

Experiences of Taiwanese Parents of Children with Autism – Disabilities

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### **Abstract**

There has been a growing awareness and discourse on the nature, causes, and interventions of autism. However, few studies have been undertaken to discuss the socio-cultural factor which accounts for the varied perspectives in interpreting and characterizing this disability. This qualitative research study is designed to understand the perspectives, experiences, and practices of parents raising a child with autism in Taiwan. The meaning of the experiences which parents and the child live are said to be constructed under the dominant socio-cultural views of autism and disability. Thus, the present study attempts to gain insights into the phenomenon in which parents and the child negotiate their experiences within their socially constructed reality. In-depth, semi-structured interviews were conducted with 10 parents of school-aged children with autism in Kaohsiung City, Taiwan. Participants were recruited using snowball sampling to build trust with the researcher and the study, and to secure participants' privacy and confidentiality. The parents' demographic information and the interview data were collected and analyzed. A constant comparative method based on the grounded theory approach was adopted to analyze the interview transcripts. Analysis of the interview data revealed three themes: the meanings of autism, family as the base of support, and the child developing into a relatively autonomous person. Results indicate that the Taiwanese parents drew on the knowledge and experience acquired from both medical and educational sources to treat, to educate, and to place their child with autism in anticipating the child would develop relative independence when reaching adulthood, particularly, in response to the expectations of their extended family and the society. They also utilized social supports to improve the well-being and situations of their families in confronting conventional conceptions of disability, especially when regarding the moral value associated with having a child with a disability. Two central themes emerged from the findings:

a) a lack of social awareness of autism, and b) a lack of support resources for the placement of adults with disabilities. These themes were important aspects of the lived experiences of families of children with autism in Taiwan.

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## **Chapter 1**

### **Introduction**

#### **Rationale**

While recent studies report that autism has resulted in families of children with autism having a considerable burden in seeking the optimal intervention and educational placement, few have discussed the underlying beliefs, perceptions, or experiences of the family. Given the fact that autism, as one of the most prevalent childhood disabilities, has generated notable social implications on the family and society, the present study focuses on the perceptions and experiences of Taiwanese parents in nurturing their child/youth with autism. The social process or phenomenon in caring for a child with an autism label renders distinctive meaning for parents, which is often disregarded or given little attention under the dominant socio-cultural beliefs, values, and practices. Families of children with autism in Taiwan are concerned specifically, with issues of the biomedical model of discourse on autism and the traditional Chinese cultural beliefs about the disability. Moreover, it is noted that culture accounts for varied understanding and perspectives on the nature and causes of autism/disability. In this regard, parents' beliefs and perspectives on autism influence their parenting practice, help-seeking behavior, and socialization with the child. A number of recent studies attend to the socially constructed meanings of autism, as represented in a specific socio-cultural context, to understand how it is conceived and treated.

The present study aims to investigate the social implications of having a child with autism in the family, with the focus on parents' caregiving experiences, and how the experiences are

constructed in their day-to-day life within the given socio-cultural milieus. The guiding questions of the research are as follows,

1. How do Taiwanese parents perceive having a child with a disability and the diagnosis of their child's disability?
2. How are parents' experiences of having and raising a child with autism shaped by the socio-cultural forces in Taiwan, specifically, what social and cultural beliefs, values, and norms are held by Taiwanese parents in raising a child with autism?
3. What issues or concerns have arisen in the context where parents nurture a child with the label of autism?
4. What services are available to address issues of autism and to what extent do parents access such services?
5. What type(s) of therapy/intervention/treatment have parents chosen and what are the reasons for such choices?

## **Chapter 2**

### **Literature Review**

In this section, I review studies regarding the issues with which parents of children with a disability are concerned, with a focus on autism in Taiwan. Within the context of traditional Chinese culture and Western biomedical approach, Taiwanese parents of children with autism provide distinct yet pertinent perspectives to understand the social implications and the lives of families with a child with autism. The meaning given to experiences that the parents acquired in raising a child with an autism label are socially and culturally constructed. Therefore, I incorporate the studies conducted in both China and Taiwan, as the Chinese culture has a significant influence in both societies. The studies and literature reviewed are based on qualitative research approaches and inquiries, including content analysis, ethnography, phenomenology, and grounded theory. In the first section, I discuss the socio-cultural influences on disability-related issues in Taiwan. Then, I explore the research on ethnic Chinese parents' perspectives and experiences of having and raising a child with a disability, with an emphasis on Taiwanese parents. Lastly, I examine how autism, as a childhood disability, is socially constructed and represented within different cultures, and the implications for further studies. The review of the research studies draws on socio-cultural factors in the contexts which parents of children with autism are based. A variety of qualitative research techniques and procedures were adopted by the researchers to inform qualitative inquiry and the research questions, such as interviews, observations, focus groups, and secondary resources.

#### **Socio-cultural Context of Disability in Taiwan**

Culture shapes people's daily experiences, attitudes, and behaviors toward themselves and society. Generally, each culture has its own customs, norms, and values on which behaviors or attitudes are appropriate and desired, and which are inappropriate and to be avoided or forbidden. Cultural beliefs and mores have an impact on people's perceptions, practices, and expectations of a normally developing child, as well as parenting and parent-child interactions in a society. As Chiang and Hadadian (2007) noted, "Culture has a very strong impact upon people's understanding of disabilities and the usage of outside support" (p. 19). Specifically, the social and cultural attitudes profoundly influence Taiwanese people's perceptions towards children with disabilities (Ho, Tang, Detar, & Wang, 2014). In line with the other East Asian countries (You & McGraw, 2011), Taiwanese family and society share the ethics and morals derived from Confucianism. However, few historical studies address perceptions of disability and people with disabilities from a socio-cultural perspective in East Asian countries (Chang, 2014). The socio-cultural perspective of disability influences how Chinese societies define people with disabilities, especially in the use of language and in discourse. According to Stone (1999), the term used to refer to people with disabilities in Chinese language was *can-fei* (殘廢), which means disabled and useless or worthless (as cited in Chang, 2014). After the 1980s, the term *can-fei* was replaced by *can-ji* (殘疾), which means disabled and ill in Mainland China. In other words, the linguistic meaning referring to people with disabilities has transformed from defining disabilities as individual incapacity (useless or worthless) to a medical condition (illness) in Chinese language (Stone, 1999, as cited in Chang, 2014). In Taiwan, the semiotic representation of disability was slightly different. According to Taiwan's first disability-related law, the Disabled Welfare Act in 1980, *can-zhang* (殘障), was used to define people with disabilities as disabled

and impaired. The term was changed to *shen-xin zhang-ai zhe* (身心障礙者), people with mental and physical disabilities, or *zhang-ai zhe* (障礙者), people with disabilities after the revision of the law in 1997 (Chang, 2014). The shift in the semiotic meanings of people with disabilities prompted the social transitions towards recognition and awareness of people with disabilities in Taiwan.

As noted, traditional cultural beliefs have a significant impact on Taiwanese's perspectives and attitudes about disability, and towards the disabled children and their families. The traditional cultural and religious beliefs such as Confucianism, Buddhism, Taoism, and Chinese folk religions have long accounted for the societal norms and values on disability in Taiwanese society (Chang, 2014; Ho et al., 2014; Kang, Lovett, & Haring, 2002). Influenced by the Chinese cultural and religious beliefs, families of children with disabilities in Taiwan are less likely to seek support from outside, and are inclined to cope with their children's disabilities by themselves or with the help of their extended family (Chang & Hsu, 2007; Chiang & Hadadian, 2007; Ho et al., 2014; Kang et al., 2002). The ethics of Confucianism and traditional Chinese cultures focus on the development of reciprocity, harmony, and morality, manifested in everyday relationships and practices among individuals, the families, and the society in their inherent contexts. On one hand, the birth of a child with a disability represents the disruptions of homogeneity, certainty, or continuity of the family and the society, and the inability to transmit cultural knowledge (Holroyd, 2003). In Taiwanese society, for instance, filial piety is the central ideology in traditional cultural customs. Parents nurture their children with the expectation that the children will take care of them in return when they are aged (Ho et al., 2014). Families of children with disabilities may feel shame or guilt as their children cannot fulfill or transmit the

obligations and norms of the family (Chang & McConkey, 2008; Holroyd, 2003). On the other hand, children with disabilities have difficulties meeting the social and cultural expectations of a well-developed and productive person. They might have difficulties or inability to fully participate and contribute to normative societal or cultural activities. Moreover, Chinese families who believe in reincarnation and karma as their religious belief may perceive a child's disability as retribution or punishment for the child's, the family's, or their ancestors' immoral behaviors from the previous lives (Chang & McConkey, 2008; Ho et al., 2014; Kang et al., 2002), or for the violations of cultural taboo, especially during pregnancy (Chiang & Hadadian, 2007; Ho et al., 2014; Holroyd, 2003). The dominant socio-cultural beliefs and values have, thus, resulted in social stigmatization, blame, and isolation of families, particularly mothers, of children with disabilities in Taiwan (Chang, 2009; Chang & Hsu, 2007; Chang & McConkey, 2008; Ho et al., 2014).

Education is deemed to be salient in advancing one's personal and social prosperity in Taiwan. People with higher educational levels have earned more respect from the society. Accordingly, Taiwanese parents go to great lengths to provide their children with the best education possible, and expect the child to achieve academically and to have a successful career in the future. However, these expectations and respect are not always found among individuals with disabilities. The right for more equal opportunities to educational, vocational, and social welfare services have been relentlessly advocated by Taiwanese parents of children with disabilities over the past few decades (Chang, 2014). In 1984, the Taiwanese government promulgated the Special Education Act, mandating early childhood special education (Kang et al., 2002). According to the law, children with a disability may choose to go to public schools or receive education at home (Chang, 2014). Even though the initial attempt was to protect the

disabled children's rights for early special education, due to the lack of adequate infrastructure and educational resources, many children with disabilities remained at home (Chang, 2014; Kang et al., 2002); only few children had the opportunities to attend special preschools, or to receive health care and social welfare services (Kang et al., 2002). The law was revised in 1997, aimed at enhancing special education services and resources for every child with a disability to accept adequate inclusive education, especially in the public-school system (Kang et al., 2002). In 2009, the law further incorporated the role of parents in the child's educational decision-making process. Currently, Taiwanese parents are given incentives to collaborate with professionals to establish the child's support network pertaining to the child's Individualized Education Program (IEP) (Ho et al., 2014). This includes pooling resources from parental groups, interventional institutions, and organizations to promote special education, planning of special education programs with the educational authorities, and coordinating schools and community resources and services to develop special/inclusive education in schools (Ministry of Education of Republic of China, 2009).

In Taiwan, school-aged children with disabilities are provided with special education programs in resource rooms, special classes, special schools, and child development institutions or centers. In conformity with the Disabled Welfare Act in 1980, the local governments began to certify applications for disability registration and provide various services for individuals with disabilities (Lai, Tseng, & Guo, 2013). The law initially classified seven categories of disabilities, including visual impairment, hearing impairment or balance disability<sup>1</sup>, speech or

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<sup>1</sup> This category was divided into "hearing impairment" and "balance disability" in 1997 (Physically & Mentally Disabled Citizens Protection Act, 1997).

language impairment, disability of limbs, intellectual disability (ID), multiple disabilities (defined as having disabilities combined with two or more categories), and other disabilities listed by the Department of Health (Disabled Welfare Act, 1980, as cited in Lai et al., 2013). The revision of the law in 1990 increased to 12 categories of disabilities, including autism spectrum disorders (ASD) (Lai et al., 2013). Students with qualified certificates of any of those disabilities are eligible for required services, such as assistive devices (i.e. hearing aids, wheelchairs), public transportation, and financial assistance. Among these, students who need medical attention or rehabilitation services can receive the services through application of the parents or referral of the health care professionals (Kang et al., 2002). As a result of the advocacy of concerned parents and professionals to promote development in public policy and social awareness on the rights of people with disabilities, the Disabled Welfare Act (1980) was replaced by Physically & Mentally Disabled Citizens Protection Act in 1997, and further revised to People with Disabilities Rights Protection Act in 2007 (Lai et al., 2013; Ho et al., 2014). In accordance with the international disability rights treaty of the United Nations, the law was amended to secure equal opportunity in social, political, economic, and cultural participation of people with disabilities in Taiwanese society (People with Disabilities Rights Protection Act, 2007). Therefore, service provisions for people with disabilities are not only charity or welfare concerns, but rather, a human right. The transitions in service provision and public policy for people with disabilities indicate that, in Taiwan, the role of the governments was reformed from a passive-reactive one to an active-enabling model (Chang, 2014).

### **Parents' Perspectives and Experiences of Disability**

**Parents as caregivers.** When a family finds out that they have a child with a disability, the impact of social and cultural beliefs, attitudes, and messages on the family can be very

troublesome. Since nurturing a child to an ideal and well-developed person is aspired and deemed to be appropriate in every family and society, parents of children with disabilities usually find themselves in “dilemmas” (Holroyd, 2003). Furthermore, since each culture and society has its own guidelines or criteria for raising and educating a child, the situation of families of children with disabilities may contrast or be outside the normative parenting parameters. It is found in both western and eastern societies, that having a child with a disability can have unexpected effects on family functioning and nature (Chang & McConkey, 2008; Holroyd, 2003; Wong et al., 2004). The feelings of shame or “losing face” in terms of deviating from societal structures and norms in families of children with disabilities may be enhanced in the eastern culture when family members conform to the expected harmony, reciprocity, and expectations of the culture. In this regard, as minority groups within the society, the voices of parents of children with disabilities are paramount, since they reflect broader perspectives and issues regarding disability and the lives of children with disabilities in the given socio-cultural contexts. A growing number of studies indicate that, in the Chinese societies, patriarchal culture renders discrete obligation and moral responsibility to mothers who have a child with a disability (Chang, 2009; Chang & Hsu, 2007; Chang & McConkey, 2008; Holroyd, 2003; Hsu et al., 2015). Focusing on the Taiwanese mothers’ experiences engaging in the disability rights movement, Chang (2009) indicates that, in the society, women are expected to give birth to a healthy child, nurture the child properly, and ensure the child achieves well in the future to honor and sustain the family and their ancestry. When giving birth to a developmentally delayed child, the Taiwanese mothers are more often blamed and stigmatized not only in public, but also in the family. Moreover, while the children’s disabilities are recognized, the mothers feel more responsible for caregiving of the children than the fathers. As such, mothers of children with

disabilities experience most distress and stigma and thus, through participating in parents' advocacy groups, they actively negotiate and reshape their identities and those of their children (Chang, 2009). The impact of social and cultural attitudes associated with disability and traditional gender norms remain significant on families of children with disabilities in Taiwan. Pertinent societal impacts are found in a phenomenological research on mothers' experiences of nurturing a child with autism in Taiwan (Hsu et al., 2015). Hsu et al. (2015) point out that, within the patriarchal family culture, Taiwanese mothers are expected to reproduce a healthy male offspring to carry on the paternal family name, continue the family line, and inherit the family property. When the mothers give birth to an autistic child, they either blame themselves or accept blame from others because they consider the child's disability as their personal fault. According to their experiences, autism has been heavily stigmatized in Taiwanese society. Since it is considered to disrupt a harmonious family life and an end of a family line, the mothers of children with autism take on the blame and the caregiving responsibility in response to culturally appropriate perspectives. As a matter of fact, caring for a child with a disability remains a mother's responsibility in Taiwan (Hsu et al., 2015).

The majority of the studies on parents' perspectives and experiences of having and raising a child with a disability place an emphasis on the societal impact on maternal roles within the Chinese cultural context, however, there is research that focuses on the fathers' experiences of having and caring for a child with a disability (Huang, St John, Tsai, & Chen, 2011; Huang, Chen, & Tsai, 2012). Specifically, Huang, St John, Tsai, and Chen (2011) contend the Chinese cultural beliefs and values elicit different experiences and meanings for fathers having a child with developmental disability in Taiwan. In a society of paternalistic culture, fathers have more power and authority within a family, especially when making decisions about a child's future.

However, when the diagnosis of the child's disability was revealed, not only did the fathers blame themselves for inappropriate fathering, but they also felt shame, guilt, or devalued as they regarded the child's disability as their moral responsibility or an extension of their life. The fathers' feelings of being devalued and powerless were enhanced when their parents rejected the disabled child or asked for a "normal" child to regain the family reputation (Huang et al., 2011). Accordingly, Chinese cultural contexts have an expectation of appropriate fathering roles, which may contribute to the distinct impact on their involvement in caring for a child with a disability. Other research on fathers' experiences engaging in the daily care of children with disabilities in Taiwan is contradicting the traditional Chinese cultural views in authoritative or detached fathering roles (Huang et al., 2012). The fathers had great hopes and expectations for early intervention, which they believed the critical period to be 0-6 years for the best improvement or recovery of their child's disability (Hsu et al., 2015; Huang et al., 2012). With such a hope of restoring their child's health, they were unrelentingly involved in everyday care of their child to support the child's development while also maintain an appropriate father-child relationship. The findings suggest that fathers of a child with a disability assume their responsibilities not only in sustaining the family's financial needs, but also in maintaining family functioning and well-being through their involvement as caregivers (Huang et al., 2012).

**Reactions to the diagnosis.** The way parents of children with disabilities perceive and respond to a diagnosis of their child's disability deeply affects their experiences of nurturing the child with a disability. Parents' experiences of the diagnosis of children's disabilities are affected by widespread socio-cultural beliefs, values, and practices associated with the disability. A diagnosis of a childhood disability usually creates negative reactions in Asian families, such as fear of labeling and judgement (Lee & Lin, 2013). However, parents' attitudes of and

experiences with the children with disabilities are not necessarily negative. In exploring the needs of Chinese parents who are caring for a child with developmental disability, Wong et al. (2004) report that even though most parents lacked information and correct concepts of their child's conditions, they accepted the diagnosis in the hope that the child will recover in the future. Similar findings are found in a recent study of parents' perceptions of their very low-birth-weight infants with developmental disabilities in Taiwan (Lee & Lin, 2013). When informed about their child's disability, the parents held on to the hope and expectation that their child will become "normal" or grow out of the disability. As a result, parents make an effort to support the children in engaging in a range of rehabilitation programs and/or treatments (Huang, Fried, & Hsu, 2009; Lee & Lin, 2013; Wong et al., 2004). Even so, many parents of children with disabilities are influenced by the socio-cultural representations, which overtly view having a child with disability as a shame or a burden to the family. Some families had experiences of various forms of social stigma, discrimination, and marginalization (Chang, 2009). As suggested by a number of researchers on cultural influences on parental caregiving experiences of children with disabilities (Chang & Hsu, 2007; Chang & McConkey, 2008; Holroyd, 2003; Lee & Lin, 2013), having a child with a disability is perceived by parents with both positive and negative consequences. Specifically, in investigating Taiwanese parents' perceptions of the impact of having a child with mental retardation on marital and sibling relationships, Huang, Ososkie, and Hsu (2011) report the impacts are mixed or bidirectional. Nevertheless, the majority of the parents either accepted their child with a disability when recognized, or gradually accepted the child while gaining more information of support services and knowledge of the child's disability. The findings suggest that parents hold viewpoints contrary to traditional Chinese beliefs and

values that having a child with disability is a disgrace to the family (Huang, Ososkie, & Hsu, 2011).

Recent research on Taiwanese parents' attitudes toward their child with a disability and experiences of raising a child with a disability indicates that parents' religious beliefs and spirituality also play a significant role (Chang & Hsu, 2007; Huang et al., 2009; Lee & Lin, 2013). For example, Huang, Fried, and Hsu (2009) note the majority of the parents believed that karma has a connection to their child's disability. Furthermore, most parents in Chang and Hsu's (2007) study worried about the cultural concept of karma may result in social stigma toward their children and families. The varied religious beliefs profoundly influence how parents perceive their child with a disability and their family, and how they nurture and interact with their child. However, many parents changed their attitudes towards their child with a disability and made new meaning out of their child's disability in terms of their religious beliefs and spirituality (Huang et al., 2009; Huang et al., 2012; Lee & Lin, 2013). In investigating parental explanatory models for the causes and the associated help-seeking behaviors for children with autism in Taiwan, Shyu, Tsai, and Tsai (2010) find most of the parents ascribed the source of their child's autism to both biomedical etiology and supernatural forces, regardless of their educational backgrounds. Since the explanations of the source of autism have not yet reached a general consensus, the parents themselves attempted to figure out and attribute possible causes of their child's disability, which often differed from those offered by the healthcare professionals. As a result, parents sought multiple educational/training programs and treatments to cope with their child's disabilities, including alternative medicine and spiritual and religious treatments, which required considerable time, energy, and financial cost for the families (Shyu, Tsai, & Tsai, 2010).

### **Studies on Autism - A Sociocultural Perspective**

To explore the concept of autism as a disability, and the experience of having and nurturing a child with the disability within a specific cultural context, this section addresses the studies on autism from a socio-cultural perspective. As noted above, culture not only provides a distinctive lens to understand the underlying meaning, assumptions, and explanations of a disability, but also affects how individuals with disabilities are perceived and treated. However, the representations of autism and the social implications of its diagnosis have received less attention in non-Western cultures, in terms of the culturally varied perspectives in interpreting and characterizing the disability. In recent years, a growing body of research attempts to understand and represent autism within a cultural context (Freeth, Milne, Sheppard, & Ramachandran, 2014). Culture shapes how people in a society perceive, understand, and define autism (Ravindran & Myers, 2012). However, limited research undertakes in-depth investigations into how autism is socially constructed in non-Western contexts and how it is represented differently across cultures (Chi, 2015; Daley, 2002; Freeth et al., 2014; Kim, 2012). In a cross-cultural investigation of how autism is socially constructed within the Korean, Canadian, and Nicaraguan cultures, Kim (2012) illustrates in Nicaragua - a society where a child with a disability is embraced and nurtured by the community and individual differences are accepted - autism is scarcely recognized and identified. Instead, a child with autism can be seen as troublesome, deficient, abnormal and needing to be cured or “fixed” in terms of the biomedical model and the Eurocentric views of autism perceived in Korea and the United States (Kim, 2012). Similarly, in examining the socially constructed meaning of autism in China, Chi (2015) points out, influenced by the medical-model discourse of disability and the traditional Chinese culture, children with autism and their families are noticeably stereotyped, stigmatized, and ostracized. As Chi (2015) indicated, the lives of individuals with autism have been heavily

medicalized due to the dominant medical-model perspective of disability and of autism in Chinese society. Moreover, Daley (2002) notes while much of the recent research strives to address the international field of autism, such as the use of various assessment tools in different cultures, less research has involved serious discussion of socio-cultural factors. In the ethnographic study with 95 families of children diagnosed with autism in India, Daley (2002) underlines seven cultural processes to understand the experiences of families of children with autism within the given socio-cultural context, including awareness and concepts of illness, help-seeking behavior, the process of diagnosis, treatment, family functioning, community and legal issues, and childhood socialization. Given the social and cultural nature of understanding and constructing a disorder, the study suggests the view of autism on a biological basis is culturally shaped in its expression and course (Daley, 2002).

The meaning and implications of a diagnosis of autism vary across cultures. Since every culture holds distinct beliefs, assumptions, and explanations about a disability, the concept of being autistic or having autism remains elusive and is interpreted in culturally distinctive ways. The notion of autism, based on the Western psychiatric system, is conventionally referred to as a neurological disorder (Ravindran & Myers, 2012). However, as Ravindran and Myers (2012) noted, “it is essential to attend to culture when considering beliefs about causes and treatments for autism, regardless of whether we approach it from a western medicine perspective or from the perspective of other cultures” (p. 315). Such a perspective takes a culturally relativistic position as opposed to the absolutist view that autism is invariantly manifested across cultures (Ravindran & Myers, 2012). Accordingly, in a qualitative study of the socially and culturally constructed conception of childhood autism in China, Hsiao and Magyar (2006) illustrate that although the causal interpretation and the meaning of autistic disorder in Chinese language are

different from the perspectives based on western psychiatry, the diagnostic criteria in Chinese versions took a parallel stance in describing and defining the disorder. This raised many questions regarding the construction of autism in terms of Chinese parenting and childhood socialization and development through the lens of culturally based variations. The researchers posit the view of autism as a dynamic social phenomenon constructed in specific socio-cultural contexts (Hsiao & Magyar, 2006). Even though there has been substantial evidence on the neurological basis of autism, the description, interpretation, and acceptance of the diagnosis vary widely across cultures (Bernier, Mao, & Yen, 2010; Ravindran & Myers, 2012). The socially and culturally constructed nature of autism provides a space for researchers to incorporate the experiences of individuals having an autism label, their families' perceptions and responses to the disability, and the wider socio-cultural context which influences people's perspectives of and attitudes toward individuals with autism. Therefore, researchers suggest further research on autism is needed to consider both macro- and micro-level of cultural influences (Bernier et al., 2010; Hsiao & Magyar, 2006; Ravindran & Myers, 2012).

## Chapter 3

### Theoretical Framework

#### Ecological Systems Model

The present study draws on the developmental psychologist Urie Bronfenbrenner's (1977, 1986) contention of the *ecology of human development* (proposed as Ecological Systems Theory) as a theoretical basis. The ecological systems model comprises a nested and hierarchal arrangement of four interactive systems, which underlies direct and indirect influences on the development of an individual, under consideration of time (chronosystem). The theory had been further modified by Bronfenbrenner and his colleagues to include the influences of individual characteristics (e.g. temperament) and genetics within the environment (known as Bioecological Model of Human Development).

The principal proposition of the ecological systems model is of the progressive and mutual accommodation between the developing individuals and their dynamic settings, which are functioning in varied and interdependent ecological systems (Bronfenbrenner, 1977). Accordingly, the developmental processes of the growing individuals over their lifespans can only be understood within the ecological contexts in which they are based. Moreover, Bronfenbrenner (1977) underscores that the ecological environment and its objective properties experienced and perceived by the subjects are equally crucial as those investigated by the researchers, which is termed "ecological validity" (p. 516). In other words, research investigating the growing person's ecological contexts needs to take into consideration both subjective experiences of the person and objective properties observed in research. A major component of Bronfenbrenner's ecological systems model is its focus on identifying the changing processes of

an individual's development as constructed through the interface of the individual and environmental influences over the life course. For example, parent-child interactions as reciprocal influences on family functioning and the developmental process of the child can, in turn, affect the child's behavior in other settings. As systematic investigations of ecological environments underlying successive processes of development of a child, the dynamics between the child and ecological contexts in the course of developmental changes are examined in system terms (Bronfenbrenner, 1977): microsystem, mesosystem, exosystem, macrosystem, and chronosystem (Bronfenbrenner, 1986).

According to Bronfenbrenner (1977), an ecological environment in which a microsystem is embedded refers to the interrelations between the developing person and the immediate settings in which the person is contained. The dynamic relations between an individual and the immediate settings are embodied or represented through particular roles (e.g. preschooler, parent, teacher, etc.) and activities in which the individual is engaging, within particular physical features of places (e.g. home, daycare, school, etc.) for particular periods of time (Bronfenbrenner, 1977). Such an ecological environment encompassing a microsystem and the other systems is a functional social system, and reciprocal relations not only exist between the researchers and subjects, but also among all the concerned people who in effect, affect the development of the individual. Moreover, the interactive influences between an individual and the immediate settings on the development of the individual child may result from the implicit or indirect effects among broader settings. Interactions between the immediate settings of an individual which underlies indirect effects on the developing individual function as a mesosystem (Bronfenbrenner, 1977). A mesosystem therefore includes a range of principal settings where the development of an individual occurs. Bronfenbrenner (1986) illustrates the

interactive influences among these principal settings in relation to family processes and the child development, including family genetics, hospital, day care, peer group, and school, in the interactions with family/home. Each of these settings primarily affects a child's development as they serve as a microsystem, and have a joint impact on the child while they function at a mesosystem level.

Another salient component of the ecological systems model is the consideration of broader social contexts, as the external influences which account for the developmental processes within and between an individual and the immediate settings. An external ecological context, both formal and informal, which does not contain the developing person yet has an impact on the immediate settings where the person grows functions as an exosystem (Bronfenbrenner, 1977). The influences of an exosystem are not independent, but interrelated with the microsystem and mesosystem on a child's development. For instance, Crnic and his colleagues (1983) demonstrate three sources of maternal social support, such as spouse, friends, and other persons in the neighborhood or community, which influence maternal attitudes and behaviors toward the infant and mother-infant interactions (as cited in Bronfenbrenner, 1986). As Bronfenbrenner (1986) noted, parental employment, parental support networks, and community appear to be the most influential exosystems in the development of a child in the modernized societies. Although the impact of an exosystem on the developing child may not be direct or explicit, it does affect the child through its interrelations with the immediate settings, as functioned within the micro- and mesosystem throughout the child's life course. Correspondingly, the external social forces on the development of a child and the family may not operate in a concrete form, yet through the structural manifestations of micro-, meso-, and exosystems. Such a social impact refers to macrosystems, as general prototypes, "existing in the culture or subculture, that set the pattern

for the structures and activities occurring at the concrete level” (Bronfenbrenner, 1977, p. 515). A macrosystem is socially constructed meaning, information, and ideology, both formal (e.g. institutional or governmental) and informal, held true by the members of a culture or a society (Bronfenbrenner, 1977). These patterns and ideologies are pervasively manifested through the interactions between a growing person and the ecological contexts. At the micro- and mesosystem levels, for example, the ideologies and knowledge held by parents and teachers in nurturing and educating a child are represented in their interactions with the child and with each other. The experience and practices of teaching and parenting thus, affect the developmental process of the child in his/her subsequent life stages.

In addition to the models discussed above, a paramount emphasis of the ecological systems model is on the developmental change and continuity of the growing person, of progressive interactions within and between the person and the ecological environments. The ecological transitions of the development of the person and events occurring in the life cycle must incorporate a life-span perspective (Bronfenbrenner, 1977). According to Bronfenbrenner (1986), it is crucial for a research model to investigate changes over time both within the person and the environments, and analyze the interrelations between these two processes. Such a dynamic, changing relation between a growing person and the ecological contexts over time functions as chronosystems. More importantly, a chronosystem model can be used to examine the cumulative effects of a series of developmental transitions over a person’s life course (Bronfenbrenner, 1986). Through interplay with the other systems, chronosystems can directly and indirectly influence a child’s development. For instance, Moorehouse (1986) investigates how a change or stability in maternal employment affects patterns of mother-child communication during the child’s preschool years, and how these patterns in turn influence the

child's school outcomes during the first school year (as cited in Bronfenbrenner, 1986). Therefore, the change in mother's work status serves as external influences in the child's development (exosystem), on family processes (microsystem) and through the family on school performance (mesosystem), over the child's preschool years and first school year (chronosystem).

Disability research invokes Bronfenbrenner's ecological model in the integration of multiple settings of a child with a disability, with the focus on the influences of home, school, and community resources (Sontag, 1996). Research efforts have been concerned with identifying supportive ecological environments for growth and development of children with disabilities, and for improving special education practices. Specifically, Bronfenbrenner (1992) acknowledges the contribution and influence of the growing person to the developmental processes, as a joint function of the characteristics of the person and the environmental influences over time (as cited in Sontag, 1996). The role of individual characteristics in the developmental processes which interact with specific ecological contexts refers to the notion of ecological niches (Bronfenbrenner, 1992, as cited in Sontag, 1996). In other words, thorough investigations of the adequate sociocultural contexts within which a child with particular characteristics of disability participates and develops are salient for disability research. Accordingly, Sontag (1996) points out the importance of the family characteristics in interrelations with the characteristics of children with disabilities and their settings. This includes, at the microsystem level, the perceptions of the significant others of the environmental properties which influence the development of the child, and the mutual adjustments between the family and child; at the meso- or exosystem level, the positive relationships between the parents and others in non-home settings; and at the macrosystem level, the belief systems of the

significant others which determine the context of raising a child with a disability. Moreover, Sontag (1996) underlines the dimension of time in disability studies, as to document the constancy and change in the development of a child with a disability over the life course. The consideration of time also encompasses the history and long-term impact (e.g. cumulative effects), within which the interactions of a child with a disability and the environments shape the successive development of the child.

Comparatively, Bal and Radke (2013) incorporate a socioecological approach in understanding the social interaction strengths of children with high functioning ASD - identified as High Functioning Autism Spectrum Disorder (HFASD) or Asperger Syndrome<sup>2</sup> - in the contexts of their home, school, and neighborhood. The researchers adopted a strength-based and context sensitive (ecologically valid) perspective, which considers the children's interaction differences, as opposed to defects, within their socioecological settings. More specifically, Bal and Radke (2013) investigate the parents' perspectives and experiences in the caregiving and interactions with the children with high functioning ASD, as socio-developmental processes, to define the ecological niches of their social-interactional competence. The parents' experience suggests that the children displayed culturally and contextually appropriate social strengths, such as emotional empathy and maintaining fairness, in a variety of shared purpose and task oriented activities (Bal & Radke, 2013). As Bal and Radke (2013) posited, "To understand the social skills of an individual with ASD requires cultural awareness of that individual's ontology, his prior experiences as well as specific local context where social interaction take place" (p. 23).

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<sup>2</sup> Asperger Syndrome has been replaced by Autism Spectrum Disorder (ASD) and no longer used in *DSM-5* (American Psychiatric Association, 2013).

The need to understand specific sociocultural contexts of families of children with disabilities is highlighted in Danseco's (1997) study. Danseco (1997) examines the studies on parental beliefs about the nature and causes of childhood disability among varied cultural groups, within an ecological framework. Parents' beliefs about the nature and causes of the child's disability affect their conceptions of corresponding prognoses and prescriptions for the child with a disability, and therefore influence their treatment/intervention choices and caretaking practices. In this regard, parental belief systems provide a context in which culture accounts for the development of a child with a disability (Danseco, 1997). The study also illustrates the interdependent influences between the cultural beliefs, the professional services, and the parental beliefs and practices (served as macro-, exo- or meso-, and microsystems) on children with disabilities. For example, parents from ethnic minority groups often need to negotiate between professional prescriptions, their own ethnic remedies, and mainstream cultural beliefs and practices to seek what they consider as the best intervention for the child (Danseco, 1997). Investigations of the interplay of culture, parental beliefs, professional practices, and childhood disability can inform culturally and ecologically valid understanding and caregiving for children with disabilities.

Starr, Martini, and Kuo (2014) study the transition to kindergarten (TTK) process of children with autism among ethnically diverse families (English-, Mandarin-, and Arabic-speaking families) in Canada. The research incorporates and examines the perspectives and experiences of the parents, the kindergarten teachers, the early childhood resource teachers (ECRTs), and the early intervention (EI) providers within six focus groups, based on Bronfenbrenner's ecological framework. The parents, kindergarten teachers, and ECRTs and EI providers (referred to as service providers) served as the microsystems of the children with ASD,

and the interconnections of these settings which contributed to the TTK processes of the children functioned at the mesosystem level. Notably, both the parents and the teachers expressed the need and desire to communicate and establish trusting relationships with each other, either before the transition or during the school years (Starr, Martini, & Kuo, 2014). Moreover, the researchers note the persistent adversarial relationships between the parents and the schools, the lack of collaboration between EI providers and the receiving schools, and the exclusion of the teachers from the school administration during the transition, accounted for the negative transition processes for the children. At the meso- and exosystem levels, however, the parents found the support of the service providers and the community organizations was particularly helpful in dealing with the challenges regarding the lack of knowledge about autism perceived by the parents and the teachers themselves, the culturally different understanding of autism of the families, and the school-focused approach of kindergarten (Starr et al., 2014). Emotional and instrumental support from the family members and other parents of children with autism are reported salient for the families in confronting issues of raising a child with autism and of the TTK processes (Starr et al., 2014). In terms of parents' cultural values and beliefs, as referred to the macrosystems of the children with autism, the ethnic minority families evidence language barriers and cultural differences in communication styles (e.g. questioning the authority) affected the interactions with the service providers and the school personnel. The culturally expected parenting styles and the reluctance to identify disability in many cultures can also affect the relationship and communication between the parents and other stakeholders, and the support and services a child would receive (Starr et al., 2014). The findings justify the salience for disability research to address parents' cultural beliefs and attitudes which influence parents' perceptions of

the child with autism/disability, parenting practices, as well as the conceptions about the cause and course of ASD and the intervention goals (Danseco, 1997; Sontag, 1996; Starr et al., 2014).

### **Phenomenology**

German philosopher Edmund Husserl (1859-1938) has been known as the principal founder of phenomenology, in which he laid a foundation and an impact on social science (Wolff, 1978). In his last significant publication, *The Crisis of European Sciences and Transcendental Phenomenology* (1935-1939), Husserl attempted to resolve the extreme situations of German society, by which he was victimized, atomized, and alienated, in the hope that his philosophizing through phenomenology might help. Accordingly, Husserl's attempts emanated from a critical feature of Western culture, which has been characterized since Plato, for the distinction between opinion and knowledge (Wolff, 1978). Such an effort has been made through the self-questioning of the attitudes, opinions, and concepts which are *taken for granted* in everyday life. The intellectual work of self-questioning is, further, made empirical and rigorous within the fields of science in general and within phenomenology specifically (Wolff, 1978).

The fundamental assumption of phenomenology is that every society or culture has certain ways of perceiving and interpreting the world as the ways of being in the world, and transmits this sociocultural thinking to the next generation, as the process of socialization or enculturation (Wolff, 1978). That is to say, every human being, in a process of socialization, has been brought up with certain notions of understanding and living within the world, which they have thought of as "natural". Phenomenology requires us to question these taken-for-granted notions, our culture, and the ways we look at and be in the world. To do so is not to reject or abandon our culture, rather, to "bracket" it, to suspend it, and to call it into question, and therefore to find out how

things themselves actually appear to us (Wolff, 1978). The process of bracketing and questioning things we usually take for granted is what Husserl termed *phenomenological reduction* or *eidetic analysis* (Wolff, 1978). For Husserl, the paramount emphasis was placed on the eidetic (essential) meaning of an experience or a phenomenon, which has been constituted by our consciousness or what Husserl called *intentionality*. By means of phenomenological reduction, phenomena - as they have been constituted by our intentionality - are no longer the perceived ones, but rather, appear as essential or as the *eidos* (Greek, essence) (Wolff, 1978). According to Husserl, the experience of a phenomenon or an object exists only in our intentionality of it, and it needs to be constituted or questioned, in order to represent its essence as what it is. However, as within the philosophical tradition of considering human experience and the means humans perceive the world as an epistemological source, Husserl's phenomenological reduction to some extent overlooks the role of body which involves cognition as a whole entity (Wolff, 1978).

The less constitutive meaning of body and of bodily existence in Husserl's phenomenology prompted the work of French philosopher Maurice Merleau-Ponty (1908-1961) in his concentration on the body. The body (*Leib*), which is constituted by Husserl as "*leibhafte Gegenwart*" (German, corporeal presence), is developed by Merleau-Ponty as "*prence en chair et en os*" (French, presence within one's own body/flesh) (Waldenfels, 2008). In his attempt to address the meaning of body in German (*Lieb*), Merleau-Ponty attributes some characteristics such as *propre* (e.g. "my" body), *vivant*, or *fonctionnel* (functional, living body) to the body (Waldenfels, 2008). In line with Husserl's transcendental perspective of bodily existence, Merleau-Ponty provides the context of the living body as an "operative concept", existing in the whole (world) as a whole, which appears to bear on the multiplicity and the novelty of experience and expression (Waldenfels, 2008, p. 77). In terms of the structural aspects of bodily

existence, however, in the place which the living body observes the whole as a whole, finds its limit within itself (Waldenfels, 2008). From this perspective Husserl posits a bodily “point zero”, which forms all orders of time and space as a system of coordinates (as cited in Waldenfels, 2008, p. 78). Merleau-Ponty further approaches this paradox by attributing the “blind spot” or “unconsciousness of consciousness” to the living body (as cited in Waldenfels, 2008, p. 84). That is, the body constitutes a duality; rather than the Cartesian split of mind and body, the body mediates the distance between self-relation (e.g. perceiving, touching, or moving) and self-withdrawal (e.g. perceived, touched, or moved). For example, one cannot see his/herself while the self is seeing; one cannot see “the seeing self”, but rather, the bodily self is seeing it as it is seen. Therefore, the body, as Merleau-Ponty’s functioning body or Husserl’s functioning I, serves as the locus for experience to unfold, to happen to, while which serves as the locus for experience to embody (Waldenfels, 2008). Any self-relation always comes and intertwines with a self-withdrawal, which determines the corporeality (Waldenfels, 2008). In these terms, the bodily existence cannot be a pure relation to the other (self-withdrawal), nor can it be a pure being-with-oneself (self-relation). Instead, the distance between self-relation and self-withdrawal signifies “a relation-to-self within the relation-to-the-other and a relation-to-the-other within the relation-to-self” (Waldenfels, 2008, p. 85). Through these intersubjective relations the living body constitutes itself in a corporeal way, in which Merleau-Ponty approaches as an indirect form of ontology, for which it is always new and deviant from the familiar (Waldenfels, 2008). As a bodily being, the experience of one’s body is lived, not owned, and can never be taken for granted.

The central role of the body in Merleau-Ponty’s phenomenology can be seen as an alternative to the Cartesian conception of body and mind/spirit. Cartesian perspective posits that

the mind is ontologically superior to the body, that the body is subject to the functions and the causal relations of physical mechanism as an object, and therefore the mind, as a subject, has a constitutive role of the self (Edwards, 1998). Such a proposition prevalently influences the practice of the Western medical model of disease and disability. For example, disabilities are categorized and diagnosed in terms of structural or functional abnormalities. As a consequence, the ill body as an object is conceived in the third-person or objective perspective in the diagnosis and treatment process, in which the ill person is described in the objective detectable signs and terms (Edwards, 1998). On the contrary, Merleau-Ponty contends that the body constitutes itself as a subject, which is an embodied/incarnated self (Edwards, 1998; Waldenfels, 2008). In this regard, the lived body of an individual with a disability constitutes the self, as the properties of the self which are associated with the disability are the sources of personal accounts and narratives (Edwards, 1998; Toombs, 1995). The disabled individuals' narratives of the self entail perspectives from both the first-person (e.g. lived spatiality) and the third-person (e.g. patterns of movement), which account for the experience of the lived body as a whole. According to Merleau-Ponty (1962), any relations between body and other objects are inevitably bound to the first-person perspective (as cited in Edwards, 1998).

Merleau-Ponty's contention of body as a subject is evident in the phenomena of communication. Since communication necessarily involves motor and symbolic/linguistic aspects of expression which stand for the states and activities of body and mind, both aspects are intertwined and constitutive for a unitary self (Merleau-Ponty, 1962, as cited in Edwards, 1998). Moreover, Merleau-Ponty proposes that, essentially, perception involves interpretation, which occurs at the level of body (e.g. sensory apparatus) (Edwards, 1998). The bodily self embodies the mental properties through perception, interpretation, and representation of objects and the

world. The relationship between the subject and the world which encompasses perception and interpretation is thus bodily, in which Merleau-Ponty (1962) conceives as an “organic relationship between subject and world” (as cited in Edwards, 1998). That is, as the subject, the body molds the character of the world, while it is also molded by the nature of the world. In this regard, objects are conceived and designed for the availability of manipulation or use, and are perceived and interpreted in terms of the physical and mental states of subjects (Edwards, 1998).

The relations between subjects and the world as the experience of being in the world are particularly substantive when it comes to individuals with disabilities. In her personal account of living with multiple sclerosis, Toombs (1995) articulates that the degenerate physical capacities, especially loss of mobility, profoundly and sometimes permanently alter the experienced spatiality and temporality. In line with Merleau-Ponty (1962), the notion of the lived body constitutes the meaning of disability as an embodied subject which *exists* or *lives* the body (as cited in Toombs, 1995). On one hand, individuals with disabilities actively engage in and negotiate the surrounding world through the medium of the body. On the other hand, loss of mobility in the lived body inevitably transforms one’s experience of being in the world, as problems with the body necessitate problems with the environment (Toombs, 1995). The uncertainty experienced in the changed bodily abilities reflects that an individual with a disability needs to “learn and relearn how to negotiate the surrounding world”, and thus changes the experience and the mode of being, which Toombs (1995) describes as no longer taken for granted (p. 13). Furthermore, the changed bodily states also transform and display a unique corporeal style, which identifies the lived body as peculiarly me (Merleau-Ponty, 1962, as cited in Toombs, 1995). Such changes in bodily expression and in the way one perceives the self which engender inability to recall or re-imagine the sense of movement refer to Merleau-Ponty’s

bodily intentionality (Toombs, 1995). For example, gradual loss of mobility disrupts the familiar and the usual style of holding a cup and drinking, which diminishes or changes an individual's bodily intentionality of using the cup. The phenomena of bodily intentionality are specifically related to the bodily space of an individual with a disability (Merleau-Ponty, 1962, as cited in Toombs, 1995). The notion of bodily space refers to the phenomenon when a person routinely uses and thus incorporates an object into his/her bodily space as an extension of the body. For people with physical disabilities, the habitual use of a wheelchair may result in the device as perceived as being part of their body.

In a phenomenological study with individuals with unilateral neglect (UN), Tham, Borell, and Gustavsson (2000) adopt the EPP (empirical, phenomenological, psychological) method based on Husserl's (1970) and Merleau-Ponty's (1962/1945) philosophical approaches to understand the daily occupational experiences of four women with UN. Their discovery processes of the disabilities due to sensory losses were interpreted according to Husserl's (1970) philosophical notion of *life-world*, as "our subjective and culturally meaningful world, which we take for granted and whose existence we never question" (as cited in Tham, Borell, & Gustavsson, 2000, p. 399). In order to investigate how individuals with UN perceive, interpret, and live their disabilities in everyday occupations, the researchers take an open and a presuppositionless stance in which their biomedical knowledge of UN is bracketed (Tham et al., 2000). In accordance with Merleau-Ponty, the participants live their bodies as the intentional subjects, from which they act and grasp their life-world (Tham et al., 2000). The neglect of the left part of their body was perceived and experienced as the loss on "a part of their medium for having a world and for being in the world" (Tham et al., 2000, p. 404). Throughout the discovery process, the participants become familiar with their neglected body parts, develop awareness and

new meaning of their disabilities, and seek and use compensatory strategies to overcome them (Tham et al., 2000). Similarly, in a longitudinal qualitative study, Lawrence and Kinn (2013) invoke Merleau-Ponty's phenomenological approach to explore the lived experience of young adults who have had a stroke from the perspectives of family members. The family members' experience of being with and caring for the young adults is iteratively and critically reflected on by the researchers to identify the changes over the effects of stroke, needs and priorities of the family, and family-centered rehabilitation outcomes over a two-year period of time (Lawrence & Kinn, 2013). Following the stroke event, the family members experienced that their taken-for-granted course of life had been abruptly and perpetually disrupted. They also reported that their perceptions of and familiar relationships with the young adults had been altered, and their efforts to resume the "normal" life for themselves and the young adults. The disruption of taken-for-granted ways of life is often reflected in the changes in their experiences and understanding of their place in the world, as familiar ways of being-in-the-world (Lawrence & Kinn, 2013). Therefore, family members incorporate a variety of coping strategies to regain pre-stroke family functioning and their own ways of being (Lawrence & Kinn, 2013).

The present study invokes Bronfenbrenner's ecological framework and Husserl's and Merleau-Ponty's phenomenological approach as the theoretical basis to understand the lived experience of children with autism and their families in Taiwan. The systematic investigation of the ecological systems over the developmental course of a child with an autism label and the dynamic, interrelated relationships between the child, the family, and their ecological contexts are emphasized. Specifically, the mutual accommodation processes of the child and family after being diagnosed with autism as a life transition event, and their experience of negotiating and being in the world through the intersubjective relations with others and the worlds/contexts lived

are the phenomena to be understood. Moreover, in approaching the sociocultural issues posed by the diagnosis of autism, the study attempts to examine parents' beliefs and understanding about the nature and causes of autism, and how these sociocultural beliefs embody in their practices and/or coping strategies in raising a child with autism, as a medium through which culture accounts for a child's development. In phenomenological terms, the sociocultural belief which is taken for granted by Taiwanese parents in nurturing and acculturating their child is essentially and persistently disrupted by an autism label. This phenomenon calls the "normal" childhood socialization and development into questions. Therefore, the knowledge and the sociocultural understanding of autism are bracketed in order to gain an insight from the phenomenon which parents bring up a child with autism in Taiwan.

## **Chapter 4**

### **Methods**

In this section, I explore qualitative research methods; specifically, the philosophical/theoretical traditions and premises of inquiry, the implications for research and evidence-based practice, the nature and characteristics of qualitative research, and the accomplishment of rigor/trustworthiness in qualitative research. Then, I explain the role of the researcher in the present study, which is vital for a qualitative research. I also elaborate on the process of the research, including the description of participants, the data collection measures and procedures, and analysis. Finally, the ethical considerations of the research process are addressed.

### **Qualitative Research**

Relatively recently, qualitative research methods have had a growing impact on such fields as education, sociology, anthropology, health care, nursing, and psychology, and have provided considerable insights into evidence-based research and practice (Babchuk & Badiee, 2010). In contrast to quantitative methods, the nature of qualitative approaches is less structured and prescriptive in its research design protocols and processes. However, the goal of qualitative research is not to provide precise arguments or absolute conclusions; instead, it is to form a strong enough assertion in terms of the transparency of the research process and protocol undertaken (Nolen & Talbert, 2011). The assertions/statements of qualitative findings open new conversations and generate additional questions (Nolen & Talbert, 2011; Richards & Morse, 2012). There has been well-established research paradigms based on the varied approaches of qualitative theory and methodology. These approaches include Grounded Theory,

Phenomenology, Ethnography, Narrative Inquiry, and Case Study, all of which constitute conventions and premises of practice (Babchuk & Badiee, 2010; Nolen & Talbert, 2011; Richards & Morse, 2012). Importantly, the philosophical orientations, assumptions, and perspectives contribute to the nature and the methodology of a qualitative approach. Nolen and Talbert (2011) outline three types of philosophical/theoretical inquiries that influence qualitative researchers' methodological decisions and interpretations of research findings: ontological, epistemological, and axiological. Ontological inquiries and assumptions account for the way the researcher perceives and believes social reality, which guides the researcher's interpretation of the nature of reality pertaining to the current condition of the study and the lives of participants (Nolen & Talbert, 2011). These ontological inquiries further influence the researcher's epistemological inquiries and assumptions, which underpin "the way the researcher thinks social phenomena should best be studied in order to be able to represent the most truthful depicted interpretation of the data" (Nolen & Talbert, 2011, p. 266). Another philosophical foundation which provides the context of a qualitative research and methodological decisions and interpretations is axiological orientations. The axiological inquiries and assumptions are based on the theoretical framework and the existing research literature in which the perceived and applied values held by the researcher, the participants, and the broader community influence the interpretation of the values emerging from the data (Nolen & Talbert, 2011). These philosophical orientations shape qualitative research's direction and questions to be answered. Thus, it is essential for a qualitative researcher to examine his/her own philosophical positions and assumptions when conceptualizing the research (Babchuk & Badiee, 2010; Nolen & Talbert, 2011).

Given the wide range of qualitative approaches that constitutes the paradigms of qualitative theories and methodologies, there are common features that characterize qualitative research. Some of the shared characteristics include, but are not exclusive to, long-term, face-to-face inquiries in naturalistic settings; the clarification/description of the role of the researcher in relations with participants; small-scale and context-based designs; subjectivity and emotionality in the research process; emergent and flexible procedures; nonrandom or purposeful sampling; rich and descriptive narrative data in the forms of text or pictures; convergence of evidence and inductive data analysis; multiple and in-depth observations of a given phenomenon; and the understanding of the meanings of participants' experiences (Babchuk & Badiee, 2010; Nolen & Talbert, 2011). The overall purpose of qualitative inquiry is to gain a comprehensive and in-depth understanding of participants' experiences and/or situations, how they construct and make sense of the world, a culture, or a social phenomenon, to inform the existing body of knowledge and social practices. A qualitative researcher represents him/herself as the primary instrument of the research (Richards & Morse, 2012; Thomas & Magilvy, 2011). Memos, notations, or field notes are frequently used to support and justify researchers' decisions and logistics of the research process (Nolen & Talbert, 2011; Richards & Morse, 2012). The qualitative researchers constantly reflect on their intentions prior to and during research processes, and communicate the intentionality in transparent and informative accounts to the readers/participants (Nolen & Talbert, 2011). This process ensures the credibility and trustworthiness or rigor in qualitative research.

The quality of qualitative research depends heavily on the researcher's reflexivity and intentionality (Richards & Morse, 2012; Thomas & Magilvy, 2011). The notions such as reliability and validity which are used to evaluate the quality of quantitative research are replaced

by *rigor/trustworthiness* in qualitative studies (Jeanfreau & Jack, 2010; Thomas & Magilvy, 2011). Since the concept of rigor is substantially accentuated in qualitative research, this quality can be assessed and achieved through the extent which the study accurately represents or interprets participants' experiences (Jeanfreau & Jack, 2010). Notably, Lincoln and Guba (1985) approach the concept of rigor/trustworthiness in four components of qualitative research: credibility, transferability, dependability, and confirmability (as cited in Thomas & Magilvy, 2011). Credibility is attained when the study provides an accurate description or interpretation of participants' experiences, which can be recognized by others who share the same experiences (Thomas & Magilvy, 2011). To establish credibility of a qualitative study, the researcher constantly reflects on how his/her preconceptions affect the research process and the relations with participants (Richards & Morse, 2012). Other strategies such as triangulation (e.g. use varied sources of data/methods), maintaining contact with participants, peer debriefing or examination, and member checking (informant feedback) prove to be useful to enhance credibility (Jeanfreau & Jack, 2010; Thomas & Magilvy, 2011). Transferability refers to the feasibility or fittingness to apply the research findings or methods in another group or context (Thomas & Magilvy, 2011). This quality can be achieved through thorough descriptions of demographics and geographic characteristics of the sample/population studied (Thomas & Magilvy, 2011). Dependability and confirmability are concepts which are also used. Both qualities demonstrate the transparency and the reflexivity of the research process by which the other researcher can follow the decision/audit trail of the findings (Thomas & Magilvy, 2011). The researcher records personal thoughts, feelings, biases, decisions, and processes in the field notes, memos, reflective journals, or diaries to maintain a sense of awareness and openness to the study and emerging evidence (Jeanfreau & Jack, 2010; Thomas & Magilvy, 2011). On the

whole, researchers' efforts and willingness to communicate the research processes and findings, as well as their worldviews, to readers shape the quality of the qualitative research.

### **The Researcher's Role**

Qualitative inquiry consists of researchers' interpretations of what they perceive and make sense of a phenomenon, as well as those of the participants. The researcher "typically involved in a sustained and intensive experience with participants (Creswell, 2009, p. 177). Therefore, the role and responsibility of the researcher are to be delineated in order to approach transparency and trustworthiness of the qualitative study. In the present study, the researcher adopts ecological systems approach and phenomenology which underpin his philosophical/theoretical orientations and assumptions for inquiry. The researcher also utilizes constant comparative method derived from the grounded theory approach as the method for data collection and analysis. In an attempt to understand the experience of raising a child with autism in Taiwan, the researcher attends to parents' perspectives of how they perceive and make sense of the world as it is lived. The philosophical/theoretical inquiries and assumptions influence the researcher's beliefs and values when engaging in the phenomenon in which parents of children with autism negotiate their everyday life. The phenomenological approach informs the researcher's interpretations of data generated, acknowledging that all human experiences and actions follow from a perception, which is also a form of interpretation (Richards & Morse, 2012).

Since the researcher was born and brought up in Taiwan, he aims to set aside his sociocultural knowledge, perceptions, and expectations which account for the meanings of the experiences held by parents of a child with autism. The researcher assumes responsibility of maintaining self-awareness of his own reactions, reflections, personal and professional experiences, and the relationship with participants (Jeanfreau & Jack, 2010). These measures

reduce potential influences and biases while retaining openness and sensitivity to the phenomena. Furthermore, grounded theory approach informs the researcher's epistemological source of inquiry as well as the methodological commitment. Grounded theory researchers acknowledge that reality is negotiated by people as it is constantly changing and evolving over time (Blumer, 1969/1986, as cited in Richards & Morse, 2012). Therefore, the researcher seeks to understand the process of the event or reality of a child being diagnosed with autism, how it is negotiated or constructed socially and culturally, and how it changes. The method allows the researcher to learn from the standpoints of participants on how they perceive or understand a process or a situation (Richards & Morse, 2012). During the research process, memos are used to document the researcher's thoughts and ideas pertaining to data collection and analysis progress, which are salient for grounded theory researchers to conceptualize and develop theory from data (Richards & Morse, 2012; Strauss & Corbin, 1998).

### **Participants**

The selection criteria for the participants of the study were parents who are the primary caregivers of their child, diagnosed with autism living in Taiwan. The criteria for selection were: Parents with children/youth aged 7-17 years old, who have a disability certificate identifying them as individuals with autism spectrum disorder, and who have attended special education classes or schools or mainstream primary or secondary schools. The reason for including such a range of ages of children/youth with autism is because the families of school-aged children have had sufficient experience in caring for the child and experiences with the transition processes. Moreover, the study aims at understanding Taiwanese parents' perspectives, beliefs, and values of autism/disability, and how this belief system influences their experiences and practices of nurturing a child with an autism label as a constructed social reality. The parents are self-

identified Taiwanese residents who live in Kaohsiung City, Taiwan and speak Mandarin Chinese. Parents' demographic information such as gender, age, educational background, employment, family status, and cultural/religious belief was collected to enhance the heterogeneity and transferability of the sample (Lawrence & Kinn, 2013; Thomas & Magilvy, 2011). The child's information such as gender, age, the age of diagnosis, the state of the disability, and education and/or services received was provided by parents for their demographic data.

### **Measures**

Family Background Information Form and a semi-structured interview schedule were used to elicit the demographic information and the voices of parents of children with autism (see Appendices A-B). The Family Background Information Form provides basic understanding of the family's socio-ecological contexts as well as the diagnosis, schooling, and intervention for the child (e.g. types of intervention/social service received, time spent in special class and/or intervention program, etc.). The information of the child with autism indicates the parents' decision-making and help-seeking processes in coping with the issues of autism, which is reflective in part, of their sociocultural beliefs. This information is further explored in the interviews with parents.

Face-to-face, one-on-one *semi-structured interviews* with open-ended questions are used in the inquiry on participants' perceptions and experiences with regard to parenting a child with autism. Interview guide is developed based on the ecological systems framework and phenomenological inquiry of the contexts/phenomena experienced by participants. Each of the child's ecological context (e.g. developmental transitions in chronosystem and changes in family process in relations with varied systems) is addressed in the interviews with parents. The

language and questions adopted in the interviews are understandable for interviewees, and allow interviewees to express in their own way. Moreover, the main questions are worded based on the experiences and knowledge of participants, to invite the detailed responses of the contexts lived or the reality constructed (Rubin & Rubin, 2012). Before each interview, a brief, general conversation is carried out to build rapport and relationship with parents. Such an informal conversation can lead the participants into ready articulation about their experiences (Chang & McConkey, 2008). This type of conversation is not recorded for data analysis processes. While in certain situations, verbal or nonverbal probes (e.g. waiting for the interviewee to respond) are used to help the researcher manage, clarify, and interpret the conversation, and to encourage the interviewee to elaborate further on the main questions/topics discussed (Rubin & Rubin, 2012).

The individual interview was audio-recorded, lasted from 1 to 2 hours and carried out at a time and place in the choice of the participant. Field notes were used during and after the interviews to support the researcher's interpretations of the interviews. At the beginning of the interviews, the researcher informed the participants of the purpose and the process of the study, and obtained consent (written and verbal) from the participants. A second or third interview was planned for each of the participants to provide opportunities for both the participant and the researcher to reflect on the original conversation, fill in missing or new information, and ensure the participant's experiences are accurately interpreted (Thomas & Magilvy, 2011). These measures involve participants as active informants in their research (known as member checking) and enhance credibility of the study (Jeanfreau & Jack, 2010; Thomas & Magilvy, 2011).

### **Procedure**

Participants were recruited through a social worker from a mental rehabilitation association in Kaohsiung City, Taiwan. The Letter of Invitation and the Consent Form for Participation (see

Appendices C-D), along with the researcher's contact information were passed on to the parents via the social worker, thus protecting the participants' privacy and confidentiality (Chang & Hsu, 2007). The snowball sampling procedure was adopted, which is found to be helpful in establishing participants' trust with the researcher and the study (Jeanfreau & Jack, 2010). First, the social worker was informed with the information and recruitment criteria of the study from the researcher. She then contacted a potential participant who met the inclusion criteria and asked about his/her willingness to participate in the study. Potential participants were given time to understand and consider the study, and were free to contact both the social worker and the researcher. Once persons decided to participate in the study, they could directly contact the researcher without letting others know. Finally, the participant who finished the study referred another participant to the study until the recognition of data saturation, which occurs when the researcher found no new information emerges and redundancy exists (Jeanfreau & Jack, 2010). Notably, the sample size for grounded theory research ranges from 10 to 30, depending on theoretical saturation (e.g. no new concepts or categories emerge from incoming data) (Shyu et al., 2010; Strauss & Corbin, 1998).

### **Data Analysis**

The demographic data obtained from the Family Background Information Form were analyzed and represented using descriptive statistics method. The audio-recorded interview data were transcribed verbatim, and then translated into English for analysis. The analysis of the data follows the systematic procedures of constant comparative method derived from Glaser and Strauss's grounded theory approach (Charmaz, 2006; Creswell, 2009; Strauss & Corbin, 1998). The grounded theory analysis is an ongoing process conducted concurrently with data collection, which involves researchers' continual reflections and interpretations of the data, asking analytic

questions, and writing memos throughout the process (Creswell, 2009; Richards & Morse, 2012). The researcher reviewed the transcripts thoroughly and repeatedly, identified the categories line-by-line (known as Microanalysis), and compared the initial categories with other pieces of the emerging data to explore the relationships among categories and develop themes (Strauss & Corbin, 1998). For example, statements and incidents of an interview were compared within the same interview, and across different interviews (Charmaz, 2006). The themes were derived from the recurrent and varied categories. Through these constant and back and forth comparative processes, the interrelated categories/themes were further integrated into the central/core category. This central category was the theme that covers the ground over all data and accounts for most of the variance (Richards & Morse, 2012). The interpretation and integration of the central category in interplay with the categories and the data, thus generate the theoretical scheme/theory. Theoretical memo writing is crucial during the analytic process, as it serves to construct the stages, properties, dimensions, or relationships of the emerging concepts and categories and tell the story of the theory discovered (Richards & Morse, 2012). The interview transcripts were coded independently by the researcher and then reviewed by the project supervisor to enhance the rigor of the findings.

The process is specified in three phases of coding procedures: open coding, axial coding, and selective coding (Creswell, 2009; Strauss & Corbin, 1998). Open coding involves discovering, naming, and categorizing the phenomena according to their properties and dimensions (Strauss & Corbin, 1998). The initial categories, are then positioned within the theoretical model (axis) to relate categories with subcategories, which specifies the varied properties and dimensions around a grouped (major) category (Charmaz, 2006; Creswell, 2009). This step, as axial coding, reassembles the fractured data after open coding to give coherence to

the emerging categories and the early development of a central category (Charmaz, 2006; Strauss & Corbin, 1998). According to Strauss and Corbin (1998), axial coding requires the researcher to ask questions about how the categories and subcategories are related, (e.g. when, where, why, who, how, and with what consequences) to describe the studied experience in a conceptual and more comprehensive manner. Eventually, as in selective coding, the major categories are integrated and refined to form a larger theoretical scheme (Strauss & Corbin, 1998). Selective coding performs intense analysis focusing on one category at a time (Richards & Morse, 2012). This includes selecting and defining the central category, which appears frequently in the data, “relates easily to the other categories”, and “has clear implications for a more general theory” (Strauss, 1987, p. 21, as cited in Richards & Morse, 2012). The development of the grounded theory evolves from the first phase of analysis progressively and inductively until no new properties, dimensions, relationships, or categories emerging the data reach theoretical saturation (Strauss & Corbin, 1998).

### **Ethical Considerations**

The present study and all of the letters, forms, and interview schedule were reviewed by Research Ethics Board of Mount Saint Vincent University. The research procedure and the data gathered are in compliance with the ethical principles and policies developed by Research Ethics Board of Mount Saint Vincent University and Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2014). The participants were fully informed of the purpose and requirements of the study, the roles of the researcher and the participant, the potential risks and/or benefits, the data collection and protection measures, and the withdrawal policies. These statements are provided in the Letter of Invitation and the Consent Form for Participation, along with the researcher’s introduction before conducting the interviews. The researcher elucidated

that the participation in the study is voluntary, the extent the data is used and confidentiality is promised, and that they have right to withdraw from the study at any time and to refuse to answer any questions without giving any reasons. In addition, it was explained that the researcher cannot provide service to the family, but if needed, he will offer the information about the required support services (listed in the List of Organizations for Family Support; see Appendix E). Privacy and confidentiality of individual participant were protected by assigning a code name on each participant's identifiable information and data in the analysis and the dissemination of the results. The personal identifiable information and the data set are kept separately in the password-protected files. In the writing of the thesis, all identifiable information (e.g. participant, school, and organization name) was changed or eliminated.

## Chapter 5

### Results

Analysis of the parents' demographic information provides a lens through which the families of the children with autism were studied. In the present study, 10 parents of the child with autism in Taiwan were interviewed, including seven mothers and three fathers. Among these families, two couples of the parents of the disabled children agreed to participate in the study, thus the study populations as a whole consisted of eight families/children with autism. The age of the parents ranged from 36 to 51 years, with an average age of 41.7 years. Their level of education included business/technical/vocational school (n = 5), university (n = 3), master's degree (n = 1), and senior high school (n = 1). Four parents worked full-time, four parents were homemakers, and two parents worked part-time. Their religious beliefs included Christianity (n = 8), Taoism (n = 1), and folk beliefs (n = 1). All the families were nuclear families. The eight children with autism were all male, and their ages ranged from 8 to 15 years, with an average age of 11.6 years (see Table 1 for characteristics of the children with autism).

Table 1.

#### *Characteristics of the Children with Autism*

No.	Age (years)	Diagnosis	Age at diagnosis (years)
1	13	Autism (mild)	10
2	9	Autism (moderate) & Developmental delay otherwise	3 & 7
3	12	Autism (moderate)	2.8

4	15	Autism (moderate)	2.5
5	13	Autism (severe) & Tourette syndrome otherwise	2 & 9
6	8	Autism (moderate)	4
7	15	Autism (moderate)	3
8	9	Autism (moderate)	3

Three themes emerged from analysis of the parents' interview data: the meanings of autism, family as the base of support, and the child developing into a relatively autonomous person. These themes are described thoroughly, associated with the quotations from the participants to depict their experiences caring for the child with autism in Taiwan. The quotes are presented in Chinese (Traditional) and English languages to reflect the cultural perspectives of the participants.

### **The Meanings of Autism**

The parents held varied beliefs about the nature and causes of autism, based on their experiences caring for the disabled child. They indicated the characteristics of their child's autism and ascribed some causes. In terms of the nature of autism, almost all parents reported language impairment and weak sociability to be the major components of autism. They regarded autism as pervasive, which consists of a variety of disabilities. Emotional disturbance, stereotypic and repetitive behaviors, and cognitive impairment were also mentioned by most of the parents. When considering the state of being autistic, they delineated a person with autism as "living in one's own world", "shutting off oneself in one's world", or "communicating with oneself, in one's own world". While most of the parents believed that the defect of brain functioning (e.g. brain damage) and hereditary factors were the major causes of their child's

autism, some parents considered themselves to be responsible for the condition. For example, one mother said:

我懷孕的時候，我不知道懷他...我我有吃到感冒藥，餉不曉得是因為這樣，或者是說催生的狀況去傷到腦部，我那時候真的...我會很自責這個現象是不是這樣。(When I was pregnant, I took medicine for colds. I don't know why... Perhaps the cold medication. Or maybe because the process of expediting childbirth hurts his brain. I was really... I blamed myself for this phenomenon.)

At the time, the professionals had no explicit explanation about the child's disability, these parents sought meanings and ways to understand the autistic condition. As one father stated:

應該是我...本身對小孩子的一個疏於...疏於去...了解他想要什麼，而造成他現在的一個...當時他妹妹也要出生了，所以或許因為這樣而造成他現在的情況，也有可能，我無法去理解他...狀態為什麼一定會這樣。(Perhaps it was because of myself paying little attention to what he needs, and making him now... It was at the time his younger sister was born, so perhaps this makes him be like this. It could be. I can't understand why...)

According to the parents, autism has been defined as a mental disability in Taiwan. On one hand, the parents relied heavily on the opinions of the health care professionals, such as psychiatrists, psychologists, and therapists. On the other hand, they explored different interpretations or meanings of the disability in the attempt to make their child well. One mother responded:

我一帶到 J 醫院我才知道原來我的孩子是...要看精神科的，對，然後，他那個重大傷病卡...發下來，也是精神科的，這個對我來講...比較大的衝擊，就原來他是精神的問題。(I found that my child was actually going to the Department of Psychiatry when I took him to the hospital. Then, his Major Illness/Injury Certificate was also issued by the Department of Psychiatry. I felt so shocked... His condition is a psychiatric issue.)

Many parents had no concept of autism at the time of diagnosis. They considered their child could recover after accepting treatment when being told about their child's condition. In the process of seeking an explicit diagnosis for treating autism, they found that autism is a lifelong and incurable illness. As expressed by most of the parents, they have experienced great helplessness, loss, and sadness. One mother stated:

因為真的外表完全看不出來，所以就是會覺得說，唉不可能不會好。但是再...一次從醫生那邊親口說，自閉症這個是個病，不會好之後，才會覺得是晴天霹靂說：啊原來他這個不是生病，他這個是障礙！就是是跟他一輩子的障礙！（You really can't tell by appearance, so I felt it was unlikely he cannot recover. But once again, I heard that autism is an incurable disease from the doctor. I felt like having a bombshell recognizing this is not an illness, but a disability! A disability accompanying him for a lifetime!)

Another mother responded:

那時候一開始感受是，想說努力...應該努力幾年他就會漸漸變好，所以一開始沒有很難過，一開始就想說我努力就好了。然後...是到後來上很多課程，發現說...醫生，

或者一些教授說這是終其一生的，伴隨他的疾病，不會好，可是可以進步，那時候我才...開始難過。(I felt maybe... maybe he can get well gradually after working for a few years, so I wasn't sad about it. I thought I can try hard to make him well at the beginning. Later, I learned that this is a lifelong disease, that he can progress, but not recover, from the professionals in many treatment programs and forums. I started feeling sad then.)

These feelings appeared as the reality which the parents bear and live with throughout their lives. Many parents recalled receiving the diagnosis as traumatic or unacceptable. They also expressed deep regret for their child's life. One mother described:

其實這個小孩他得自閉症，是我們...就不會說我們感冒看醫生，就是醫生幫你診斷，啊你拿了藥就聽他的話把藥吃完就好。然後反而，唉！你聽到是自閉症以後，你會發現...他的這個病醫生是沒辦法把你醫好的，然後變成...他只是給你心理建設說：你要有心理準備去...接受你後面的路...就漫長的路就是帶他去跑治療，可是，他不見得會好。(His autism is not like... like us seeing a doctor when having a cold, that you just listen to the doctor and take the medicine and get well. Instead, you find that the doctor can't cure him when recognizing it. It turned out to be... the doctor just provided you mental preparation... to accept a long way of doing therapy, but he does not necessarily get well.)

Most of the parents noticed their child's condition and sought professional help at the early stage. As indicated by the parents, there were no convincing results at the time of diagnosis. This

was partly due to the fact that only after the age of three years could a definite condition/diagnosis be identified, as one mother pointed out. Therefore, these parents sought either the same professional's advice at the different ages of their child or the advice of more than one professional at the time, to confirm the child's disability. One father stated:

第一次去 Q ( 醫院 ) 的時候他，當然醫生他...他可能心裡面的...什麼，他可能也不太想貼標籤啦，就跟我們大概講一下說：疑似自閉症這樣子而已啦。啊當然，也沒有做什麼後續的建議或是什麼的，然後我們才會去第二次去 K ( 醫院 )，去 K ( 醫院 ) 的時候可能就是比較確定了這樣子。(When we went to the Q hospital for the first time, the doctor felt he... perhaps the doctor was unwilling to label him. He just told us he was suspected to be autistic and that's all. Certainly, there was no prognosis or anything. We then went to the K hospital for a second assessment. It was assured when we went to the K hospital.)

Once the child's autism was confirmed, the parents could not but accept it as conclusive. Their child was deemed to accept treatment or intervention, even though they had little understanding about autism. When they recognized their child's disability, most parents turned to focus on the child's therapy or rehabilitation. One father reported:

我們本來一開始會懷疑一個醫生，會懷疑第二個醫生，然後只要有...三個以上醫生是說他是這樣的話，你只能接受，你當然只能接受，因為他就是這樣你不能說一直...不接受他，就讓他...一直不好下去，就是要...接受他，然後要幫他找資源。(We

were doubting one doctor at first, and another as well, yet when more than three doctors say he is, you cannot but accept it. You certainly can only accept it, because he is just like this. You can't keep denying that and let him get worse. Just... accept him, and then find the resource for him.)

The terms “therapy” and “rehabilitation” were frequently used to describe the intervention process by the parents. Many parents began the intervention early, as they believed early intervention plays a crucial role for the child. The concept of the “golden period” of development was shared by the parents, during which the effect of treatment/intervention was significant. One mother said:

尤其在...零到六歲的時候，那是一個黃金期，那個是很重要的，對，那...我們當然就很希望他能夠接受這個治療，這個是很正常的反應。所以那個時候，在醫院的時候，我們就有請那個護士小姐幫我們安排那個...恩在醫院那時候在 K 嘛，就有給他安排了，馬上就給他安排。(Especially at the age of zero to six years. That's a golden period. That's very important. Then... we certainly hoped he can accept the treatment. This is a normal reaction. So, when we were in the hospital, we asked the nurse to arrange that. It was in the K hospital, so we arranged that for him, immediately after he was diagnosed.)

As the child's primary caregiver, several mothers had forgone their career opportunities or asked for leave to spare their time taking the child to do therapy. This phenomenon existed only among the mothers, and lasted over the years. One mother stated:

我兒子從 3 歲...發現，我我上班帶他跑治療跑了半年以後，我我就在考慮說：我是不是要當全職的媽媽這樣帶他...做治療，因為我不想錯失...剩下來的兩年多的黃金期，所以我那時候就辭掉工作。(My son was diagnosed since three... After I took him to do therapy as well as worked for a half year, I was wondering if I should be a full-time mother to take him for therapy, because I didn't want to miss rest of the two years of the golden period. So I quit my job then.)

A range of intervention programs was chosen by the parents, as suggested by the health care professionals, early interventionists, therapists, and other parents. These programs included acupuncture (Chinese medicine), speech therapy, occupational therapy, physical therapy, psychotherapy, music therapy, art therapy, sensory integration training, and group guidance. In addition to seeking professional intervention, many parents employed the knowledge learned from the special educators or the therapists to educate their child by themselves. One mother stated:

因為你很多課你都是會在旁邊看，啊你都大概知道老師...老師教的方法是什麼，然後又剛好，他進小學之後，碰到的那兩個老師也很 OK，所以他就是，會...會給我那個...大概\*\* (孩子) 功課是要給\*\*教什麼的，所以就是我...我是可以教的，因為\*\*...我教他他會聽我的，所以，我就可以自己教，對。(Since you watched on-site in a lot of programs, you kind of learned the ways the therapists taught him. Then, he met two good teachers after entering elementary school. The teachers showed me what to teach

about his homework, so I can teach him. He listened to me when I taught him. So, I can teach him by myself.)

One father responded:

職能方面的話，那以前在 C ( 醫院 ) 做的時候我有去看他們在...看他們在在做一些，做一些...治療，那包含他...手腳協調方面，勦他以前手腳協調沒有那麼，現在那麼好，勦現在，除了說復健，恩復健之外，像平常我還都會帶著他打球，勦打羽毛球，勦打羽毛球訓練他手眼協調，他羽毛球還打的不錯。(I used to watch them doing occupational therapy in the C hospital, including... some treatment for his hand-eye coordination. His hand-eye coordination was not as good as now. Now, besides doing the rehabilitation, I usually take him playing badminton to train for his hand-eye coordination. He plays quite well.)

When the parents had acquired more experience working with the specialists, they chose some different ways to educate their children, in accordance with the child's conditions. While the most parents regarded the received interventions to be helpful for themselves in nurturing their child, some parents chose different approaches to raise their disabled child. One mother said:

我並不是否定我相信那也是人家專業出來的，只是說...我會覺得反正...死馬當活馬醫嘛，我我如果照你這樣走我兒子以後，我就要不斷地畫圖片給他那種...那我現在我不試試看，我不用...圖片的時候，我用正常小孩子的方式...去教他，當然你一開始看

不到成果，可是慢慢地是有的。(I wasn't denying that and I do believe that was out of their profession. It just... I felt like giving medicine to a dead horse anyway. If I had followed their ways, I would have kept drawing pictures to instruct him... So, I tried not to use the pictures, but rather I taught him by means of teaching normal kids. You can't see the results at first for sure, but gradually there were.)

Once their child grew out the age of early intervention, the parents relied on other approaches to educate the disabled child. They placed greater emphases on self-care independence than sociability and academic performance. These approaches mainly came from their beliefs and experiences of the received interventions and partly from the experience acquired in schooling (e.g. special education). Most of the parents applied both the educational and medical resources to enhance the child's conditions. One mother stated:

就是透過生活裡面教他了，就沒有...有在桌上這樣子教了，啊那個是必要的，但是那個就是在早療的時段，一旦進入國小之後，我覺得生活實際的教導比那種，在桌上的在那邊...真的...有，有用很多。(I just instructed him through the actual life and not on the table anymore. It was necessary to teach him on the table, but only in the stage of early intervention. After entering elementary school, I felt the instruction in the actual life is much more helpful than the teaching on the table.)

However, their endeavors of coping with the child's disabilities were not confined at home. In addition to seeking professional help, the parents drew on social services and the support from other parents of a child with a disability. Almost all of them had acquired information and resources regarding autism from the other parents and the social support, such as the social

welfare foundation or autism association, to understand the disability in caring for their child. In the course of doing therapy or rehabilitation, they gained some advice and experience from the other parents in terms of what interventions or which therapists and institutions to choose. The kind of information exchange was particularly sought by the mothers. Most of the parents went on to receive the intervention/treatment in other institutions suggested by the parents they met in the original institution. One mother stated:

去上了以後，會認識那種的媽媽，阿她就...就是我們會自己...像我現在也會阿，我去看到那一些很嚴重的小孩，我就會叫他們去找哪一個老師，因為有些老師對...有些功能的小孩子他比較，就是懂得如何去教他啦。(I was acquainted with the mothers of disabled children when I attended the clinic. Then she... like ourselves... Like me now, I went there and saw those kids with severe disabilities, so I told them which therapist to find. Because some therapists... to some children's disabilities, they just know how to teach them.)

Besides adopting the social support in attending to the child's autism, these parents formed a parental support network. All of the parents had experiences participating in the parental groups, such as the group in the welfare foundation or the church group for parents of the child with a disability. Most of them attended the parental group regularly or attended the foundation to interact with other parents. Some parents perceived the bond in the parental groups was as close as a family. One mother said:

去那邊覺得，唉自己可以放鬆，你不用那麼警戒，因為大家都是一樣，有自己的痛苦，啊有自己的難處，大家都可以很體諒。那你跟一般的朋友也可能他們不見得會了解，但是跟他們講他們（家長）都會知道，而且可以詢...可以給你很多的幫助。（I went there and I felt myself relax. You don't have to be that watchful, because everybody is the same, having our own pain and hardship. Everybody was being considerate. You told some friends and they may not understand, but you told them [the other parents] and they all know, and could give you a lot of help.）

They formed a rapport with the other parents and supported each other in caring for the disabled child. As they pointed out, such a network or relation was to help the parents themselves through the difficulties they encountered. Many of the parents regarded the support groups as the opportunity for respite and growth for parents. One father stated:

我們教會方面有有針對特殊兒，有開一個...特殊兒的班級，那...也也很多，齣除了說\*\*（孩子）之外，還有好幾個...好幾個家長也在這邊，齣一同...一同在這邊，一起成長這樣子。（Our church has managed a group especially for children with special needs.

Besides our child, there are many parents growing together here [in the parental group].）

Many parents believed the experiences of participating in the parental groups were supportive and valuable, not only in coping with the child's disability, but also in understanding themselves and the child. They also noted and recognized the imperative of caring for the disabled child's siblings when they were involved in the support services. The received support services/resources made them more aware of the wellness of themselves and their typically

developing child. Through their involvement in the various seminars and forums for the family of a child with autism, these parents gained more awareness and experience in facing the issues of autism.

In the process of comprehending and treating autism, the parents made meanings for the child's disability out of their cultural and religious beliefs. As many of the parents noted, traditional folk beliefs such as karma or the debt/sin from the previous life/lives had an impact on their perception of the child when their child was found to have autism. These cultural and religious beliefs were primarily derived from the parents' original or extended family (e.g. in-laws) and the socio-cultural norms and values in Taiwan. However, after they recognized the child's disability, these parents gradually changed their beliefs and adopted new meanings to appreciate and live with the child's autism. One mother said:

我們都知道什麼前世啊，因果，對不對...我不喜歡這種講法...我自己是覺得...我比較傾向的講法是，\*\* (孩子) 他很聰明，他知道...他知道我們會很愛他...所以他才當我們的小孩，你懂我意思嗎？(We all know about reincarnation or karma, right? I don't like this philosophy. I felt... I am inclined to believe that he is smart, he knows we would love him very much, so being our child. Do you know what I mean?)

One father stated:

我反而因為...因為基督教的信仰，讓我要能夠更接納，接納\*\* (孩子) 這個小孩子，嘿，把他看為是...神給我們的一個祝福。那以前我可能，可能會認為說... \*\*

(孩子) 是一個詛咒，咒詛，為什麼？可能人家說的，啊上...上輩子欠...欠的債之類

的，啊所以反而會...會朝負負面的方面去想。(I become rather... Because of the Christian belief, I become more tolerant of the child, and see him as a blessing of God. I used to consider... perhaps he is a curse. How come? Like people said, [the child is] my debt from the previous life or something... So I used to think in a negative way.)

The impact of these socio-cultural beliefs were evident in both mothers and fathers. Most of the parents believed the prevailing folk beliefs in Taiwan imposed negative meanings or connotations on the child with a disability. This phenomenon remained as the parents found the stigmas (e.g. talks or looks) toward themselves and their child from the elders and the people.

One mother responded:

鄰居講的那些話，有一些長輩啊，講我兒子怎麼樣怎麼樣，因為他有一些...情緒嘛，那你...不知道的人，就不知道怎麼教他，然後就會講那一些話，你知道聽了真的是很難過。(Some elders in the neighborhood talked about my son because he had some... emotions. Then... people who don't know [autism] don't understand how to instruct him. Then they talked some words like that [criticism]. You know I felt really sad when hearing that.)

Another mother stated:

當有這些東西...行為出現之後，人家就是指責跟排斥的眼光，這是我們做家長的很難把他們帶出去的原因，因為不知道要怎麼樣去面對那些人的眼光...跟接受。(When these behaviors were displayed, people expressed censuring and excluding looks. This is

the reason why we parents have difficulty taking them out. Because we don't know how to face... and take those looks.)

Many of the parents considered the people in Taiwanese society had no complete awareness or acceptance of autism yet. As they pointed out, autism was usually regarded as a state of being unsociable and having no connection with others. Some parents believed individuals with autism were more disadvantaged than people with a physical disability. Almost all these parents had experiences of being misunderstood or excluded and indicated the necessity and aspiration to receive more support and rapport from the public. One mother said:

其實我們社會...政府對這種推廣跟建設跟認識都太少了，什麼是自閉症，不知道，就是...很孤僻，可是他們不知道說自閉症是還有很多的行為。(Actually, our society... the government [in Taiwan] has little awareness and promotion and implementation for this. What is autism? Not known. Just... being unsociable, yet they don't know there are various behaviors.)

The meanings of autism remained obscure for most of the people in Taiwanese society. This phenomenon arose when the child was found to be autistic through the parents' efforts in seeking professional accounts to improve the child's condition. During the process of searching for ways to alleviate the consequences of the disability, the parents acquired more understanding about autism and the underlying issues. They gradually learned how to face the issues using the resources and support from the other parents and thus, developed new meanings other than the conventional ones to account for the reality.

### **Family as the Base of Support**

The diagnosis of autism changed the ways the parents nurtured the child and their family life. Almost all parents recalled their usual family life was suddenly altered after receiving the child's diagnosis. This phenomenon developed when the parents had to take care of both a typically developing child and the child with autism or their spouse was unwilling to recognize the diagnosis. Most of the parents perceived such a change in life led to confusion, difficult challenges, and a negative impact on their quality of life. While they turned to work on improving the child's condition, many parents experienced burden or discordant familial relationship when lacking support of their spouse in caring for the child. One mother stated:

先生不能接受，甚至有情緒，然後孩子的情緒，還有哥哥的情緒，都會變成...我所有的壓力啦，就像心理老師說：他們三個人的情緒都壓在我一個人身上。就我一旦崩潰，他們可能全部都崩潰。(My husband was unable to accept it [the diagnosis], and even had emotions. Then the child's emotions, and his big brother's emotions as well. All these turned out to be my stress. Like the psychologist said, their emotions were put on me only. Like once I have a breakdown, they may all have a breakdown.)

These feelings were not only reflected by the mothers, but also expressed by some fathers, especially when they assumed specific responsibilities in nurturing the child. One father said:

在生活上，能夠自己去...去最簡單的，比如說就最簡單的...上上個洗手間這樣子，我訓練他就訓練很久的時...很久的一段時間吶，那當然，這一段時間，家裡的生活方面，整個生活品質一定是下降。(For him being able to... like the simplest, to go to a

washroom in the actual life, I trained him for a very long time. Of course, during this time, our family life... the overall quality of life was certainly lowered.)

When the parents placed their focus on educating the disabled child at the time, they left less time and energy to the typically developing sibling. Most of the parents either asked their spouse to assume the responsibilities in nurturing the typically developing child or expected the typically developing child to be autonomous in caring for him/herself. One mother responded:

因為我那時候在帶\*\* ( 孩子 ) 跑復健...所以哥哥其實都是丟幼稚園給爸爸接，對哥哥的...功能什麼時候發展啊還有什麼，我一點印象都沒有，所以...所以對手足這一塊是...那時候是沒有，沒有餘力去照顧另外一個。(Because I was taking him to do the rehabilitation then, I left his older brother to be picked up by his father in the kindergarten. To his [the typically developing child] ... states of development and else, I had no impression at all. So, in terms of the sibling... I had no extra energy to take care of another one then.)

Such situation existed for a long period, until many parents found their typically developing child displayed the feeling of unfairness or the negative emotions/behaviors (e.g. complaining or arguing) toward the disabled sibling. As some parents noted, they expected their typically developing child could develop as usual, without special attention or care. However, when the parents recognized the circumstances between the disabled and typically developing child, they took on the responsibility to educate their typically developing child in appreciating the condition of the disabled sibling. One mother stated:

就要常常跟他一個人相處的時候跟他講，哥哥的狀況，然後說：如果是這個這個狀況，你可以怎麼怎麼做，嘿。然後去跟他分析說哥哥，他...可是，恩，我比較常跟弟弟講的就是：你設身處地去想哥哥的狀況，當你心情有...你心裡有話，你講不出來，表達不出來，你內心會怎麼樣。(When I was alone with him [the typically developing child], I usually explained his older brother's condition to him, and taught him what to do when facing these conditions. But what I told him more often is: "You put yourself in your older brother's shoes. What would you feel when you have something in your mind, yet you can't speak out or express it?")

Many of the parents adopted the social, medical, and educational resources to help them in supporting their typically developing child. They had the belief and expectation that the typically developing child can understand or support the disabled sibling. Some of the parents noted the relationship between the child with autism and typically developing child improved while they paid careful attention to the typically developing sibling. One mother said:

他有跟他同學講說他弟弟有自閉症，然後就是讀特教班的這樣，他們同學有來看（弟弟），嘿啊，所以，哥哥這一塊，他...就越來，而且到\*\*\*（基金會），他會看到其他的孩子，其他的...自閉症的孩子，他就會覺得...uh...他就會看到弟弟的，弟弟其實可愛的地方啦。(He [the typically developing sibling] told his classmates that his little brother has autism and studies in the special class. His classmates came to see him [the disabled child]. So, his older brother is more... Besides, he saw the other children with

autism when we attended the association. He just felt... He saw his little brother's lovely traits actually.)

When the parents laid a rather equal emphasis on nurturing their typically developing child, they found the child expressed the willingness to share the responsibility in supporting the disabled sibling. Many parents recognized that their typically developing child displayed more sympathy and concern to the situation of the family. Some of the typically developing siblings worked with their parents as a coordinator or facilitator to care for the disabled sibling. Their involvement in caregiving of the child with autism gradually modified the patterns with which the family addressed the child's disability. One mother described:

哥哥是接受蒙特梭利教育的，所以，他生活自理什麼都很厲害，我就叫他陪弟弟去洗澡，然後他說他不會幫弟弟洗，我我說：沒關係，媽媽會去做後面的那個善後，我說。其實就讓他們在廁所玩，然後讓弟弟去學哥哥怎麼洗澡。(His older brother received the education of the Montessori approach in preschool, so he is good at self-care independence. So I asked him to take a bath with his little brother [the disabled sibling]. Then he said he doesn't know to bathe his little brother. I said, "It's okay. Mom can deal with the aftermath". Just let them play in the bathroom actually, and let him learn from his older brother how to bathe.)

The parents sought to improve their child's condition before they were informed of a definite diagnosis. Most of the parents noticed their child's conditions when they found the child had difficulties in speech or communication (e.g. having no responses to others) at the age of speaking, typically developing by 1-2 years of age. They recognized their child's disabilities

through the parenting of or interactions between the child and typically developing sibling/children. Some of the parents attended to the child's conditions when the child expressed unusual emotions or behaviors (e.g. keeping crying or screaming). One mother said:

本來會叫爸爸媽媽那時候，可是後來就沒有了...就覺得...他最明顯除了情緒還有就是他會看...他可以自己看電風扇，或者是看燈，然後...可以看很久，然後我發現這個孩子怪怪的這樣，就他不喜歡跟孩子們玩，他都自己一個人坐在那邊看電風扇，或者看那個燈這樣。(He could call mom and dad then, but gradually [the child's speech] disappeared later on. I felt... Most noticeably, he had emotions, and he also watched the fan or the light by himself and... for quite a while. Then I found he was kind of odd. Like he disliked playing with the other kids. He always sat there watching the fan or the light alone.)

The parents' attitudes toward the child's disability determined the roles and responsibilities undertaken by the family members. Most of the parents assumed the primary caregiving roles/responsibilities to the child as much as they could, and expected the typically developing sibling could support the disabled child when they are no longer able to care for the child (e.g. aged or gone). They made the greatest effort to mitigate the child's disability in the hope that the child would not become a burden to their sibling. One mother stated:

她還是想說...是可以帶在身邊，啊我是跟姊姊講，我說：你有你自己的人生，啊以後你也會有你的家庭，你願意成為他的監護人，我已經非常感恩了。就是說，總

是有... 诶你他也許住在某一個機構，诶有一個監護人願意常常去看他，這差很多

啊。(She [the typically developing sibling] still felt... it is feasible to bring him [the disabled child] with her to care for him. But I told his older sister: “You have your own life, and your own family as well after all. I am so grateful that you are willing to become his legal guardian anyway”, I said. It’s just... perhaps he will live in an institution, yet it would be quite different if there is a guardian visiting him often.)

Another mother said:

就是比較希望他不要成為哥哥的負擔啦，因為畢竟我跟爸爸會老，然後... 也不可能

叫哥哥都不管他啊，也不能跟哥哥說：你就是你有你自己的人生，我還是說你就

是：弟弟... 媽媽爸爸老的時候需要你協助的地方，就是... 就是還是要麻煩你這樣。(I

just hope that he would not become his older brother’s [the typically developing sibling] burden, because his father and I will age after all. Yet... it is unlikely to tell his older brother not to care about him at all. I couldn’t tell his older brother: “You just live your own life”. I still said to him: “When mom and dad are old and need your assistance, your little brother... still has to bother you”.)

The parents expressed concerns about the disabled child if they were unable to nurture the child in the future. The mothers appeared to bear more stresses on improving their child’s condition than the fathers, even though these fathers assumed some caregiving responsibilities in collaborating with the child’s mother. This phenomenon occurred if the parents received less support and rapport from their original or extended family. Most of the parents believed their

extended families' attitude toward the child with autism had an impact on their caregiving of the child. One mother stated:

其實那一段時間其實真的很煎熬，那我盡量跟家庭保持聯繫，齣，比如說像過年過節我就回去，但是，孩子對於...他要面對這個家族裡面的阿...啊，姑姑啊，阿姨這些啊，其實對於孩子來講，當然也是一個學習，可是也是一個壓力，因為，我姊姊我妹妹她們就是會用那個方式去引導他，可是對於...真的是不適合。(It was actually a hard time then, but I tried my best to keep contact with my original family. For example, I went back on New Year's day and the other festivals. Yet, this child... He faced these relatives in the family, like his aunts. Actually for him, it was certainly an opportunity to learn, but also a stress, because my sisters always used that [conventional] way to guide him. But for... [a child with autism] it was unsuitable really.)

Another mother mentioned:

應該說長輩啊，什麼都覺得他們就是有問題的孩子，會拖累這個家，所以長輩那時候是說：看哪裡可以送，就不要讓他回來的那一種（機構），那...這邊我就沒有聽長輩的啊，因為長輩不了解自閉症，沒有他們沒有接受教育，所以比較不能理解，那可是因為我們又團住，所以我這邊的...壓力會比較大。(Usually the elders or other relatives felt they are problematic kids and would be a burden to this family. So the elders suggested me to find an institution for him to stay permanently there, but I didn't listen to

the elders about this. Because they didn't receive an education and don't know autism, they couldn't understand. But we live together, so there is more stress... for me.)

Many of the parents sought support from their original or extended families in the hope that their families could appreciate the family's situation. They strived to maintain the bonds with their original or extended families to relieve the concerns of their families on them. Most parents noted that although their families may not have fully realized the child's disability, they were willing to accept the child. Some of the parents expressed gratitude toward their original or extended families when they found their families had a rapport with the disabled child and supported them in nurturing the child. One father responded:

外公外婆就是...蠻接接納這個小朋友的，蠻接納\*\* ( 孩子 ) 的，所以在跟\*\* ( 孩子 ) 之間的互動，就跟正常的小孩一樣，夠沒有很特別歧視他，反而會...反而會更加的疼愛他，夠，反而會更加疼愛\*\* ( 孩子 )，夠那當然，我身為\*\* ( 孩子 ) 的爸爸看到還覺得，蠻...蠻感動的啦，也蠻感謝他們能夠接納...接納\*\* ( 孩子 ) 這樣的小孩子。(His grandparents are really tolerant to the child... really tolerate him. So they interact with him just as interact with a normal child, without any discriminating on him. They instead love him more dearly. Then of course, as his father, I felt really touched... and appreciated they would accept... a child like him.)

One mother said:

不管是我先生的家人，還是以我的家人，大家...uh...不會排斥他啦...就是知道他是個...特別的小孩，對，恩，但是他們...uh...比較遠的親戚會不知道...怎麼跟他相處，嘿，那阿嬤因為是...常常跟他接觸，所以就還好，恩，那...她還不錯就是...因為有時候有一些長輩，他恩...他們會覺得...怎麼這個小孩是這樣，啊阿嬤不會，嘿，阿嬤很疼他。(Either my husband's or my families, everyone... wouldn't exclude him. They know he is a special kid... But they... Some distant relatives would not know how to get along with him. And because his grandmother was in contact with him very often, it's okay for her. And... she was nice actually. Because sometimes there are some elders... they felt like... what's wrong with this child. Yet his grandmother wouldn't think so. His grandmother is very fond of him.)

The support of the original/extended families toward the child with autism alleviated the parents' stress of being misunderstood or blamed when they confronted the prevailing socio-cultural belief on the child's disability. However, some of the parents took on the caregiving responsibilities on their own to prevent it from causing their families troublesome or affecting the familial relationship. As some parents noted, they visited the child's grandparents and relatives less frequently than usual, as the child grew older and the child's condition bothered their families more. One mother said:

他們有一些家族的活動，比如說，啊一起出去吃飯啊，或一起去哪裡玩，我就會比較...沒有辦法，那他們就會說：那你不帶他出來試試看怎麼知道。唉，可是我會比

較抗拒是因為...萬一弟弟有情緒的時候，是沒有人可以幫我的，而且甚至會影響到大家，那我不知道大家對這樣子的...忍受程度有多高。(There were some family events, like gathering together to have a meal or an outing. I would rather... not participate. Then they [the relatives] would say: “You never tried taking him to participate; you never know”. But I would resist to do so... Because nobody can assist me if he has emotions, and that even could affect everybody. I am not sure to what extent they can tolerate this...)

The relationship between the child’s family and extended family also influenced how the parents perceived themselves having a child with autism. Some of the parents, especially the mothers, felt they bore the responsibility of their families in terms of how they reared the child with autism. This phenomenon was reflected by several mothers when the child’s father assumed the primary responsibility for the family finances. They expressed the feelings of frustration, uncertainty, and aloneness, especially when struggling with the ways they nurtured the disabled child. One mother stated:

生了\*\* ( 孩子 ) 之後，其實我一直覺得很...孤單吧，因為，會覺得...自己一直都是這麼順，那為什麼會突然...有這樣的孩子，我也會變得不太敢講，也不太敢讓家裡面的人擔心，因為他們一直覺得你是很好的，uh...就是各方面來講，都是 OK 的，所以我也變得會不太敢說自己...有太多困難的地方。(Actually I always felt... alone, after giving birth to the child. Because I felt myself always going so smoothly, how come I suddenly... have a child like this? I would become not daring to speak out and let my

families worry. Because they always felt you are fine, like... everything is all right. So I became not daring to speak about myself... having many difficulties.)

Most of the parents regarded the process of seeking an adequate way to address the child's disability as lengthy and hard. They believed the support/rapport of their families, especially of their spouse, was paramount in walking through the process. Moreover, many parents considered the attitudes of the family members, including the parents themselves and typically developing siblings, as crucial in caring for the disabled child. While they paid close attention to the typically developing sibling, they found the typically developing child was thoughtful and willing to attend to the disabled sibling. When most of the parents received the support of their original/extended families in nurturing the child, the parents instead supported the child on their own. They endeavored to ease the child's disability in caring for the child as lasting as they can with the hope that the typically developing sibling can support the child without difficulties in the future.

### **The Child Developing into a Relatively Autonomous Person**

When the parents talked about their child's condition and disabilities, they expressed their hopes and concerns about the child's future development. On the one hand, they considered their child to have a deficiency in certain areas of development. On the other hand, they found their child has some admirable characteristics and strengths (e.g. unique logic or strong visual ability). Almost all the parents had struggled with how to educate their child with autism to improve the well-being of the child. They explored and adopted varied approaches until they found the most viable manner that fit their child's characteristics. One mother said:

我現在是比較擔心他未來的工作啊...對，因為...我我覺得自，因為我兒子...應該是因為本身他的認知是 OK 的，對，啊我覺得...譬如說他職場的適應，還有我覺得台灣的教育比較缺...譬如說他英文很好，可是我真的不知道怎麼用什麼管道...讓他去強化他的強項，我到現在還...嘖，怎麼講，還沒有找到這一條路就對了。(I am more concerned about his future career recently. Because I felt... Perhaps because his cognition is okay, I felt... [worried about] like his adaptation in the workplace. And I felt the education in Taiwan has a lack of... Like his English is very good, but I really don't know through what way... for him to enhance his strengths. Until now, I haven't found this way.)

Most of the parents attempted to understand and improve the child's conditions from an early stage of the child's development. In addition to the autistic characteristics, many parents found the other conditions which influenced their child's early development. They sought to relieve these conditions through the health care professionals and were informed that the child's condition had a connection with autism as a result. One mother stated:

他在還沒有發現自閉症以前啊，都覺得這個孩子很愛哭，他從來沒有一覺到天亮過，他通常的睡眠大概就是...三個小時他就會醒過來一次，那時候不知道他是因為自閉症的關係，他...後來才會發現說，很奇怪是不是他對某種東西是...過敏，然後去做了抽血的檢查才發現他對牛奶、雞蛋，還有牛肉，還有...麩質的食品，麥啊...那些都是嚴重過敏。(Before his autism was found, I felt this child cried a lot. He never slept

the night through. Usually... he woke every three hours during sleep. I wasn't known this was because of autism... Then, I wondered whether he is allergic to something and took him to do a blood test. Then I found he had a severe allergy to foods containing milk, egg, beef, and gluten.)

The parents gained more awareness of the child's conditions or characteristics while seeking support from the health care professionals/interventionists and the child's educators (e.g. special or resource teachers). They expressed more worries about the child if the child grew older yet his condition got worse. Most of the parents believed receiving an adequate intervention and education could alleviate the child's disabilities. While many of the parents considered their child gradually improved or progressed, some parents found their child confronted more difficulties when growing into further developmental stages. One father said:

當然我們不是說否認說，我們這段...這些年來的一個努力或是夠，或許說我們沒有做這些努力的話，他的狀況會越來越差，那可是讓我們覺得說唉他...他越大的話，就是一些狀況，然後一些...一些，一些我們需要去解決，需要去克服的事情越來越多這樣子。(Certainly, we wouldn't deny our effort for these few years. Perhaps his condition would worsen if we didn't make these efforts. But we felt him... As he is older, there are more conditions and more... something we need to deal with and overcome.)

They noted their child had more difficulties adapting when the child transferred to the further level of education or unfamiliar environment, in which the child was required to acquire new knowledge and skill (e.g. having lunch at school or doing therapy in the hospital). Some parents found their child encountered more challenges in experiencing the different

developmental phases (e.g. adolescence). They sought support of and collaborated with the child's educators and the health care professionals/interventionists to attend to the child during the transitional processes. Most of the parents believed the support of the family members and the child's educators played a crucial role in assisting the disabled child going through the transitions of development. One mother stated:

父母看待這個孩子的...的心態啊，然後，在他每一個他...在困難的時候，家庭...就是父母...的整個家庭的支持系統，是不是有足夠的能量，可以支持他，我覺得這個是非常重要的。他在轉變的時候，你有沒有那個力量可以幫助他。(I felt it's the attitude of the parents in treating this child, and the family... whether the whole family support system has sufficient energy to support him every time he had difficulties. I felt this was very important. Whether you have the strength to help him when he is in transition.)

One father said:

他每一個階段，每一個年級，他所遇到的老師，說實在的我們說，都...都遇到很不錯的老師啦，啊所以他，他在...成長的過程當中，各方面的轉變，都是因為有遇到好的老師，啊所以都...對他的教導，跟他...跟他整個性格的轉變都幫助蠻大的。(In every of his [growth] stage and school year, we felt he met the nice teachers actually. So he... In his developmental process, his change in all respects was because of meeting these good teachers. So, their instruction to him was quite helpful for the transformation of his character.)

The parents conferred with the child's educators in seeking the optimum and supportive environment to place the disabled child. They worked closely with the child's educators to understand and enhance their child's situations through the parent-teacher meetings, the contact books, or the IEPs. Most of the parents placed their child in the regular or inclusive classroom from preschool age in the attempt that the child can socialize with the typically developing peers at the early stage of development. When the parents found that their child had not progressed/improved or the environment was no longer suitable for the child, most parents sought to place the child in another environment. One mother stated:

在普通班他幾乎都是坐著，因為他都聽不懂嘛...所以他坐，他很會發呆欸，就是發呆或著想到什麼事情在笑，這樣。所以，我我讓他待普通班的目的就是...人際互動而已啊，後來，那幾年就差不多了，我就覺得差不多可以轉特教班了。(He sat there all the time in the regular class, because he didn't understand the instruction at all... He sat there being in a daze badly or thinking about something and laughed. I placed him in the regular class solely for interpersonal interaction so... Then, after those years I felt it was about time to transfer him to the special class.)

Another mother mentioned:

就是我們會...那個...詢問老師的意見啊，因為有時候老師跟他接觸，知道他的情況，那老師也比較了解，怎樣對他...比較有幫助，因為我們都是...我們的...那個設想就是...在怎樣的環境可以對他有最大的幫助，我們就選擇那個環境，嘿。啊那時候老

師覺得他比較適合在特教班。(Like we would... ask for the teacher's opinions. Because when the teacher had contacted with him, they knew about his situation. They also more understood how to better support him. Because we all... Our consideration was... to choose the environment which is most helpful for him. And the teacher felt he was more suitable to study in the special class then.)

In addition to supporting the disabled child's placement in the appropriate environment, the child's educators assumed the responsibility to help the child adjust to the new environment. Most of the parents approved of the educators' endeavors in arranging for the child's classmates to support him as assistants, introducing the parents and the child with autism to the other parents and the teachers in the same class, or dedicating their private time to understand and interact with the child. They believed the educators' willingness or warm-heartedness to accept and support their child with autism was pivotal in improving the child's condition. One mother said:

他上課有時候會走來走去，然後也會叫，會有一些...語言，比如說他會：啊...！一下子就大聲啊，或怎樣，那那個時候我覺得說，他是階段性的，然後，老師是可以包容，那那...還有一點就是說，老師很用心是，老師有...請幾個同學去輔導他，比如說...比如說他們要在學校用午餐嘛，他們那時候小一二年級的時候。(He walked around in the class sometimes, and screamed or suddenly spoke something aloud... I felt his condition was temporary then, and his teacher was being tolerant. Furthermore, the teacher was mindful that she asked a few classmates to guide him, like serving and eating school lunch when they were in first/second grade.)

Another mother stated:

我是覺得關鍵點是那個導師，嘿，然後如果導師很接納，我覺得整個班級，或是其他的...就是有專科的老師啊，什麼科學，或是體育老師，這也會很接納他。可是如果這個老，導師不耐煩，我覺得他的同學，或是其他專科、專任的老師，也會顯得不耐煩。(I felt the key was the class teacher. If the class teacher accepts him so, the whole class or the subject teachers, like science or gymnastics teacher... will accept him too. But I felt if this class teacher is impatient, his classmates or subject teachers appear to be impatient as well.)

The parents sought to improve the disabled child's self-care skill and independence through schooling (e.g. socializing with the typically developing peers or the IEPs) since the early and primary education of the child. Most of the parents believed well-developed self-care skill and emotional stability were fundamental in enhancing the well-being and future placement of the child. They expressed the hope and expectation that to a certain extent, the child can take care of himself to relieve the burden of the family or to be settled in an adequate institution (e.g. community home or sheltered workshop) after 12 years of the compulsory education in Taiwan. One mother said:

不管是他以後，是由姊姊來照顧他，還是說，由姊姊...監護，讓他在...在那個日托的...就是那種全日型的社區的家園裡面，我們的孩子必須要把他...盡我們的能力把他訓練到別人好照顧，因為我們...親生父母的...的，主要照顧者的耐性跟容忍度都很

OK, 可是, 我們現在還有一個盼望是, 他...當他交到別人手中的時候, 他也是好照顧的。(Whether his older sister looks after him or keeps custody of him when he lives in the community home in the future, we must do our best to train our child... for others to care for him smoothly. Because we the parents... the primary caregivers are tolerant and patient. Yet, we now hope that he is easily cared for when he is handed over to others.)

One father said:

我們比較希望說, 至少在生活自理方面啊, 他能夠懂得自己去照顧自己啦。那一些...比如說一些...一些生活上的一些基本的技能啊, 夠基本的技能, 比如說, 一些他...或許他去其他一些...以後可以去機構, 夠人家去教他...做的一些事情的一些技能, 比如說包裝啊, 夠或是說洗車啊, 或是說種菜啊, 這些比較那麼不會繁瑣複雜的事情。(We more hope that he knows to take care of himself, at least in self-care independence. Like some... some basic life skills. For example, perhaps he will stay in the other institution and be trained with some skills, like packaging, car washing, or growing vegetables; such less complicated things.)

The parents expressed not only the aspirations, but also deep concerns for placement or employment of the child when their child grows into the adulthood. Most of the parents worried that there are few opportunities/quotas for their child to stay or work, or their child is unable to meet the requirements of placement at the sheltered environment. They pointed out the imperative needs for the establishment of more sheltered institutions and workshops for

individuals with a disability. Some of the parents indicated the necessity of a sound social support resource/system to educate, accommodate, and care for the disabled individuals, especially when their parents are no longer able to look after them. One mother stated:

他們也是有一些工作能力，他們也不想，就是變成這個社會的負擔，可是，就是...  
沒有缺，那就是希望說，欸可以有更多的，那個...類似像小型作業所，或者是日托  
可以...可以成立。(They have some ability to work, and don't want to become a burden of  
the society. Yet, it's just... no vacancies. So, we hope more institutions... like sheltered  
workshops or community homes can be established.)

Another mother said:

畢業後，就是看孩子能不能...能不能工作。然後能不能工作還有一個講到就是，庇  
護工廠，或者是小型作業所，都要看...即使孩子可以工作，可以在那個有保護的環  
境下工作可是...不一定有名額，因為，庇護工廠的人就是這麼多，然後可以做工作  
的就是，可能一待就是 10 幾年。(After graduating from high school, we shall see if he  
has the ability to... to work. Then there is another question regarding the sheltered  
workshops... Even if our child can work under such protective environment, they don't  
necessarily have quotas. Because there is a certain amount of people in the sheltered  
workshops, those who have worked there could stay for over a decade.)

As the parents noted, there is a lack of long-term/lifelong care facilities for the disabled adults in Taiwan. Most of the educational and medical/interventional resources were focused on

the early life stages of the child with autism. Therefore, the parents made the greatest effort to improve the child's condition since the early childhood, either by means of the education or the medical support system. Their endeavors were shown by seeking the most feasible/suitable approach and environment to treat and place their child when they recognized the child's conditions/characteristics. The parents sought to enhance the self-care skill of their child as much as they could in educating the child and expected their child would gradually grow to be autonomous. In doing so, they believed there is an imperative to have access to ample opportunities for their child to lead a fulfilled life.

## **Chapter 6**

### **Discussion**

The present study investigated the perspectives and experiences of 10 parents (eight families) of children with autism in Taiwan, to understand their beliefs and practices in caring for a child with autism, and how their experiences were constructed/lived within the given sociocultural context. Results indicate that the Taiwanese parents of the child with autism sought to understand meanings of autism and search for the most advantageous approaches and environments to treat and place their child upon recognizing the child's disability. They drew on the knowledge and experience acquired from both educational and medical sources to educate their children with autism in the hope that the child would be able to be relatively autonomous after developing into adulthood, particularly, in response to the expectations of their extended family and the society. In raising their child with autism, however, these parents experienced misunderstanding, stigmatization, and/or exclusion from the public, resulting from the conventional conceptions of disability. They utilized the social supports to improve the well-being and situations of their families in confronting such phenomenon and derived their own understanding and ways to address their children's disabilities. The findings suggest a lack of social awareness of autism as well as support resources for the placement of adults with a disability appear as the central themes which account for the lived experience of families of children with autism in Taiwan.

In this section, I elaborate on the findings based on Bronfenbrenner's ecological systems model, and Husserl's and Merleau-Ponty's phenomenological perspectives. I then compare the findings with those of the relevant research studies to incorporate the perspectives of the existing body of literature. At the end, I examine the limitations of the present study and indicate the

needs and directions for future research effort to address the related issues identified in the present study.

### **Ecological Systems Model**

The present study acknowledges the subjective nature of the parents' experiences in nurturing their child with autism, through which they perceived and made sense of the features of their everyday environments. Within the environments where the children with autism lived there are four interactive ecological contexts, namely, microsystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner, 1977), under the effect of time as chronosystem (Bronfenbrenner, 1986). In the present study, the parents' perceptions and interpretations of the autistic child's ecological environments demonstrate the interdependent influences between the child's family, educators, peer groups, health care providers/interventionists, extended family, the community, the social support, the parental support network, and the society, over the course of the development of the child. The dynamics within and between the children with autism and their immediate settings, including home (parents and typically developing siblings), school (educators and peer groups), hospital/clinic (health care providers and interventionists), and social support (summer camps or church groups) serve as functioning microsystem which primarily influenced the development of the child (see Chapter 3, p. 24). For example, the relationships between the children with autism and the typically developing siblings (referred to as sibling relationship) have interdependent influences with the parents' perceptions and practices toward the children with autism, and expectations of the future development of the disabled child. When the parents paid careful attention to the typically developing child, he/she expressed rapport with the disabled sibling and the family. Accordingly, at the microsystem level, the parental beliefs about the nature and causes of autism (Danseco, 1997), the perceptions

of the family members toward the environmental properties, such as the received interventions, social support, and education, and the mutual accommodation between the family and the disabled child (Sontag, 1996), have the underlying impact on the successive help-seeking and decision-making processes for the treatment and educational and future placement of the disabled child. As the results suggest, the child's educators and classmates (peer groups) played a major role in supporting the child to adjust to the school settings, which serve as the primary microsystem for the children with autism. Furthermore, the interactions between the parents and the educators and health care providers/interventionists influenced the parents' beliefs and conceptions of autism, the diagnosis, and their child's conditions. This contributed to their caregiving practices and help-seeking process. The communication between the parents and the educators also affects the processes of seeking and decision-making of the educational placement and the developmental transitions of the children with autism. Such a reciprocal relationship between the family and the other immediate settings, which rendered the joint impact on the child's development serves at the mesosystem level (see Chapter 3, p. 24). As an example, the parents maintained close connections with the child's educators in the forms of contact books, IEP meetings, parent-teacher meetings, and private contact to understand and improve the situation of the disabled child at home and school.

The families of the child with autism in the present study, invoked and engaged in social support services and activities such as church groups, social welfare foundations, and respite services in maintaining the family's well-being. The reciprocal relationship between the family and the social support was reported to be particularly valuable for the parents in appreciating and caring for the children with autism and their typically developing siblings. These interactive connections, as an active mesosystem and/or exosystem (see Chapter 3, p. 25), enhanced the

sibling relationships and the family functioning, which had positive influences on the families in supporting their disabled child. In line with the ethnically diverse parents in Starr, Martini, and Kuo's (2014) study, the Taiwanese parents in the present study, considered the rapport and support from the family members and the other parents of children with autism as salient in overcoming the hardship of the family. At the exosystem level, for example, this concerned the parental groups at the social welfare foundation or the church for respite or growth of the parents with a child with autism/disabilities. The interconnections between or among parents of children with disabilities, referred to as parental support networks (Bronfenbrenner, 1986), influenced the parents' decision-making regarding which intervention or support to seek and receive. The parental support networks therefore influenced their beliefs and experiences of the interventions and the resources received and the anticipated outcomes of the intervention.

The underlying culturally expected parenting styles and ideologies of autism/disability had prevalent impacts on the parents' beliefs and conceptions about the meaning, cause, and course of autism (Danseco, 1997; Hsiao & Magyar, 2006; Starr et al., 2014). Such broader socio-cultural influences are the patterns, knowledge, and ideologies in which the families of the child with autism were based performing at the macrosystem level, as represented or manifested through the micro-, meso-, and exosystems among the children with autism (see Chapter 3, p. 25). For instance, the meanings of autism adopted by the parents, the professionals, and the public rendered distinct and joint impact on the children with autism, and further, the interactions between the families and the professionals, and the seeking of support resources for the children with autism. When there were no convincing accounts for the child's autism, they sought to understand and mitigate their child's conditions through varied sources. Correspondingly, the Taiwanese parents' cultural and religious beliefs which reflected the broader socio-cultural

influences were revealed in the parents' perceptions of disability, and experiences and practices nurturing their child with autism, which also influenced their relationships with the child's extended family, the community, and the public. The rapport of the extended families however, particularly between the child's grandparents and parents mediated the negative consequences of misconception or stigma from the community and the public in terms of lacking accurate understanding of autism and the impact of folk beliefs in Taiwanese society (Chang & Hsu, 2007; Lee & Lin, 2013). As the results revealed, the parents had experienced varied forms of stigmatization or exclusion from the people who held the views of autism as a result of karma, debt, or sin from the previous life or as having an unsociable personality. Such socio-cultural impact underlay the Taiwanese parents' help-seeking and coping process in relations with the professional and social support, within which they relied more on the support of their family members and partially their extended families (Chang & Hsu, 2007; Chiang & Hadadian, 2007; Ho et al., 2014). Parents' relationships with their extended families were reported as the source of support and stress on their caregiving with the children with autism, adhering to Chang and Hsu's (2007) study. The impact of socio-cultural beliefs and values were often reflected by the mothers in the present study, in that they took on major responsibility in caring for the disabled child, and thus, experienced additional stress in decision-making about the adequate treatment and placement of the child (Chang, 2009; Hsu et al., 2015).

In macrosystem terms, the notion of the critical period (0-6 years) of development for a normally developing child was particularly underscored by the parents of the child with autism or other disability (Hsu et al., 2015; Huang et al., 2012). This notion, either formally or informally, impacts the parents' parenting practices as well as coping and help-seeking process (Shyu et al., 2010). As the findings informed, the Taiwanese parents of the child with autism

sought professional support and intervention early, and dedicated most of the time and resources to educate their children during this period. As reported by Shyu, Tsai, and Tsai (2010), parents of the child with autism in Taiwan apply a range of educational, interventional, and religious resources in dealing with the absence of acceptable explanations of their child's condition and the socio-cultural views on autism/disability. Even so, the parents in the present study gradually changed their cultural and religious beliefs and attitudes to appreciate and approach their child's disabilities, by which they made new meaning and understanding diverged from the prevailing socio-cultural conceptions, ideologies, and practices (Huang et al., 2009; Huang et al., 2012; Lee & Lin, 2013).

Notably, Bronfenbrenner (1986) underlines the developmental change and continuity within and between the developing child and the ecological contexts, which influenced the successive development of the child functioning as chronosystem (see Chapter 3, p. 26). The developmental process of the disabled child in interplay with the environments over time incorporates the history and the long-term impact as the child is growing (Sontag, 1996). As the results indicated, the diagnosis of autism had a cumulative impact on the parenting practices and the familial relationship (Huang et al., 2011). For example, some of the parents mentioned their spouse was unwilling to recognize their child's diagnosis or disability at first, which subsequently posed burden and discordant familial relationship in caring for the disabled child. Accordingly, the parents' perception of the diagnosis influenced their attitudes toward the disabled child, the following help-seeking process, and the family functioning over the course of development of the child with autism. Furthermore, the support of the family members and the relationships between the parents, the child with autism, and the educators or the health care providers or interventionists were the most influential factors during the developmental transition

of the children with autism. Some of the classroom teachers or the principals, for instance, introduced the parents and the child with autism to the other parents and the teachers at the meeting before the school year began, to build rapport with the parents and the child with autism. Similar findings are reported by Starr, Martini, and Kuo (2014) that, at the mesosystem level, the communication and trusting relationships between the parents and the kindergarten teachers are responsible for the child with autism in adapting to the school environment before and during the transitional process. The parents in the present study also considered the advice from the children's educators as support for the transitions of the children with autism. However, at the exosystem level, the inadequacy of long-term/lifelong care resources and employment opportunities in the society was noted by the Taiwanese parents as a significant impact on the future development of the disabled children. Such an issue becomes more detrimental when the parents can no longer support their disabled child in the future. As a result, in Taiwan, the parents of the child with autism placed a strong emphasis on the need for resources to support their autistic child during the early development of the child.

### **Phenomenology**

The present study attempts to understand the ways the Taiwanese parents perceive and interpret their caregiving experiences with children with autism, and thus, shape or negotiate their experiences within the socio-cultural context in which they are situated. Essentially, the ways the parents of the child with autism perceive, interpret, and negotiate their experiences caring for the autistic child are embodied in their everyday life as their unique ways of being in the world. One of the principal assumptions of the present study, based on Husserl's phenomenological approach, is that every human has been brought up with pre-determined beliefs, concepts, and experiences in one's own culture or society, and obligated to transmit these

sociocultural understandings to successive generations, as the process of socialization/enculturation (Wolff, 1978; see also Chapter 3, p. 31). These sociocultural understandings, experiences, or ideologies which everyone has been brought up with profoundly influenced the ways one perceives, interprets, and understands one's own disabilities and those of others (Chiang & Hadadian, 2007; Tham et al., 2000). As a matter of fact, the meaning of having or living with autism/disability held true by the individuals with autism and their family members is subject to how the disability/illness is conceptualized, defined, explained, and so treated, in the culture or the society (Chi, 2015; Daley, 2002; Kim, 2012; Ravindran & Myers, 2012). In the present study, for example, the parents' experiences caring for their child with autism were closely contingent on the attitudes of the extended family toward the autistic child. As the child's extended family perceived the autistic child as problematic or burdensome to the family, the parents experienced more stresses and difficulties in educating the child, especially when they assumed the primary caregiver's role and responsibility.

Typically, giving birth to and nourishing a healthy, well-rounded offspring to sustain the family line as well as prosperity has been the moral responsibility for Taiwanese mothers (Chang, 2009; Hsu et al., 2015). As the results illustrated, the mothers took on the major responsibilities in nurturing, educating, and placing the child with autism in conformity with the expectations of the extended families and the society. Nevertheless, for both parents of the child with autism, having and raising their disabled child has often been perceived as a consequence of personal or familial immorality, such as past-life debt, sin or karma, or inappropriate parenting in the society (Chang & McConkey, 2008; Ho et al., 2014; Hsu et al., 2015; Huang et al., 2011). For instance, some of the parents noted that they had received censoring or excluding looks or comments from neighbors and the public, implying blame to the parents for failing to nurture and

educate the disabled child, or judging parents for the perceived immorality or misfortune the child brings to the family. Such socio-cultural perceptions held by many Taiwanese people toward the children with autism/disability engendered the feelings of shame or guilt for the parents, making some less inclined to seek support outside the family circle (Chang & Hsu, 2007; Chiang & Hadadian, 2007; Ho et al., 2014; Kang et al., 2002). Moreover, the parents mentioned the conventional/normative parenting styles and practices toward their child with autism initiated by some of the extended family members or the elders in the community were the source of stresses for them and their relationships within the family and community circles. In phenomenological terms, the conventional measures of nurturing and educating a child are deemed to be correct (taken for granted) by some of the extended families and the community members, regardless whether such approaches are appropriate for the children with autism/disability. Instead, when the parents received support from their extended family, they felt relieved from the blame and burden in caring for the disabled child under such circumstances.

The experience as one lived constitutes the subjective and culturally meaningful world, which embodied one's unique life-world (Husserl, 1970, as cited in Tham et al., 2000). In other words, the meaning of having autism was constituted in terms of how the experience is lived by the individuals with autism and their relations with the socio-cultural contexts. Therefore, the present study incorporates the role of the body to understand how the experience of living with autism/disabilities was shaped and negotiated within the worlds of the children with autism and their caregivers. The role of the body, based on Merleau-Ponty's phenomenological perspective, serves as a subject which encompasses human consciousness/intentionality as a whole entity of "the self" (Edwards, 1998; see also Chapter 3, p. 33). For example, the experience of having

autism was perceived as “living in one’s own world” by some parents of the child with autism, as the children manifested their subjective, meaningful world through the distinctive patterns of expression, play, and behavior. As the results indicated, the parents considered the world of their child with autism as having its own meaning, represented in the drawing and playing, yet seldom understood or questioned by the others as it is expressed. Instead, when their children expressed these behavioral patterns, they were more often seen as deviant or problematic in the eyes of others. As a matter of fact, the behavioral patterns of the children with autism, as they are communicated, conveys both mental and physical states/experiences of the self, which involves motor and symbolic aspects of expression (Merleau-Ponty, 1962, as cited in Edwards, 1998). Through the presence of the bodily self of the children with autism, they are actively shaping the character of the world, which is also shaped by the nature of the world in the relationship with the others (Merleau-Ponty, 1962, as cited in Edwards, 1998; see also Chapter 3, p. 35). Hence, the interactive relationship between the bodily self of the children with autism and the world or others constitutes the unique way and experience of living their body. In the process of educating the children with autism, for instance, some of the parents noted that although their child had difficulties in communicating with others, they gradually acquired new experience and displayed different patterns of the bodily expression/experience. Thus, the body of the children with autism, as it is lived, serves as the medium whereby the children with autism socialize with, display, and negotiate the surrounding world.

The relation with the self (self-relation) has the equal importance to the relation with the other (self-withdrawal) in the body (see Chapter 3, p. 33). Essentially, the body constitutes and mediates both aspects of the bodily experience (Waldenfels, 2008). The bodily experience of an individual with autism/disabilities in communicating with and negotiating the surrounding world

through the medium of the body depends on how she/he perceives and interprets the world/others, and how she/he is perceived and interpreted by the world/others.

Interconnectedness between self-relation and self-withdrawal, thus determines the corporeality (Waldenfels, 2008). When it comes to children with autism, for example, the parents believed that even though their child had difficulties while expressing his emotional and cognitive states and/or experiences, he is able-bodied. According to Holroyd (2003), in the Confucian societies such as Hong Kong and Taiwan, an impaired body or mind is viewed as incomplete and a loss of personhood, which has a moral standing in the world. This suggests that the presence of the disordered body or mind of the children with autism/disabilities calls into question the fundamental moral value conveyed by the body, in establishing the autistic child's personhood and self (Edwards, 1998; Holroyd, 2003). As such, the parents of the child with autism in Taiwan assumed the primary caregiving responsibility to ensure that, to a certain extent, their children with autism can develop independence and ability to care for themselves when they reach adulthood.

### **Implications for Future Research**

1. The present study drew on the perspectives of 10 parents of the child with autism in Taiwan, including seven mothers and three fathers, to understand the experience of caring for a child with autism/disabilities, as well as the socialization process of the autistic child within the socio-cultural contexts they lived. Although the results may not be able to be generalized to the larger population of parents of children with autism/disabilities, the intent of the present study was to provide an accurate description and interpretation of the parents' experiences and an insight into the phenomenon in which the experience of having and living with autism takes place.

2. Regarding the parents' cultural and religious beliefs, demographic information indicated the majority of the parents are Christian ( $n = 8$ ), which had an impact on their caregiving experiences and the socialization process of the autistic child. For example, some parents chose to place their child with autism in a church group to socialize with the peers with such beliefs. However, some of the parents were not Christian before their child was diagnosed with autism. This suggests the possibility that the parents changed their cultural and religious beliefs as a means to cope with the child's autism. Future research may address the change of the parental cultural beliefs in relations to their child's diagnosis, to understand the socio-cultural implications of an autism diagnosis toward parents' help-seeking/coping process.
3. All the sampled families were the families of the male child with autism. According to Lai, Tseng, Hou, and Guo (2012), the prevalence rate by gender is 6.06 to 1 (boy/girl) in 2010 Taiwan. As the gender ratio had been growing while the study was conducted, Lai et al. (2012) also recognizes that there is a disproportion of boys among children with autism in Taiwan. In this regard, future research may increase the sample size or employ different sampling procedure, such as selective sampling, to include more girls with autism into the study.
4. In consideration of geographic differences in the prevalence rates of ASD among the seven cities and eighteen counties in Taiwan, the urban areas, where the study was undertaken, had higher prevalence rates than rural areas from 2004 to 2010 (Lai, Tseng, Hou, & Guo, 2012). However, the difference of the prevalence rate ratios by area (urban/rural) during this period suggests that the discrepancies between urban and rural areas in accessing the resources and in the awareness of autism are gradually lessening (Lai et al., 2012). This

enhances the transferability of the present study, as future research may employ the findings and/or the methods of the study to investigate another cohort/context which shared the similar culture, demographics, and geographic characteristics.

5. The age criteria for selection of children with autism in the present study is parents with children/youth at 7-17 years of age (see Chapter 4, p. 44). As the results indicate, only one child with autism who had attended special vocational high school for the preparation of future career/employment was sampled, in terms of the age of the child. Future research may include more children with autism who have such experiences to understand the phenomenon/process of transition into adulthood of the children with autism/disabilities.
6. In terms of individual characteristics of the children with autism in interfacing with their ecological settings, the strengths/disabilities of the children with autism within the settings they are based need further consideration/discussion in future research. For instance, some parents noted their child with autism displayed strengths in certain areas while having difficulties in the others. Future research may invoke the strength-based and context sensitive approach to examine and define the ecological niches of the children with autism (Bal & Radke, 2013). The consideration of the individual characteristics of a child with autism/disability in interplay with the ecological contexts can inform parents in seeking adequate/advantageous environments for the placement and development of the child.
7. The present study places the particular focus on the situation of the families of the child with autism within the given socio-cultural context. Although there are limitations to apply their perspectives/experiences to understand the families of the children with other disabilities, the themes emerged in the present study can inform future research on the field of disability studies. For example, the cultural conception of karma/morality associated with

a child's disability and its meaning to the family has been noted amongst the families of the child with a disability in the Chinese population (Chang & Hsu, 2007; Chang & McConkey, 2008; Huang et al., 2009; Ho et al., 2014). Therefore, future research may take into consideration culture to gain awareness of the situation of the families who live within such contexts.

## **Conclusion**

In Taiwan, autism was defined and categorized as a childhood psychiatric issue rather than a psychological condition. This creates challenges for the families of children with autism, since the diagnosis of autism signified the innate, perpetual, and incomprehensible condition accompanied with the autistic child as part of the self. While a large proportion of the resources were put into identifying and treating autism in Taiwan, few had been implemented to support the children with autism and their families even when they mature. Furthermore, the categorization and diagnosis of autism, based on Western psychiatric approach (e.g. The Diagnostic and Statistical Manual of Mental Disorders, DSM), and the conventional conceptions upon disability contributed to the meanings for and understandings toward individuals with autism in the society. Despite the fact that these models and mores, in macrosystem terms, are inevitable in constructing the typical standards for developing and functioning of the society, there are spaces and a necessity for the government and the people in Taiwan to gain more awareness of this disability, and to lay more stress on the welfare and well-being of the children with autism and their families. On the whole, living with autism is not only medical or social concerns, but also experiences of humanity.

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## Appendix A

## Family Background Information Form

Please complete the following items. You do not have to answer any question that makes you feel uncomfortable. If you have any questions in completing the form, please feel free to ask.

1) Gender:  Male  Female

2) Age:  < 25  26-35  36-45  > 46

3) Current occupation: \_\_\_\_\_

Full-time  Part-time

4) What is the highest level of education you have obtained?

High School

Business, Technical, or Vocational School

Community College

Bachelor Degree

Master's Degree

Doctoral or Professional degree

Other \_\_\_\_\_

5) What is the religious belief of your family?

Buddhism  Taoism  Christianity  Folk Beliefs  None  Other: \_\_\_\_\_

6) Family Structure:

Single-parent Family  Nuclear Family  Extended Family  Step Family

7) How many child(ren) do you have? \_\_\_\_\_

8) How old is your child(ren) with autism? \_\_\_\_\_

9) Is your child(ren) with autism:  Male  Female

10) How old was your child(ren) when diagnosed with autism? \_\_\_\_\_

11) What type of autism/disabilities is your child(ren) diagnosed with? \_\_\_\_\_

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12) What education has your child(ren) with autism received? \_\_\_\_\_

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13) What grade is your child(ren) with autism in? \_\_\_\_\_

14) Has your child(ren) with autism involved in any autism-related support service and/or intervention program?  Yes  No

If yes, please note: \_\_\_\_\_

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15) How long has your child(ren) with autism involved in the support service/intervention program noted above? \_\_\_\_\_

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16) Have you attended any workshop/parenting education program related to autism?

Yes  No

If yes, please note: \_\_\_\_\_

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17) Have you involved in any parental support group or support network related to autism?

Yes  No

If yes, please note: \_\_\_\_\_

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## Appendix B

## Semi-Structured Interview Schedule

[Beliefs about the nature and causes of autism]

1. Based on your experiences, how would you define/describe autism?

[Experience of the lived world/Being in the world]

2. Would you please tell me how you felt upon being told about your child being diagnosed with autism?
3. Would you please tell me what your life is like after recognizing your child's diagnosis?

[Disability characteristics in relations with immediate settings/Childhood socialization]

4. Please tell me about your child.
5. Please tell me about your child's life in school.
6. Please tell me about yourself as a parent of a child with autism.
7. As a parent, what do you feel the most important skills that your child needs to learn?
8. Please describe how your family members perceive and interact with your child with autism.

[Parental beliefs and values/Culture/External settings]

9. You have mentioned in the Background Information Form about the cultural/religious belief of your family. Would you be comfortable discussing your cultural/religious beliefs and how they influence your decisions in raising your child with autism?

[Support service]

10. As you have noted in the Background Information Form about the services you use in supporting your child, would you please tell me why you choose these services?

11. Do you feel these services/intervention programs help you and your child?

[Developmental transitions/Future]

12. Based on your experiences, what are the most important turning points of your child's life?

Please describe each of these turning points. How do they affect your child's development?

13. What resources will you use to support your child's successive development?

[Conclusion/Invitation for next interview]

14. Is there anything else you would like to share today?

## Appendix C

## Letter of Invitation

Dear Parent,

My name is Kai Pin Chen and I am a student in the Master of Arts (Child and Youth Study) program at Mount Saint Vincent University, Halifax, Nova Scotia, Canada. I am writing to you in regard to my thesis research: Experiences of Taiwanese Parents of Children with Autism – Disabilities. The purpose of this study is to understand your experiences in parenting a child/children with autism, to gain an insight into how autism is constructed in the society. Your perspective is valuable, and your experiences of nurturing a child/children with autism should inform other parents, social workers, and child care professionals about issues related to autism. Information gained from this study should increase our understanding on the process and context in which children with autism develop, and the awareness of the welfare of the families.

The study will be conducted in interviews with the parent in the family, who is the primary caregiver of the child with autism. The interview will be held at a time and location of the participant's choice and takes approximately 60-120 minutes to complete. A second or third interview may take place to examine if your perceptions are accurately interpreted and to provide feedback based on the initial interview. The interviews will be audio recorded and transcribed, and notes will be taken during the interviews. All information obtained in this study will remain confidential and anonymous. Only the supervisor of this research and I will have access to the data. The identifiable information and the interview data will be numerically coded, and stored in a locked file cabinet in the research supervisor's office and as password-protected electronic files on the researcher's computer for five years. Quotes from interviews will be used in the thesis,

however, no names or identifying information will be reported in the thesis or in future presentations or articles. Following completion of the thesis, a summary of the findings will be provided to you.

Please understand that participation in this research is completely voluntary. You may skip or decline to respond to any questions that you are uncomfortable answering. Also, you may withdraw from this study without giving any reason at any point without consequence. If you would be willing to participate in this research, please read the following consent form and seek clarification on any points. You are welcome to contact the researcher prior to or during the involvement of the research. If you have any further questions or concerns regarding this study or your involvement, please contact me at 0965421530 or by e-mail at [Kai.Pin.Chen@msvu.ca](mailto:Kai.Pin.Chen@msvu.ca) or you may contact my thesis supervisor, Dr. Mary Jane Harkins at [MaryJane.Harkins@msvu.ca](mailto:MaryJane.Harkins@msvu.ca) or at 1-877-433-2889. If you have any questions and would like to speak to someone who is not directly involved in the study, you may contact the chair of the University Research Ethics Board c/o MSVU Research and International Office at (902) 457-6350 or via email at [research@msvu.ca](mailto:research@msvu.ca).

Thank you for considering this research project.

Sincerely,

Kai Pin Chen

Master of Arts (CYS) Student

Mount Saint Vincent University

## Appendix D

## Consent Form for Participation

Thesis Title: Experiences of Taiwanese Parents of Children with Autism – Disabilities

Thesis Student: Kai Pin Chen

I, \_\_\_\_\_, am willing to participate in a one-on-one interview as part of a research study being conducted by Kai Pin Chen as part of his Master of Arts thesis in the Department of Child and Youth Study at Mount Saint Vincent University. I understand that the research I will participate in will explore my experiences and perceptions in caring for a child/children with autism. Information gained from this study should increase our understanding of the life of families of children with autism and recognition of the socio-cultural contexts where the development of the disabled child expands.

I have been informed that my time commitment for the individual interview will be approximately 60-120 minutes. I am aware that the interview will be audio-recorded and that once the interview has been transcribed I will be contacted (via information provided below) and given the opportunity to review my transcript and suggest modifications. I understand that the transcripts will be kept in a locked file cabinet in the thesis supervisor's office for five years and that electronic files on the researcher's computer will be password protected.

I understand that my participation in this research is entirely voluntary and that I can withdraw at any point without consequence. I also understand that I can withdraw at any time up to one

month after the interview. After that point, the data will be stripped of identifiers and unable to remove individual data. I know I can skip or decline to respond to any questions that I am uncomfortable answering. I understand that all information obtained in this study is confidential and that no participant will be identified. I am aware that all recordings, transcripts and forms will have numerical codes to maintain confidentiality. I also understand that quotes from interviews will be used in a future publication of the thesis to illustrate themes arising from the data. No identifying information will be reported and my identity will not be revealed in anyway. However, I am also aware that the researcher is legally obligated to report any information that is shared with her which may indicate that a child is being abused or harmed in any way. If I need assistance, I understand that the researcher cannot provide the service, but he will offer the information about the required support services (listed in the List of Organizations for Family Support). I am aware that I can have a summary of the research findings if I wish, when the thesis is completed.

If I have any questions, I may freely contact the researcher at 0965421530 or by email at Kai.Pin.Chen@msvu.ca or the research supervisor Dr. Mary Jane Harkins at MaryJane.Harkins@msvu.ca or at 1-877-433-2889. If I have questions about how this study is being conducted and wish to speak to someone who is not directly involved in the study, I may contact the chair of the University Research Ethics Board c/o MSVU Research and International Office, or by phone at (902)-457-6350 or by email at Reserach@msvu.ca

I have read the information provided above. I understand that by signing below that I am agreeing to participate in this research study. I will keep a copy of this consent form.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

I agree to the interview being audio-recorded: \_\_\_\_\_

Phone Numbers I can be reached at: \_\_\_\_\_

and/or

E-mail Address \_\_\_\_\_

Times I may be reached at: \_\_\_\_\_

Researchers Signature: \_\_\_\_\_

Postal address or email where a summary of the results may be sent:

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## Appendix E

## List of Organizations for Family Support

Home for The Disabled Bureau of Social Affairs of Kaohsiung City Government –

[http://barrier-free.kcg.gov.tw/index\\_en.php](http://barrier-free.kcg.gov.tw/index_en.php)

Autism Awakening Academy (AAA) - <http://www.autismawakening.org/>

Foundation for Autistic Children and Adults in Taiwan (FACT) - <http://www.fact.org.tw/>

Autism Society Taiwan - <http://www.autism.org.tw/modules/news/>

Kaohsiung Autism Association - <http://www.ksautism.org.tw/style/front001/bexfront.php>

Kaohsiung Autism Foundation - <http://www.starfamily.org.tw/>

Eden Social Welfare Foundation - <http://eden.international/>

Play and Culture Intervention, PCI - <http://www.taiwanplay.com.tw/>