mental retardation—with a particular focus on the issues of education, social competence, and family relationships—I concentrated on these issues and tried to elicit participants' memories and experiences during interviews.

Creswell (2003) also stated that there were four major types of data collection methods that can be used for the qualitative study: observation, interviews, collecting documents, and audiovisual materials. Each of these data collection methods had its advantages and disadvantages. To acquire appropriate information and data for this study, face-to-face interviews were not only the most proper method for data collection but also provided me with opportunities to obtain the historical information related to their perceptions toward these issues as well as a chance to clarify questions in person when necessary.

Taylor and Bogdan (1998) mentioned that qualitative interview studies were divided into three types based on the purposes of the studies. The first type was the life history or sociological autobiography. The second type was in-depth interview directed toward learning events and activities that could not be observed directly. The last type of qualitative interviewing was intended to yield a picture of a range of settings, situations, or people within a short period of time but with large numbers of interviewees. To obtain appropriate information related to mothers' perceptions toward their teenagers with mild-moderate mental retardation, the first type

of qualitative interview, life history or sociological autobiography, was the proper choice for this interview study.

Lastly, in mentioning how to collect data during the interview, Merriam (1998) pointed out that there were three basic methods to recording interview data, they include (a) tape recording; (b) note-taking during the interview, and (c) writing based on the research's memory after the interview. Among those three methods, tape recording ensured me that everything said by my interviewees can be preserved for additional time to analyze. Since I conducted these interviews in Taiwan and analyzed the data after returning to Hawaii, I believed that tape recording each interview not only helped me to conduct interviews without feeling stressed and distracted, but also was a great means for further review and reference. In addition, after I finished conducting each interview, I saved the interview data on the separate cassettes. A code I added to each tape served to protect the participant's confidentiality. Lastly, I transcribed the interview data into MS Word, so that it was convenient for me to sort and arrange the data into different categories and begin to analyze it.

# **Data Analysis**

Taylor and Bogdan (1998) mentioned that the process of data analysis of the qualitative research project contained three steps: (a) discovery; (b) coding, and (c) discounting data. Each of these three steps also included multiple sub-processes for the research: read and reread data; look for emerging themes; develop concepts; read the literature; develop charts, diagrams, and figures to highlight patterns in the data; and write analytic memos during the discovery stage. In addition, researchers needed to develop a story line, list all major themes and concepts, code the data, and sort data into coding categories during the stage of coding. Furthermore, researchers also needed to understand the effects of interview settings and use member checks to obtain

thoughts and opinions from participants after interviews to check whether participants' experiences and thoughts were well-presented. Creswell (2003) also stated that there were six steps of data analysis for qualitative studies: (a) organizing and transcribing interviews; (b) obtaining a general sense of information; (c) coding; (d) generating a description; (e) narrating qualitative data, and (f) interpreting the data. Although the terms used for describing these data analysis processes were different, the concepts of data analysis processes were very similar. Thus, I followed these principles to analyze the data I collected during interviews.

First, I transcribed data into a MS Word after I finished each interview. Second, I carefully read and reviewed these transcriptions to obtain general ideas of the participant's thoughts. Third, since this interview study emphasized how Taiwanese mothers' perceive their young teenagers with mild-moderate mental retardation with a particular focus on the issues of education, social competence, and family relationships; I reviewed the data and classified it into various themes based on my research questions. Fourth, I created charts and diagrams to help me investigate relationships between themes. Fifth, I brought all the data together and compared it so that I could find out the similarities and differences of mothers' perceptions toward their young teenagers with mild-moderate mental retardation based on the research issues. Sixth, I used a narrative passage to convey the findings from the data analysis. Seventh, I compared my findings with previous studies related to my research topic to find out whether my findings are similar or different. Finally, I used member external validity checks as a means to enhance the validity of this study; therefore, I sent the transcriptions of the interviews to each participant to verify whether their thoughts and opinions were correctly presented.

# CHAPTER 4 RESULTS

### Objective 1

The first research objective of this interview study was to identify and describe the perceptions of 10 Taiwanese mothers of teenagers with mild-moderate mental retardation on the issue of education (Appendix C). After transcribing the data into the MS Word document, several themes were identified and described as follows:

## 1. Negative perceptions of their young teenagers' learning settings

Six mothers said that their young teenagers were receiving education in inclusion settings, while four mothers reported that their young teenagers were enrolled in self-contained settings. Four out of six mothers whose young teenagers were placed in inclusion settings mentioned that they were unsatisfied with their young teenagers' learning in these inclusive learning environments. The reasons included: (a) the teacher not trained in special education; (b) large class size; (c) time constraints, and (d) the general education teacher rejected having students with disabilities in his/her class due to limited knowledge about special education. The following notes extracted from the interview reports provided sufficient examples to illustrate these concerns.

#### Mother A said:

Since the general teacher in the inclusion classroom has limited knowledge about children with disabilities, the teacher is kind of rejecting the children with disabilities... The teacher worries that the students with disabilities will cause trouble for the class.

#### Mother F mentioned:

Before entering junior high school, I asked the school personnel to place my child in an experienced teacher classroom. However, the school assigned my child to a teacher who

does not have any special education background. I think the teacher doesn't even know how to teach a student with a disability.

# Mother I reported:

There are 36 students in my son's class...36 is a big number for a teacher and I believe the general education teacher is struggling to complete the syllabus within a tight curriculum...This teacher has no special education background to assist students with disabilities.

Besides these complaints mentioned above, three out of four mothers whose young teenagers enrolled in the self-contained setting also hold negative viewpoints toward their teenagers' learning settings. These included: (a) the school equipment being too old; (b) the teacher's not being professional, and (c) students with various disabilities were placed together. For example, Mother B said:

There are students with various disabilities in my daughter's classroom, such as students with Epilepsy, MR, Down syndrome, and hyperactivity. I don't think the teacher can handle the class well, especially with the heterogeneous grouping of students with different disability types in one class.

#### Mother D mentioned:

I think the teacher is not a professional in the special education field. Since the general education teachers in the junior high school are supposed to assist students in getting good grades to get into a good senior high school, the school personnel often assign the teachers who are ready to retire or who can't help students get good grades to teach in the special education classroom.

#### Mother J stated:

I think the school needs to improve assistive technology equipment for students with disabilities, but they have a limited budget.

Although seven out of ten mothers stated that they were unsatisfied with their teenagers' learning setting whether in inclusion or self-contained classrooms, three mothers believed that their teenagers were placed in a good learning environment. For example, Mother C responded:

I think the school facilities for students with disabilities are very good. Besides, the teacher is very professional, because she has a special education degree and is very patient with the students as well.

#### Mother F noted:

I am happy that my daughter was placed in this classroom. If I have any questions, I can communicate with the teacher at any time.

# 2. Struggling between academic and vocational oriented education

Four major concerns about academic needs were expressed by the mothers during the interviews: learning independent living skills, acquiring vocational skills, learning interpersonal communication skills, and trying his/her best in learning academic subjects. Among ten participants, five out of ten mothers believed that learning non-academic subjects should be a priority. Their opinions are cited as follows.

#### Mother D said:

I don't wish my son to focus his studies on academic subjects. I hope he can learn some vocational skills, such as basic cooking, or washing cars so that he can make a living by himself.

#### Mother F mentioned:

Since I know I am unable to take care of my son forever, I only hope he can learn some independent living skills, such as learning how to take transportation by himself, and how to wash and dress by himself.

Although half of the participants believed that their young teenagers should focus on non-academic skills at junior high school level, the rest of five interview participants expressed that they would like their young teenagers to learn as much as possible in academic subjects. For example:

# Mother A reported:

I don't ask my son to get good grades in academics, but I ask my son to try his best in learning things that are taught at school. Even until now, I still believe that my son has the potential to learn new things, so I don't want to give up on him at this time.

Mother H even provided an insight about why learning academic skills is more important than learning vocational or independent living skills at this time. She stated:

Of course I hope my son can learn some vocational skills. However, I think learning academic subjects, especially language and math, is more important for him to build his independent living skills later on... I wonder if my son cannot do some basic calculation and learn to express clearly express himself, how he can learn to live independently and vocational skills later on.

3. Socioeconomic status provided as a means to assist young teenagers learning after school

Three interviewees from double income families stated that they sent their young teenagers
to private learning centers after school and/or during the weekend. They agreed that it was worth

spending money to assist their young teenagers as long as they felt their teenagers with disabilities could learn more. For example, Mother A mentioned:

I send my child to attend a movement education class...Movement education improve not only his movement coordination of the total body and his perception in space, but hand-eye and foot-eye coordination as well. I believe this can help him more concentrate on learning, and might help him decrease his hyperactive behavior...Although I need to spend more money; I believe it is worth it.

#### Mother F said:

I send him to a private learning center after the school everyday because it is close to my workplace...I believe that the teachers there can assist him to finish his homework.

#### Mother H also stated that:

My son likes English and Music; thus, I registered him for these classes...As long as he is interested in learning English and Music, I will continue to support him.

# 4. Encouraging their young teenagers to work hard to reach their goals

The majority of interviewees (8 out of 10) reported that they have discussed the need to work hard to reach their goals with their young teenagers. Bus/taxi driver, car sales person, historian, model, police officer, and cashier were the jobs that these mothers mentioned their teenagers wanted most.

#### Mother G said:

My daughter tells me that she wants to be a cashier and work in a supermarket. I explained to her if she would like to be a cashier, then she needs to learn basic math and learn how to use the calculator. Therefore, she pays a lot of attention to her math assignments, and also

works hard at practicing math...Honestly; all I can do now is support and encourage her...I still try to identify skills that are appropriate for her and ones she is also interested in.

Since my son really likes cars, he tells me that he would like to be a bus driver. I told my son that being a bus driver is a good job; however, I also explained to him that bus drivers need to recognize the name of each road. Otherwise, how can he take the passenger to the right destination? Therefore, my son currently pays a lot of attention to the guideboard, and also tries to memorize the route of the bus.

#### Objective 2

Mother H stated:

The second research objective of this interview study was to identify and describe the perceptions of 10 Taiwanese mothers of teenagers with mild-moderate mental retardation on the issue of social competence (Appendix D). Four themes were identified and are described in the following paragraphs.

### 1. Lack of peer/classmate friendships and extracurricular activities after school

Surprisingly, all of these interview participants unanimously stated that their young teenagers spent most of their leisure time at home after school. The young teenagers spent most of their leisure time at home watching TV, listening to music, playing computer games, and singing songs. Two participants also mentioned that their young teenagers prefer to spend their leisure time talking with their relatives on the phone and riding their bike with family members at a nearby park. The findings mentioned above illustrate that these young teenagers have little or no interaction with their peers after school. For example, Mother B stated,

Since my daughter doesn't know how to get along with others, she has almost no friends either in school or after school. Therefore, most of the time, my daughter stayed at home

after school. For my daughter, watching TV and listening to music are her two favorite hobbies in her leisure time.

# Mother D said:

Honestly, my son has few friends, and doesn't like to do any outdoor activities. He spends most of his leisure time listening to music and singing songs at home after school.

# Mother F reported:

He enjoys watching baseball games on TV with the family during his leisure time. In addition, he also likes to play the computer games at home.

# Mother I also shared her opinion. She reported:

Since my son doesn't have good interaction skills with his peers, he has few friends, not to mention going out with peers after school. My son has specific interests. He doesn't like to do any outdoor activities, or stay at home to watch TV. What he likes to do during his leisure time is talk with his relatives on the phone.

# 2. Effective communication as a means to assist their young teenagers in building friendships at school

The information gained from these 10 mothers revealed that only half of them had discussed with teachers their young teenagers' issue pertaining to social competence and relationships with peers at school. Five out of ten mothers stated that they only discussed this topic with their young teenagers since they had a poor working relationship with the teachers. The results also demonstrate that, for those parents who had discussed their teenagers' social competence with teachers, their teenagers seemed to have a better relationship with their peers at school. The following notes cited from the interview reports are good examples.

#### Mother C commented:

I think my son has a good interaction with his peers in the class. My son likes to help people at school. For example, if his classmate forgets to bring the pencil box, my son usually willingly lends his classmate pencils without any hesitation...He often willingly plays with his classmates during recess, and they are equally willing to play with him.

# Mother G responded:

I regularly discuss my daughter's social situations in the school with the teacher. I know that my daughter often actively plays with her peers. The teacher also told me that my daughter is such a considerate child; she always likes to help her peers at school...I am proud of her.

For those parents who had not discussed this issue with teachers, their teenagers tended to be isolated at school. For example, Mother E said:

To be honest, I don't have a good relationship with the teacher, but I asked my daughter about her social situation at school. I believe most of her classmates don't like her, and, therefore, my daughter is usually isolated in the school...I can accept this. I certainly don't want to force anyone to be nice to my daughter.

### Mother H mentioned:

I have never discussed this issue with the teacher, but I openly asked my son about his interaction with peers in the school. My son told me that he feels lonely, and that no one wants to play with him. As a result, he usually works on his assignments during recess or goes to the resource room to play with other teenagers with disabilities...I don't know how to help him, but I don't blame his peers.

### 3. Mothers' careers as barriers for mothers to communicate with teachers

As mentioned above, five mothers rarely discussed their teenagers' social competence with teachers, as a consequence, their teenagers tended to have a limited interaction with their peers at school. Three mothers stated that they were too busy with their jobs to talk with the teachers about social concerns. For example, Mother A claimed:

I am terribly busy with my job...The teacher of my child is often not be available to meet with me when I have time. I just cannot ask the teacher to meet with me anytime I am available...It is really difficult for me to find a time to visit the teacher.

#### Mother F also mentioned:

Since I became a vice manager in my company, I can hardly find a time to visit the teacher, I have to take care of lots things and I am expected to stay at my office overtime...This is why I send my child to a private learning center...I don't even have time to review my child's homework.

#### 4. Community acceptance of persons with disabilities

The information gained from these 10 interviewees illustrated that the acceptance of young teenagers with mild-moderate mental retardation by the community members was split. Five mothers stated that the community members had accepted and interacted with their young teenagers with disabilities while the other five interviewees reported that their young teenagers had no interaction with their communities. The opinions acquired from these interviewees are outlined as follows:

# Mother C commented:

To be honest, I think I am very lucky and I think that I have good neighbors. Most of my neighbors know that I have a son with a disability. Since my son is very polite and always

actively says hello to the neighbors, my neighbors can accept him and they sometimes have conversations with my son.

# Mother G also reported:

Since my daughter is very outgoing and polite, the neighbors are willing to interact with her.

Sometimes, one of my neighbors invites my daughter to join their B.B.Q party... I think my neighbors are nice.

Compared with Mother C and Mother G, Mother I reported a different experience. She stated:

My son does not interact with the neighbors. Actually, the neighbors are not willing to talk with any of my family members... When we attended the community activities, the neighbors always pretend not to see us, and sit far away from us.

Mother J also experienced a similar situation. She said:

I think my neighbors simply cannot accept my daughter. One time, my daughter approached a woman in the park, wanting to shake hands with her. But the woman hit my daughter with the newspaper...

#### Objective 3

The third research objective of this interview study was to explore the perceptions of 10 Taiwanese mothers of teenagers with mild-moderate mental retardation on the issue of family relationships. (Appendix E). As with objective 1 and 2, several themes emerged and are described as follows:

# 1. Husbands' perceptions of their young teenagers with disabilities varied

Interview participants reported a wide range in the attitudes their husbands held toward their young teenagers with disabilities. Their attitudes ranged from totally acceptance to gradual acceptance to total nonacceptance. Five of the ten interview participants stated their husbands

were accepting when the children were first identified as having disabilities. The following quotes exemplify this acceptance. For example, Mother C commented:

To be honest, I think I am very lucky. My husband totally accepted that we had a child with Down syndrome from the beginning. When the Down syndrome organization or school holds activities, my husband is generally willing to attend with my son...He always thinks that our son is very considerate.

#### Mother F also said:

My husband has a good relationship with our son. Actually, my husband accepted that we have a child with disabilities early on...My husband doesn't mind telling his colleagues that he has a child with cerebral palsy and mild mental retardation, my husband always takes my son to attend B.B.Q parties held by our friends.

However, two of the ten mothers mentioned that their husbands could not accept having children with disabilities. This lack of acceptance eventually led them to divorce. For instance, Mother B reported:

My husband could never accept having a child with a disability. Every time I wanted to discuss our child with him, he always said that he was busy...Many of these conversations ended with us having a serious argument. To be honest, my husband does not seem to care about our child.

# Mother D also had a similar experience. She stated:

My husband just could not accept having a child with disabilities. He tries to escape this truth. My husband became angry and left home for a couple of days when I tried to discuss how we might raise our child with disability with him.

# 2. Birth order could influence husbands' perceptions of their young teenagers with disabilities

Since Chinese regard their first-born child as a special child who is supposed to take care of their parents, the first-born child with a disability might more profoundly influence the father's perceptions. Unlike the participants whose husbands accepted their young teenagers with disabilities from the beginning, three of the mothers reported that their husbands did not accept their first-born child with disabilities until other were born without disabilities. For example, Mother A said:

The first-born child with disabilities was a shock to both my husband and I...You know that he needed time to adjust... But, since our second child was born without a disability, my husband became more accepting of our first-born child.

#### Mother H stated:

In the beginning, my husband would not accept that fact that our first-born son is a child with a disability. After the birth, he constantly blamed himself... Gradually he began realize that although our son is a child with mental retardation, he is very considerate and innocent. Eventually my husband learned to accept having our child with a disability.

#### Mother J also claimed:

My husband barely accepted our first-born child with a disability in the beginning... He became very depressed. It was only after our second, third, and fourth children were born without disabilities that he gradually began to accept our first-born child.

# 3. Achieving better marital relationships with their husbands

The data obtained from these interviewees indicate that the husbands' perceptions toward a child with a disability also influences their marital relationships. Those interviewees, who mentioned that their husbands accepted their children with disabilities, either in the beginning or

later on in their marriage, also described a better marital relationship with their husbands. For example, Mother F said:

Having a child with a disability has had a positive influence on our relationship...As a result of our child with a disability, my husband has became more considerate of me...He now routinely shares housework with me to decrease some of my stress.

# Mother H also had a similar experience. She mentioned:

I think our relationship became closer due to our having a child with a disability...Sometimes, I am really tired and don't want to prepare the dinner, so my husband takes us to the restaurant.

Unfortunately, there were two interviewees who reported that having a child with disabilities was a major reason that led them to divorce. Mother B commented:

Having a child with mental retardation negatively influenced my marriage, but I don't blame anyone. Truly, my husband justly could not accept having a child with a disability. Before we divorced, my husband blamed me for having a child with a disability, he said it was my fault because, he believed my genes were not good... Three years ago, he divorced me.

# Mother D shared a similar situation. She reported:

I think having a child with a disability did indeed negatively influence our relationship.

Since my son was first identified as a child with Down syndrome, my husband no longer wanted to come home... A few years ago, my husband just asked me for a divorce.

# 4. Sibling relationships

Two interview participants stated that they were not worried about sibling relationships because there was only one child in their family. Four interviewees reported that they never

heard any complaints from siblings without disabilities as to their mothers being partial to their teenagers with disabilities. Other reasons cited were, the age gap between the siblings without disabilities and the teenagers with disabilities, and the fact that those siblings without disabilities were more independent. The following notes were obtained from the interviewees.

#### Mother F stated:

I really do spend a lot of time taking care of my teenager with a disability. But, my older son without a disability never complains to me. My older son is very independent... Ever since my older son was in elementary school; I explained him that his younger brother is a child with special needs and I therefore need to pay more attention to teaching his younger brother. I think this may be one of the reasons why he is independent...

#### Mother I mentioned:

My three daughters never complained to me about this issue. I think this may be the age gap.

The three of my daughters are 23, 21, and 19 years old, while my son with mental

retardation is only 13 years old. All three of my daughters are college students, while my

son is a junior high school student...My daughters always tells me that I should pay more

attention to my son because they can take of themselves.

The remainder of the interviewees stated their children without disabilities did sometimes complain to them about their being partial to the teenagers with disabilities. These complaints included spending too much time with siblings with disabilities and treating them too well. For example, Mother E reported:

Since my older daughter is a child with epilepsy and mild mental retardation, I pay more attention to taking care of her. On occasion my younger daughter has expressed doubts that I am her birth mother. She frequently comments that I am very permissive with her older

sister and overly strict with her... I always try to explain to my younger daughter that my reasons for doing this are due to her sister's situation.

#### Mother H said:

My younger daughter always says that I spend too much time on my older son with disabilities. She complains that I always accompany her older brother to study and do homework and never accompany her...I always tell her that she is an excellent child and I believe that she can do things well by herself. At the same time, I try to explain to her that her older brother is a child with special needs, so I need to pay more attention to him.

These two examples above provided by Mother E and Mother H illustrated that how their younger children without disabilities resented time that their parents spent with their siblings with disabilities. In addition, it also revealed that parents had to constantly communicate with their younger children without disabilities in order to solve their concerns.

# 5. Negative perceptions still held by parents-in-law

Only one interview participant stated both her parents-in-law accepted having a grandchild with a disability. Although, two interviewees mentioned that while their fathers-in-law had passed away their mothers-in-law did accept having the grandchild with disabilities. Five interviewees mentioned their fathers-in-law passed away and their mothers-in-law could not, or would not, accept their grandchild with disabilities. Two interviewees said that both their parents-in-law had passed away before their grandchildren were born. The data obtained from my interview participants illustrated that the majority of the parents-in-law could not accept having grandchildren with disabilities. The following notes were obtained from the interviewees.

#### Mother C stated:

My father-in-law passed away, but my mother-in-law accepts having a grandchild with disabilities. She sometimes makes a phone call to me to ask about my son's situation...She has told me that although my son is a child with Down syndrome, he is very innocent and friendly...

#### Mother F stated:

My parents-in-law never blamed me for having a child with disabilities. Both of my parents-in-law can accept my young teenager with disabilities, and they really like interacting with my son. So, my son likes to spend summer time at their home.

# On the other hand, Mother D said:

My mother-in-law cannot seem to accept having a grandchild with Down syndrome. Before getting divorced from my husband, my mother-in-law even asked me not to take my son to the wedding ceremony of her daughter because she told me she didn't want to have people know that she has a grandchild with disabilities...I took my son to the wedding nevertheless. During the ceremony, my mother-in-law removed herself from me, and also pretended not to know me or my son.

#### Mother H noted:

My mother-in-law doesn't care for my son with disabilities, because she thinks having a grandchild with disabilities causes her to lose face.

# Objective 4

The final objective of this qualitative study was to discuss whether these 10 Taiwanese mothers changed their attitudes toward people with disabilities after their having a child with a disability, as well as to investigate their opinion regarding the relationship between karma and

disability. (Appendix F). After re-reading the transcripts, three themes were identified and are described as follows.

# 1. Acquiring more disability-related knowledge and gaining self improvement

All of the ten interviewees said that they had indeed learned a lot from their experience. The interviewees mentioned that they learned about disability issues, acquired medical knowledge, and became more optimistic and more patient.

For instance, Mother C reported:

I changed my attitude toward everything in my life...Through taking care of my teenager with disabilities I became more optimistic in daily life... I now have a greater appreciation for the small and simple things of my life.

#### Mother E said:

Since having a daughter with epilepsy and mild mental retardation, I have gained a lot of knowledge about medical and special education through taking care of her.

# Mother F mentioned,

Before having a child with a disability, I think I was an irritable person. I was always busy at my job, and I didn't want to waste my time with any small things...After my son was identified as a child with cerebral palsy and mental retardation, I chose to slow down my pace, and not rush everything. I now realize that there were more important things in my life...Compared with before, I think I have become more patient, and treasure everything I now have.

#### 2. Changing attitudes toward persons with disabilities

All interviewees unanimously stated that their attitudes toward people with disabilities dramatically changed in a positive way. In the study, four mothers said they used to view persons

with disabilities in a sympathetic way while the other six stated they rarely had any experience interacting with people with disabilities before having a child with a disability. One of the interviewees even stated she used to feel that persons with disabilities were weird and strange, and she never wanted to have any interaction with them. These positive views are described as follows.

# Mother A reported:

Before, I held a positive attitude toward persons with physical disabilities because I thought they were just like us, there was no big difference. However, for persons with mental retardation, I used to feel sympathy for them...Now, I would like to try my best to support them, regardless of their disabilities.

#### Mother I said:

To be honest, before having a child with a disability, I had no experience interacting with persons with disabilities, and I didn't want to know them...Now, I really want to help and support them; I also hope that the public can provide them with more opportunities to interact within the community where they live.

#### Mother J stated:

Before having a child with disabilities, I didn't have an opportunity to interact with people with disabilities. I was even afraid of being hurt by persons with disabilities; therefore, I just didn't want to know them...Now, I hope the public can begin to accept people with disabilities. I no longer hesitate to support and assist people with disabilities...I am not afraid of interacting with them anymore.

# 3. Karma was still heavily emphasized as the primarily cause of disabilities

Eight out of ten interviewees stated they definitely believe that karma does exist. Some mothers said they might have done something bad in their previous lives, which led their children to be born with disabilities. Other mothers reported they might owe their children a debt from their previous lives, so those children with disabilities demanded payback in this life. Other mothers mentioned that they might have been the benefactors of the children with disabilities in their previous lives, so the children came to pay a debt of gratitude in this life. The following statements were cited from interviewees.

# Mother A reported:

In fact, I strongly believe in karma. I think my son and I did something bad together, perhaps we murdered or burglarized someone in our previous lives. As a result, in this life, my son was born with disabilities, and I became his mother. I think this is a punishment.

#### Mother E said:

Of course, I believe that is karma. Before having a daughter with disabilities, my family's economic status was below average. Since she became one of our family members, both my husband and I found stable and well-paying jobs. The quality of our lives became better...Several years ago, a fortune-teller told me that my daughter came to me to pay a debt of gratitude because I saved all of her family in my previous life...Some of our friends told us this is good fortune that our daughter was brought to us.

# Mother J shared a similar opinion. She noted:

I believe this is karma. I have consulted with a fortune-teller, and he told me that I was a bad person and I did something to set up my daughter and led to her death in my previous life... Therefore, in this life, my daughter just came to ask me to pay my debt... I believe this

is what I owe her, so what I can do is try my best to take care of her. Then, I would be able to clear off this debt.

Among all the participants, only two mothers reported they did not believe in the relationship between karma and having children with disabilities. For instance, Mother C reported:

Neither my husband nor I believe in karma. I know, some mothers may think they did something bad in their previous lives, so they have children with disabilities in this life. For me, what I want to do is try my best to take care of my son, and to assist him to grow.

Mother D reported:

I personally don't like this idea of karma. I think having a child with disabilities is a ratio issue, and should not be related to the karma.

# CHAPTER 5 DISCUSSION AND CONCLUSION

This qualitative study investigated the perceptions of 10 Taiwanese mothers of teenagers with mild-moderate mental retardation, with a particular focus on the issues of education, social competence, and family relationships. In addition, this study explored whether the mothers had changed their attitudes toward people with disabilities after having teenagers with disabilities.

#### **Education**

Seven out of these ten mothers stated that they were not satisfied with their young teenagers' learning settings regardless of inclusion or segregated classrooms. The reasons included: teachers were not professional; teachers had limited time to assist young teenagers with disabilities due to larger size of classes; general education teachers objected to having students with disabilities in their classes due to their limited knowledge in special education; students with various disabilities were placed together; and there was inadequate appropriate assistive technology to assist these young teenagers with disabilities in learning. On the other hand, the other three interviewees believed that their young teenagers were in appropriate learning settings because parents had access to teachers easily and the schools provided appropriate facilities for students with disabilities.

Since all interviewees asked me to keep the names of the schools their young teenagers attended confidential, I could not reveal the names of the schools in this papers. However, based on the information gained through interviews, young teenagers with disabilities of these 10 participants were attending five different schools. Among these five schools, three were located in the middle-upper class neighborhoods. In this study, only three mothers held positive perceptions toward their teenagers' learning settings, and their teenagers were all attending different schools. For example, two were enrolled in two different middle-upper class

neighborhoods while the other was not. On the other hand, seven interviewees reported that they were unsatisfied with their young teenagers' learning settings and that their young teenagers were enrolled in four different schools. Among these four schools, three were located in the upper-middle class neighborhoods and one was not. Thus, in this study, there was no significant information that demonstrated schools in the upper-middle class neighborhood provided a better special education than those schools that were not located in the upper-middle class neighborhood.

The interview information about these schools their teenagers enrolled in illustrated that eight out of ten interviewees had young teenagers attending schools that were heavily academically oriented. Seven interviewees who claimed that they were unsatisfied with their young teenagers' learning settings also believed that the schools their teenagers attended seemed to greatly emphasize on assisting students without disabilities to pass the Basic Competence Test (BCT). This BCT was used by graduating junior high students to apply to senior high school. Thus, these mothers seemed to believe that the school their young teenagers attended preferred to provide more academic resources for students without disabilities rather than students with disabilities.

The information gained from the interviewees revealed that mothers had different viewpoints on their teenagers' education. In the area of academic expectations for their young teenagers, five out of ten mothers believed that learning academic subjects was more important than the other five interviewees who stated that learning non-academic skills—such as vocational skills, independent living skills, and interpersonal communication skills—should be a priority. However, according to the National Education Act, specific vocational training is not particularly emphasized until the students finish their nine-year compulsory education (Government

Information Office, 2004). It is similar to the transitional services first mandated in the Individual with Disabilities Education Act (IDEA) in the United States, that required transitional plans and services are made available to students with disabilities by age 16. Thus, learning basic academic subjects is still the priority for students with mild-moderate mental retardation who are at the junior high school level.

In addition, socioeconomic backgrounds of interviewees might also influence their young teenagers' learning after school. The socioeconomic status was determined by a few factors, including: family income, education, and employment (Hunt & Marshall, 2002). In this study, three out of six mothers from double income families with college degrees believed that it was worthwhile and appropriate to provide learning opportunities for their young teenagers with disabilities after school. They stated that they were willing to pay fees as long as their children were interested in specific subjects outside of school or if the learning center could help their children with academics. These results illustrated that socioeconomic status of mothers of young teenagers did play an important role in assisting their children's learning.

Regarding the future goals of their teenagers, the majority of the interviewees (8 out of 10) responded that they had discussed this issue with their teenagers. Two mothers reported that they had never discussed it with their teenagers because they did not think that their teenagers could understand it at that time. Mothers mentioned that their teenagers had discussed wanting to be a bus/taxi driver, car dealer, historian, model, police officer, and cashier as future goals. Most mothers said that what they could do was to encourage their teenagers to work hard to achieve their goals, while persuading them to learn appropriate vocational skills in the near future.

# **Social Competence**

The second objective was to find out mothers' perceptions toward these young teenagers' social competence patterns within families, at schools and within the communities they live. All interviewees stated that their young teenagers spent most of their leisure time at home and none of them stated that their teenagers had the chance to interact with their peers after school. The answers gained from the interviewees illustrated that these young teenagers had a difficult time making friends after school, and assisting their young teenagers in building their social network after school was a major concern for these mothers.

Research done by Chen and his colleagues (2002) demonstrated that the students at school tend to hold positive attitudes and higher levels of pessimism for their peers with disabilities, and indicated that the students tend to accept their peers with physical disabilities more easily than people with mental retardation. In this study, five out of ten participants, who reported that they often had communication or discussion with the teachers about their teenagers' social competences at school, said that their teenagers had positive interactions with their peers at school. On the other hand, the other five interviewees who stated that they rarely had discussions with the teachers reported that their teenagers seemed to be alone at school. The results revealed that effective communication between mothers and teacher could play an important role in assisting these young teenagers to develop their social competence at school.

Besides the effective communication between mothers and teachers that could assist young teenagers with disabilities in building friendships at schools, other researchers found that the socioeconomic status of families may also be an important factor in supporting children with disabilities to develop both in academic and social networks (Hunt & Marshall, 2002).

However, this study uncovered an interesting phenomenon. Most mothers who reported discussing their young teenagers' interaction patterns at school with teachers had only one wage earner in the family, either her husband, herself, or retirement pension. Several of these mothers stated that since their husbands worked at the managerial level, they had plenty of time to communicate with the teachers without worrying about financial issues. Conversely, those who reported that they rarely had time to talk to teachers, or had a bad relationship with the teachers were all from double income families. This pattern might illustrate that career women have insufficient time to communicate with teachers due to their work, which could impact their children building friendships at school.

With regard to social interaction patterns of people with disabilities within the community and the communities' perceptions toward people with disabilities, some previous research demonstrated that the public perceives various disabilities in different ways (Furnham & Pendred, 1983; Schneider & Anderson, 1980; Westebrook et al., 1993). Their results revealed that the public tended to hold a more positive attitude toward people with physical disabilities than people with cognitive disabilities or mental illness. Nevertheless, the information gained from the interview participants in this study illustrated that the communities that these interviewees live in hold both positive and negative attitudes toward their young teenagers with disabilities. Five interviewees said that the communities they lived in were able to accept their teenagers with mental retardation while the remaining five interviewees stated that their communities were not accepting of their young teenagers with mental retardation. Although only half of the interviewees stated that their communities accepted their young teenagers with disabilities, it was a good sign to see that Taiwanese tend to accept interacting with people with disabilities gradually, based on the results of my study. This also paralleled with the results of other

interview studies done by two Taiwanese researchers that the public slowly, but gradually, accepted interacting with persons with disabilities (Her, 1999; Sheng, 1999).

# Family Relationships

To address whether having teenagers with disabilities influenced interviewees' family relationships, three questions were discussed. The first interview question was to investigate husbands' perceptions about having a teenager with disabilities. In this study, five mothers stated their husbands accepted having children with disabilities at the beginning, three mothers reported their husbands gradually accepted it with the growth of the children and the birth of subsequent children, and two mothers said that their husbands could not accept having children with disabilities and their marriages ended in divorce.

Although the results illustrated that their husbands' perceptions of their children with disabilities varied, a surprising pattern was found. For example, in this study, the birth order might have been a factor that influenced their husbands' perceptions of their children with disabilities. Three mothers said that their husbands became more accepting of their first children with disabilities after their subsequent children were born without disabilities. Another pattern of the effects of birth order was also found. For three out of five mothers who reported their husbands accepted having a child with disabilities at the beginning, their children with disabilities were not first born in their families. This phenomenon seemed to parallel with some researchers' opinion that if the first-born child with disabilities in a Chinese family, the parents might feel shame and regard their first-born child with a disability as a disgrace to the family (Axelrod, 2003; Chou & Palley, 1998; Liu, 2001).

The second point in the issue of family relationship was whether having children with disabilities will influence their marital relationship. Some research reported that having children

with disabilities would adversely impact marital relationships and increase divorce rates (Friedrich & Friedrich, 1981), while other research stated that there were both positive and negative influences on marital relationships when having children with disabilities (Risdal & Singer, 2004). Surprisingly, in this study, eight mothers who stated that their husbands accepted their teenagers with disabilities either at the beginning or with the growth of the children also described improved better marital relationships since the birth of their children. The information obtained from those eight interviewees illustrated that they had an improved marital relationship after having a child with a disability because their husbands became more considerate, showed more care for families, and grew more tolerant. The other two interviewees reported that their marriages ended in divorce that was directly due to issues related to their children with disabilities.

Next, the third question explored whether other children without disabilities felt their mothers were partial to their siblings with disabilities. Research involving siblings of children with disabilities had produced findings that the impact on the siblings without disabilities could be both positive and negative (Baxter et al., 2000; Dyson, 2000). In this study, two mothers said they were not worried about this issue because there was only one child in their family. Four interviewees reported that their children without disabilities rarely complained to them about being partial to their siblings with disabilities. They stated it was because their other children without disabilities had an age gap with their siblings with disabilities, and their children without disabilities were generally older and more independent. The four remaining interviewees reported their younger children without disabilities complained to them about this issue.

Complaints included that parents spent too much time with their siblings with disabilities, and treated their siblings with disabilities better. To deal with this issue, mothers stated that they

constantly explained to their younger children without disabilities why their siblings with disabilities required more time and attention.

This study encountered another pattern related to the effects of siblings' birth order. Naseef (2001) mentioned that the younger children always felt that they were supposed to be protected and spoiled by their older siblings as well as their parents, thus, they might expect that parents should take care of them due to their age. Similar with Naseef's opinion, in this study, three of out four interviewees who stated that their children without disabilities rarely complained to them about being partial to their siblings with disabilities were all older than their siblings with disabilities. On the other hand, three out of four mothers who mentioned that their children without disabilities complained to them about this issue were all younger than their siblings with disabilities. The information gained from these mothers illustrated that the relative age of children without disabilities might influence their perceptions of their siblings with disabilities.

Furthermore, grandparents may serve an important role in supporting children with disabilities and their families (Katz & Kessel, 2002). But due to impaired intergenerational relationships, health and educational factors, and geographical distance, the perceptions of children with disabilities held by grandparents may not be supportive for the affected families. When discussing with interviewees how their parents-in-law perceived their grandchildren with disabilities, only one mother mentioned that both her parents-in-law accepted having a grandchild with disability. Two mothers reported their fathers-in-law passed away and their mothers-in-law could accept their teenagers with disabilities. Five mothers said their fathers-in-law had passed away and their mothers-in-law were unable to accept having grandchildren with disabilities. The remaining two interviewees responded that both of their parents-in-law passed away before the birth of their teenagers with disabilities. The information obtained revealed that

the majority of interviewees whose parents-in-law were alive could not accept their grandchildren with disabilities.

# Perceptions on Disability Issues

As mentioned in the literature review, some parents experienced positive consequences from taking care of their children with disabilities (Abbott & Meredith, 1986; Hastings & Taunt, 2002). These positive consequences included developing traditional family strengths, having a closer and stronger family, expanding tolerance for human differences, and experiencing personal growth. Other studies, however, illustrated that parents did indeed feel negative consequences as a result of having children with disabilities (Baxter et al., 2000; Shearn & Todd, 2000). These negative effects included experiencing a loss of self, marriage quality, and family cohesion. Surprisingly, ten mothers in this study unanimously stated that they learned a lot as a result of this experience. And all of them reported they had made great personal improvements, which included learning about disability issues, acquiring medical knowledge, having a positive outlook toward their lives, and becoming more patient.

When discussing whether they changed their attitude toward people with disabilities after having children with disabilities, all mothers reported that their attitude toward people with disabilities indeed changed to be more positive. Of those interviewees, four out of ten said they used to be sympathetic to people with disabilities, while six out of ten stated they rarely interacted with people with disabilities before their children were born. Remarkably, all interviewees reported that having children with disabilities led them to have a more positive outlook toward people with disabilities and realized they should be more supportive to assist others whose children have disabilities.

Finally, Chinese tend to share beliefs in reincarnation and in the influence of deeds from the past life on the present life, or karma (Deepak, 2001). Eight out ten interviewees reported that they indeed thought the existence of karma related to their children having disabilities. Only two mothers said that they did not believe there was a connection between karma and their teenagers with disabilities. Of the eight interviewees, two believed that they did something bad in their past lives, which led them to have children with disabilities. Four said they owed their children with disabilities from their previous lives, so now they must payback the debt in their present lives. Two mothers believed they might have been the benefactors of their children with disabilities in past lives, so the children came to pay a debt of gratitude in their present lives. The opinions drawn from the interviewees demonstrated that the majority of interviewees in this study believed that karma was a factor in their young teenagers being born with disabilities, and support other researchers' findings that the concept of karma is considered a causative factor for Chinese with children with disabilities (Liu, 2001; Sheng, 1999).

#### Limitations

There were several limitations in this qualitative study. First, since the research project's pool of participants was limited to the mothers of young teenagers between ages of 13 and 15, the results of these findings cannot be generalized to all mothers of children or young adults with disabilities. Second, because I only conducted the interviews in Taipei, the results of this study do not represent the mothers of teenagers with mild-moderate mental retardation in the rest of the cities of Taiwan. Third, since I did not interview fathers and siblings of those teenagers with mild-moderate mental retardation for the interviews, the perceptions from mothers do not represent those of the entire family. Fourth, mothers' perceptions toward their teenagers with

mild-moderate mental retardation may change over time, and information I collected during the interviews may express merely what they felt at that particular time.

# Recommendations

In closing, the results of this study suggest a number of recommendations that may direct future research. Since this research focused on 10 Taiwanese mothers' perceptions toward their young teenagers with mild-moderate mental retardation, future researchers are encouraged to investigate from different perspectives. For instance, fathers may hold similar concerns toward their children with disabilities as their wives, or their emotions, worries, and perceptions of children with disabilities maybe quite different (Lillie, 1994; Vadasy, Fewell, Meyer, & Schell, 1984). Consequently, researchers can first investigate Taiwanese fathers' perceptions of their children with disabilities. Next, since parental socioeconomic status (SES) may affect family's ability to support their children with disabilities, the researchers can examine whether parents from different socioeconomic statuses have different perceptions of their children with disabilities in Taiwan. Third, since this study focused on Taiwanese mothers' perceptions of their young teenagers with disabilities who live in Taiwan, the researcher can investigate how Taiwanese mothers in the United States compare with those in Taiwan regarding their perceptions of their young teenagers with disabilities. Fourth, the results of this study illustrated that the relative age gap may influence children's perceptions of their siblings with disabilities, so I would also recommend that researchers explore the effect of the relative age gap on interaction patterns between siblings with and without disabilities. Furthermore, researchers can also investigate whether perceptions of children without disabilities toward their siblings with disabilities change with their growth.

The results of these future studies could provide valuable information for educators and services providers. When combining these results with the present study, both educators and services providers can get a better understanding of the different perceptions toward children with disabilities held by the Taiwanese population.

# APPENDIX A Consent Form

Agreement to Participate in Taiwanese Mothers' Perceptions Of Teenagers With Mild/Moderate Mental Retardation

Ying-Ting Huang 1550 Wilder Ave. Apt 713, Honolulu, HI 96822

Dear Taiwanese mothers,

I am conducting research in relation to the perceptions of Taiwanese mothers of their teenagers with mild/moderate mental retardation. For this study, I will collect information about how Taiwanese mothers perceive their teenagers with mild/moderate mental retardation, with a particular focus on the issue of education, social competence, family relationships, and your current perception toward persons with disabilities. I hope that participating in this project will help you become more aware of your perceptions of your teenagers with mild/moderate mental retardation. In addition, results of this study will help educators and service providers in the United States to get a better understanding of Taiwanese mothers' perceptions of their teenagers with mild/moderate mental retardation, and will become a valuable source to them when they provide assistance and services to this population.

The project data will be collected between February and March in Spring 2006 from approximately 10 mothers of teenagers with mild/moderate mental retardation who are living in Taipei, Taiwan. Data will be collected in the form of the interview including background information such as your age, job and job description, educational degrees, and family members. I will also ask some questions in relation to this interview study including your experience of taking care of your teenager with mild/moderate mental retardation, especially on the issues of education, social competence, family relationship, and your current perception toward people with disabilities. The interview should take at 60 minutes or more, and will be tape recorded. During the interview, you have right to ask me stop tape recording at any time if you do not want some of your opinion to be recorded.

Audio tapes will be kept secure in a locked cabinet, and will be destroyed upon completion of the project. Your answers will be put together with other answers and your name will not be used. Although you may recognize your story in articles about this research, others will not know that it is your story, or that you were a part of the project.

All participation will be voluntary, and the identities of all participants will be kept confidential. Interview questions are fairly simple and straightforward. It is likely that you will have no problems as a result of participating in this project. It is possible that answering some interview questions could cause you some worry. If you feel worried, you may stop answering the questions at any time and you have right to withdraw your consent to be interviewed at any time without penalty.

# APPENDIX A Consent Form (Continued)

I certify that I have read and that I understand the above information. I have also been given satisfactory answers to my questions concerning the project, and I agree to participate in this project. I understand that I may refuse to participate or withdraw my consent at any time without penalty. I herewith give my consent to participate in this project with the understanding that such consent does not waive any of my legal rights, nor does it release from Ying-Ting Huang or the University of Hawaii at Manoa or any employee or agent thereof from liability for negligence.

Signature of participant:	Date:
•	s to your questions or have comments or complaints
about your treatment in this study, please	e contact: Committee on Human Studies, University of
Hawaii, 2540 Malie Way, Honolulu, HI	96822. Phone: 808-539-3955

# APPENDIX B Interview Ouestions

#### **Basic Information:**

- 1. What is your name?
- 2. Do you mind sharing your age with me?
- 3. What is your highest educational degree?
- 4. How long have you been married?
- 5. What is your current job title? What are your job duties? What are the resources of your family income?
- 6. How many people are in your family? What is their relationship to you?

#### **Interview Questions:**

- 7. Tell me something about your child (i.e. name, age, and what kinds of disabilities he/she has?).
- 8. Does your child receive education in inclusion or segregation? What is your opinion of his/her learning setting?
- 9. What are you expectations of your child from an educational aspect?
- 10. Have you communicated with your child about his/her goals for himself/herself? What are his/her current personal goals?
- 11. What does your child like to do in his/her leisure time?
- 12. Have you ever heard from the teacher regarding your child's interactive patterns with peers in the school? What are they? And how do you feel?
- 13. What are your child's interactive patterns with your neighbors? And how does the community perceive your child?
- 14. What are your husband's perceptions on having a child with mild/moderate mental retardation?
- 15. Does your young teenager with disabilities influence your marital relationship?
- 16. Do your other children feel you are partial to the child with a disability? And how do you deal with this issue?
- 17. How do your parents-in-law perceive their grandchild with mild/moderate mental retardation?
- 18. What have you learned from raising a child with disability?
- 19. How do you perceive people with disabilities before and after you had a child with a disability?
- 20. How do you perceive the relationship between karma and disability?

APPENDIX C
Interview Questions Addressed the Issue of Education

Interview Questions										
	Α	В	С	D	Е	F	G	H	I	J
1. Does your	1.Inclusion	1.	1.	1.	1.	1.	1.	1.	1.	1. Self-
child receive	2.	Self-	Self-	Self-	Inclusion	Inclusion.	Inclusion	Inclusion	Inclusion	contained
education in	Teacher	contained	contained	contained	2. Teacher not	2. Teacher	2.	2.	2. Large	2.
inclusion or	reject	2. One	2.	2. Teacher	trained in	not trained	Teachers	Teachers	size of	Equipments
segregation	having	teacher	Classroom	not	special	in special	are nice	are nice	class;	being too
setting? What is	students	teach all	facilities are	trained in	education	education;	and		teacher	old; teacher
your opinion	with	subjects	comfortable	special		large size of	profession		not	not trained
toward his/her	disabilities	(not trained	; teachers	education		class	al		trained in	in special
learning	in the	in special	are			}			special	education
setting?	class/not	education);	professional						education	
	trained in	students	;							
	special	with various				·				
	education	disabilities								
		placed								
<u> </u>		together								
2. What are	1. Don't ask	1. Don't ask	1. Learn	1. Acquire	1. Learn	1. Learn	1. Ask her	1. Ask	1. Learn	1. Learn
I -	him to get a	_	•		interpersonal	independent				independent
1 -	good grade		living skills	skills		living skills		his best in		living skills
		2. Ask her		!	2. Try his best		academic	academics	skills	
1		to do her				cational				
	best	best in				skills				
aspect?		academic								

APPENDIX C
Interview Questions Addressed the Issue of Education (Continued)

Interview Questions	Key thoughts from each participant										
`	A	В	С	D	Е	F	G	H	I	1	
3. Have you communicated with your child about his/her goals for himself/herself? What are his/her current personal goals?		1. Yes 2. Taxi driver	1. Yes 2. Car sales person	1. Yes 2. Historian	1. Yes 2. Model or dancer	1. Never	1. Yes 2. Cashier	1. Yes 2. Bus driver	1. Yes 2. Police officer	1. Never	

APPENDIX D
Interview Questions Addressed the Issue of Social Competence

Interview Questions	Key thoughts from each participant										
	A	В	С	D	E	F	G	H	1	J	
1. What does your child like to do in his/her leisure time?	Plays computer games     Watches TV	music 2. Watches TV	2. Plays	1. Listens to music 2. Sings songs		Watches baseball on TV     Plays computer games	1. Plays computer games	1. Plays computer game 2. Watches TV	1. Chats with relatives on the phones	1. Watch TV	
with the teacher regarding your child's interactive patterns with	myself 2. Alone at school 3. I don't blame		help peers.	be with peers	1. No, I ask him myself 2. Alone at school 3. I can accept	1. No, I asked him myself	peers	asked him myself 2. Alone at school. 3. I hardly	myself 2. Little interaction	1. Yes 2. No interactio n. 3. I can accept	

APPENDIX D
Interview Questions Addressed the Issue of Social Competence (Continued)

Interview Questions	Key thoughts from each participant										
	A	В	С	D	Е	F	G	Н	I	J	
3. What are your child's interactive patterns with your neighbors? And how does the community perceive your child.	the neighbor	2. Accepted	2. Accepted	2.	accept	interaction	2.	1. No interaction 2. Couldn't accept		1. No interaction 2. Couldn't accept	

APPENDIX E
Interviews Questions Addressed the Issue of Family Relationships

Interview Questions	Key thoughts from each participant										
	A	В	C	D	Е	F	G	Н	I	J	
1. What are your husband's perceptions on having a child with mild/moderate mental retardation?	1. Couldn't accept from beginning 2. Accepted later on.	accept; escaped	1. Accepted from beginning	1. Could not accept; escaped	1. Accepted from beginning	from beginning	1. Accepted from beginning 2. He is especially partial to her	ſ	1. Accepted from beginning	1. Couldn't accept from beginning. 2. Accepted later on	
2. Does your child influence your marital relationship? Why or why not?	1.Positive 2. We compromise the ways of teaching the child (Better)	(Worse)	1Positive 2. More considerate (Better)	1. Negative 2. Doesn't like to go home (Worse)	1. Positive 2. More closer (Better)	1. Positive 2. More care about this family (Better)	1. Positive 2. More considerate (Better)	2. More	1. Positive 2. Closer (Better)	1. Positive 2. More considerate (Better)	

APPENDIX E
Interviews Questions Addressed the Issue of Family Relationships (Continued)

Interview Questions	Key thoughts from each participant										
	A	В	C	D	E	F	G	H	I	J	
3. Do your other children feel you are partial to the child with disabilities? And how do you deal with this issue?	1. Yes. 2. Explain and discuss the situation to children without disabilities	child only)	N/A (one child only)	1. No.	1. Yes. 2. Explain and discuss the situation to children without disabilities	1. No		1. Yes. 2. Explain and discuss the situation with siblings	1. No	1. No	
perceive toward their grandchild with	law passed away 2. Mother- in-law can't	law passed away 2. Mother-	law passed away 2. Mother- in-law can accept	1. Father- in-law passed away 2. Mother- in- law can't accept	1. All pass away	1. They accept the child, and treat him well.	law passed away	1. Father- in-law passed away 2. Mother- in-law can't accept	away	1.Father-in- law pass away. 2. Mother- in-law can't accept	

APPENDIX F
Interviews Questions Addressed Mothers' Attitude Changed

Interview Questions	Key thoughts from each participant										
	A	В	С	D	Е	F	G	Н	I	J	
1. What have you learned from raising a child with disability?	1. Know more about disability issues	1. More patient; acquire medical knowledge	1. More patient; more optimistic	1. More optimistic	1. Acquire medical and special education knowledge	I. More patient	More patient; know more medical knowledge	1. Know more about disability issues	1. More patient	1. Know more about disability issues	
perceive people with disabilities before and after you had a child with a disability?	sympathy	1. Before: no interaction. 2. After, support them	1. Before: no interaction. 2. After: they are innocent	was sympathy 2. After: put my	sympathy 2. After: support	1. Before: no interaction. 2. After: try my best to help them	1. Before: was sympathy 2. After: still the same	1. Before: don't understand this population 2. After: more patient with them	1	1. Before: no interact 2. After: support them	
3. How do you perceive the relationship between karma and disability?	1. I believe it	I believe	1. I don't believe	1. I don't believe	1. I believe it	1. I believe it	1. I believe it	1. I believe it	1. I believe it	1. I believe it	

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