LIVING IN NEW ZEALAND WITH A CHILD WITH SPECIAL NEEDS: THE PERCEPTION AND EXPERIENCES OF CHINESE IMMIGRANTS

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by

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Abstract

This study aims to understand the Chinese immigrant parents' perception towards their children's special needs, based on the social constructionism ideology and to capture the essence of their experiences living in Christchurch, New Zealand. These experiences have been presented with a narrative inquiry approach. The researcher draws on personal and social interactions throughout the research in learning about this topic. Seven Chinese families with children with special needs were recruited, four through word of mouth and three through a special school. Mothers of these seven families were interviewed using open-ended questions.

The open ended research plan led to four phases in this study. The first phase involved carrying out a brief survey among practitioners in Christchurch to understand the contemporary issues regarding working with Chinese families with children with special needs. The second phase included investigation of the connotation of special needs in Mandarin terms. The third phase consisted of recruitment and interviews with the first four families, and then in the final phase, with another three families.

Themes emerged from the data included: Parenting practices, the role relationships within the family unit, the perceived important skills for the child, parental investments, familial support, social support and professional support. These themes were incorporated into two parts: The primacy of the family unit, and Support.

The centrality of parenthood in Chinese society in terms of the cyclic enactment of acceptance, and responsibility was highlighted. With one exception, the parents in this study reported engaging in different activities including learning about the child's disorder, carrying out intervention at home and adjusting the family lifestyle to the child's needs. The parental investment indicated parental resilience in facing the child's problem. The findings of the study were used to draw out commonmyths the
professionals have regarding Chinese families with children with special needs, and to suggest strategies for more appropriate services and areas of future research.
CHAPTER ONE
Planning the Research: Developing Theoretical Framework

The Journey of My “Re-search”

Confronting My Assumption: Qualitative Doing with Quantitative Thinking

Coming out from a meeting with [my research supervisors], I wandered around the university campus, feeling lost. How can I ‘be myself’ in my research? What is ‘my real thinking’? What are my underlying assumptions about this topic? How would I feel if I were one of my participants? What are my expectations?

All these ‘foreign’ questions bombarded me.

Before this meeting, I thought my task was to collect data and then to put them into categories associating them with one another, as many others had done. I thought the purpose of my study was to see whether my data ‘fits’ the findings of the existing literature or not. And perhaps, to identify a few of the implications for practitioners who work with Chinese families. I thought that was the way ‘to do’ research. That was ‘the format’ of ‘real’ research, the ‘requirement’ for a research paper. And so, I assumed that was what my supervisors would like me to do.

But today, all my conceptions were challenged. ‘It is the process that tells one as much as, if not more than, the results’ and ‘I am one of the participants in my research’.
It was the first time for me to realize that I had never paused to ‘doubt’ or to ask questions during my academic journey. I had never explored within my inner true and honest self to reflect on or critique what had been presented to me as ‘standard academic practice’.

Facing these ‘foreign’ questions, I realized that my thinking had become very rigid. I couldn’t think outside the square that I had built all these years.

It all reflected how deeply I had buried my true self all the way throughout my academic journey...

(Journal Entry, 26 March 2003)

To share this excerpt from my diary is to reflect the challenges I have had during the process (I would rather say ‘journey’) of carrying out this qualitative study. As a positivist oriented and trained student, I never realized that the first step of qualitative research is self reflection. The reason I chose the word ‘re-search’ is because in my experience, through doing this study I started to search the ‘self’ that I had lost in the education system in which I had been brought up.

“Re-searching” the Awareness: My Positivistic Orientation

“Imagine your beloved aunty has a child with special needs, how would you respond to the child? What would your aunty think of her child?” This is a question my supervisor threw at me after she had seen my fore-structure. Obviously, my fore-structure was ‘not quite right’.
The enthusiasm to carry out this research is burning but it doesn’t help me move forward. Stigma, intervention, shame, guilt, disappointment…what else? I can’t think of any other terms when I think of the words ‘special needs’, ‘Chinese parents’ and ‘attitude’. Aren’t these the issues? At least, most of the literature I have read so far talked about these.

But, would I respond this way if it happened in my family? What would I say to people about my child if I had a child with special needs? I am not sure…but I don’t think it would all be just negative, I believe.

So, should I assume the issues I have read about are all that my participants would say to me? No, obviously not...

(Journal Entry, 1 April 2003)

My impression about qualitative study was that it was interpretive in nature hence it was what I called a ‘soft’ science, lacking in reliability and validity. I thought it should not be employed as an independent research methodology but should be used in addition to the quantitative and statistical approach so that the research results were ‘usable’.

Learning about qualitative study put my presumed research method in dispute. I began to realize that under the influence of the positivist oriented academic system, my conception was that my research method should be standardized and repeatable, and my purpose as a researcher was to test a pre-formulated hypotheses. Therefore, I carried with me the information from the previous literature I had read and tried to work out a way to ‘prove’ my hypotheses. I never thought about viewing the world with another perspective, or even about considering myself one of the elements that would affect the dynamics of my research findings. On the contrary I thought, in keeping with the structuralist explanations,
I should distance myself from my participants in order to avoid interpretivist explanations that refer to human intentions and emotions (Bergan, 1993; Prus, 1996; Giddens, 1974; Williams, 1976).

"Re-searching" the 'Missing Person' in My Academic Journey: Closing the Gap Between the Academic Findings and the Real Life Experience.

Realizing my preconceived idea about my research findings would possibly cause me to lose the richness of my data, I began to immerse myself in reflecting my assumptions through reading, questioning, challenging and exploring alternative ways of thinking in approaching my research. During this process, I started to confront my own prejudices and bring with me the awareness of my existence as part of my study. This was when I really started learning about qualitative study. I began to understand that the interpretive nature of a qualitative approach should not be seen as its limitation but on the contrary, it allows a presentation from the point of view of the subjects of the study rather than presenting it from the perspective of the researcher. The interpretive and flexible approach was necessary if I were to understand the way my participants interpret and give meaning to events, things and to their own behaviours (Crotty, 1998; Rice, 1996; Taylor & Bogdan 1998). Given that my aim is to reveal the process underlying subtle and complex interacting phenomena within some Chinese immigrants in New Zealand who had children with special needs, qualitative study becomes the more appropriate approach because it provides insight into how people make sense of their experience. This insight cannot be easily provided by other methods such as the quantitative approach (Bogdan & Biklen, 1998; Denzin & Lincoln, 2000; Taylor & Bogdan, 1998).
Refining the Research Objective

This 'open ended' research started with the objective to understand the experiences of Chinese immigrants with a child with special needs living in New Zealand. Following the progressive research discoveries, four research questions emerged:

1. What are the contemporary issues among the professionals in Christchurch when working with Chinese families with children with special needs?

2. What connotations of special needs exist among Chinese in their language?

3. What are the perceptions of Chinese immigrant parents towards their children's special needs?

4. What are the experiences of Chinese parents living in New Zealand with children with special needs?
My Theoretical Framework

Where do I come from?
Growing up in a long house\(^1\) where I could observe the different family dynamics and how the social context shaped the developmental pathways of my many younger cousins, I developed assumptions that: First, as children move from infancy to adulthood they undergo fundamental changes that systematically influence the ways that they perceive and respond to their world, and the ways that their families, teachers, peers and others with whom they relate to respond to them. Second, the experiences of children and youth throughout their schooling, including the ways that they are prepared for it and their reactions to it, strongly influence their individual development. Third, the social experiences of children, both within and outside of the family and the feelings that resulted from those experiences have a major impact on their individual development. Fourth, individuals have diverse learning, social and emotional needs and differ considerably from each other in the ways that they approach their world.

With these underlying assumptions in mind, I was attracted to the Child and Family Psychology Programme. My training as a Child and Family Psychologist has further cultivated the notions of development, diversity, and ecology. I am trained to take a developmental stance and to appreciate the diverse individual learning, social, and emotional needs and behaviours of an individual, and understand that these needs and behaviours must be understood within the larger context of the family, the school, and the social and cultural environment in which they live. This framework specifies a holistic approach to understanding my participants, in which the physical, emotional and social needs of children and the family are seen as intertwined.

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\(^1\) A long house is an extended family home. The structure of my long house was like a motel where there were 8-10 rooms, one for each nuclear family
Together with my developmental stance, the philosophy of social constructionism I embedded into the course of this study. I see that the common ways of understanding the world, the categories and concepts we use, are historically and culturally specific. From this view, I needed to focus not on the disability of my participants in the abstract, but rather on the way in which the labels are produced and reproduced in social interactions within institutional and cultural contexts. As this research is aiming at understanding the experiences and making meaning of the experiences of these Chinese families with children with special needs, I will employ narrative inquiry in presenting my dissertation. I believe narrative inquiry is the best means to bring cohesion to shared beliefs and transmitted values. The experiences of these families are meaningful and according to narrative inquiry, their behaviours are generated from, as well as informed by this meaningfulness (Polkinghorne, 1988).

In order to make my assumptions visible, I will briefly outline the basic elements of the sociocultural theory, social constructionism and narrative inquiry which constituted the theoretical backdrop of my aforementioned framework.

**The research approach: the qualitative research principles.**

Qualitative methodologies have emerged as some of the most important tools in understanding the complexities of a particular population in its social context (Taylor & Bogdan, 1998). Previous qualitative studies have proven the power of this methodology in describing and clarifying the interdependence of human interaction, cultural attitudes, institutional processes, and public policies (Taylor & Bogdan, 1998).

Denzin and Lincoln (1998) described qualitative research as “multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them” (p. 3).
According to Creswell (1998), during the process of a qualitative study, the researcher should “build a complex, holistic picture, analyze words, report detailed views of informants and conduct the study in a natural setting” (p. 15). It is not about reporting a condition characterizing a phenomenon but it is the process of interaction between the researcher and the surroundings. A qualitative researcher uses a variety of methods to collect data. Researchers are limited only by the demands of the research question, funding and degree of creativity (Creswell, 1988).

From the ideology of qualitative study, I have developed a new way of thinking and started to re-adjust my conception regarding my role as a researcher with respect to the following assumptions:

First of all, I became aware that I can never take a value-free stance. I bring with me my values, and biases as a person. These include my way of thinking as a Child and Family Psychologist and my cultural values as a Malaysian Chinese. Therefore, my challenge was to discover and expose my own assumptions, values and biases so that my interpretations could be understood and critiqued within my framework (Denzin & Lincoln, 1998).

Second, I attempted to remove the distance that creates a barrier to understanding the lived experience of the families by approaching and interacting with them as a member of their community. Rather than taking an ‘objective stance’, I took an ‘empathic stance’ in order to understand their experiences. As Josselson (1994) put it, qualitative study is ‘a way of approaching the data that allows for discovery rather than seeks confirmation of hypotheses and that fosters exhaustive quests for explanation rather than the illusion of finding the preexisting truth’ (p. 30).
Third, my role is as an active learner who can tell the story from my participants' point of view rather than as an expert who knows more about the experiences than those living it. I will allow my participants to speak in their own voices rather than conform to the words and categories chosen for them by previous literature. They will also be encouraged to formulate their own conceptualizations concerning their experiences.

Fourth, I see reality as both contextually and socially constructed. As multiple realities exist, my job is to describe these realities in great care (Creswell, 1998). The purpose of my study is not to uncover the preexisting truth but to uncover the meaning: how people make sense of their lives, their experiences and their world.

Fifth, I attempt to understand my participants’ experiences from an insider’s point of view; in doing so, I aim to develop a firm grasp of the basic dimensions of the issues in question and if necessary, I will move beyond conventional wisdom and preconceived notions.

Sixth, the foundation of my study is the quality of judgment, honesty, self-awareness, reflection and fairness that I bring to every aspect of it, from the participant recruitment method to the creativity and discernment involved in the process of data analysis. All these skills determine the richness of the elicited data.

Seventh, my role is to capture the perspectives of individuals affected by the circumstances in their lives and by the communities in which they live as well as the differing multiple perspectives of the various stakeholders involved in those same circumstances and communities (Sofaer, 1999).
There are many theories, methods and evaluation criteria coexisting currently in the transitional state of qualitative study (Denzin, 1997; Taylor & Bogdan, 1998; Bogdan & Biklen, 1998; Denzin & Lincoln, 2000). Many of the theories share a common ground, i.e. emphasis on understanding meanings and interpretations (Rice & Ezzy, 1999). The particular method that I chose to employ in this study is social constructionism. The reason I chose this theory is because it blends with my developmental background and the theoretical approach I have learnt as a Child and Family Psychology student. A fuller account of my theoretical framework for this research is outlined in the following section.

*The theoretical approach: the sociocultural theory.*

This research focuses on the cultural domain within the ecology of the families. It addresses the cultural context of these families by focusing on how culture, i.e. values, beliefs, customs, would affect the attitudes and decisions of the Chinese parents with children with special needs in New Zealand. In Vygotsky’s sociocultural theory, social interaction – in particular, cooperative dialogues between individuals and more knowledgeable members of the society – is necessary for them to acquire the ways of thinking and behaving that make up a community’s culture (Wertsch & Tulviste, 1992). Vygotsky believed that members of a community are helped by the experts in the community to master culturally meaningful activities, and the communication during the interactions becomes part of the individuals’ thinking. As the individuals internalize the essential features of the communication, they use the language within them to guide their own thoughts and actions in acquiring new development (Berk, 2001).

*The theoretical approach: social constructionism.*

From the emphasis on the function of language in constructing meanings for the daily living events, I incorporate the ideology of social constructionism into my theoretical framework for this study. In the view of social constructionists, the meaning of an act is socially constructed and this construction process is rooted in language (Burr, 1996). The
traditional, general view of the relationship between language and a person is that people use language to express their internal state that already exists. In this way, language and the thoughts or feelings of a person are independent. However, a social constructionist sees language as a pre-condition for thought and as a form of social action. The conceptual frameworks and categories used in a culture are acquired by all people as they develop the use of language. The use of language is more than simply a way to express ourselves but is a form of action where the world gets constructed (Burr, 1996).

Social constructionism stresses the necessity of taking a critical viewpoint towards the taken-for-granted ways of making sense of the world, including how we see ourselves (Burr, 1996). It challenges the outlook that conventional knowledge is based upon objective, unbiased observation of the world and alerts us to be ever doubtful of our assumptions about how the world appears to be. Within social constructionism, there is no such thing as objective fact. All knowledge is derived from looking at the world from a specific perspective according to one’s interest at the particular point.

Like Vygotsky (1978), the social constructionists acknowledge that the common understanding of the world, the categories and concepts we use, are historically and culturally specific. Not only are they specific to the particular culture and time of history but also to the products of that culture and history, and are dependent upon the particular social and economic conditions prevailing in that culture during that particular period. Therefore, the forms of knowledge that are held in any culture are artifacts of it, and we should not assume our ways of understanding are necessarily more truthful than other ways. In this view, I must turn my attention to a historical study in understanding the social practices of my research participants (Burr, 1996).

Social constructionism rejects the traditional psychological and sociological positions where explanations of social phenomena are explored within a person or from the social
structures. Social constructionism proposes that explanations of the social phenomena are to be found in the interactive processes that take place routinely between people, but not exclusively either in the individual psyche or in social structures. Further, that there cannot be any “given determined nature to the world or people and there is no essence inside things or people that make them what they are” (Burr, 1996, p. 14). For example, rather than seeing disability as being a consequence of individual differences, it can be understood as a result of perceptions rooted in social practices that mark out some differences as being abnormal and pathological (Burr, 1996).

Consequently, the focus of this study will be on the process rather than the structure and from questions about the nature of people or society to considering how certain phenomena are achieved by people in interaction. The “goings-on between people in the course of their everyday lives are seen as the practices during which the shared versions of knowledge are constructed” (Burr, 1996, p. 14). The ways of understanding the experiences of these families are a product of the social processes and interactions among people (including me), who are constantly engaged.

*The presentation of my dissertation: narrative inquiry.*

Over the past four decades, there has been a dramatic evolution in both policy and practice of the public support and attitude towards individual with special needs and their families (Fergusson, 2001). However, reviewing the history of professional responses to the birth of children with special needs, until recently, the patterns of research and practice still assumed that the special needs itself inevitably overwhelmed all other considerations. Unfortunately, the direction of the logic shifted, but the supposedly tragic connotation of such births were consistently presented as inherent and absolute (Fergusson, 2002). More recently, parental narratives challenge the interpretations of the literature assuming causal connection between ‘disabled child’ and ‘damaged family’. This brought to the awareness that the assumptions of inherency of family responses to a
child with disability need to be reconsidered (Krauss, 1993). Together with the growing knowledge of the influences of the social and historical forces on human responses, there is a greater need than ever to capture a full range of details of daily life and family history when studying families with children with special needs (Fergusson, 2002). Nevertheless, this interpretational orientation is still the least common approach among the family researchers (Fergusson, 2002).

This research aims to employ an interpretive approach by extending narrative accounts from parents and relevant associates. The stories that pack all of that history and culture into a shared family narrative will be collected and analyzed in hoping that from the elaboration of the stories, I will be able to rediscover the rich body of information available in the stories that these parents tell about their experiences. These stories are not only the description of the participants’ past experience but also the currently living experience. This is because through identifying the stories these parents choose to remember and the way they convey these stories serve to clarify their current circumstances or state of cognition (Engel, 1993). In other words, the narratives these families have of their own lives enabled them to construe what they are and where they are headed (Polkinghorne, 1988).

Throughout the presentation of this dissertation, I will insert my personal experiences during the process of carrying out this research. Entering the field as a narrative inquirer, it would be impossible for me to be a disembodied recorder of my participants’ experience (Clandinin & Connelly, 2000). My physical presence would no doubt create interactive events between myself and my participants, therefore the effects of my presence will be considered when interpreting the research data. My participation in the interactions has given me an experience; this entails the experiences of my participants, which I set out to explore (Clandinin & Connelly, 2000). It is important to understand that the lives of my participants did not begin the day they met me nor did they end when I terminated this research. Furthermore, as a person, I entered the field in the midst of
living my own story, so did my participants. The interactions between me and my participants during this research were a nested set of my stories and my participants’ stories. “Doing narrative is a form of living” (Clandinin & Connelly, 2000, p. 80). As we will see later in Chapter Four, my individuality has influenced the responses, reactions and perceptions of these parents.

"Re-searching" My "Chineseness": The Implanted Attitude and Conceptualization of the Meaning of Education in Me as a Chinese Student

One of the challenges of qualitative research is to determine what an experience means for the person who had the experience and be able to provide a comprehensive description of it (Moustakas, 1994). In my case, this challenge does not only apply to my participants but even more to me, as I am a member of the Chinese community. Consequently, revealing my discourse as a Chinese person turns out to be one of the key elements of this qualitative study.

My previous ‘cognitive dissonance’ described earlier in this chapter led me to explore my attitude towards learning, which later helped me to understand my research process and my participants’ perception better. Shifting from viewing the completion of this piece of work to meet the academic requirement to making it a life experience for me, I vividly intuited the realism of my “Chineseness”. As a child, I was taught to live according to parental or collective expectations. It is common in my community to have no hobbies except studying. And this, we considered as diligent and hardworking.

It has been well documented that most Chinese live in a very academically oriented community. Parents have high expectations of their children’s academic performance and give priority to academic achievement (Bond, 1996). Everything a child learns, including hobbies like music and art, is assessed on achievement rather than enjoyment (Wong, 2002). Learning in Chinese tradition is rarely thought of as a fun activity but rather as a
disciplined activity that presents challenges and difficulties, even an ‘ordeal’ for developing one’s character (Chao, 1996; Lee, 1996; Li, 2001; Mencius, 1970).

The European view of learning is as the process by which individuals’ minds acquire what is out there in the community. Consequently, motivational factors such as interest, curiosity, willingness and commitment are part of the internal make-up that serves to facilitate the learning process (Li, 2002). In contrast, the Chinese regard knowledge as something that is indispensable to their personal life. Knowledge includes not only the externally existing body but also social and moral knowing. Chinese beliefs on the characteristics of learning therefore are to be diligent, to remain humble, endure hardship, perseverance and concentration (Lee, 1996; Li, 2002; Tu 1979). Some researchers have critiqued Chinese school pedagogy as being teacher centered and stifling of creativity (Gardner, 1989a; Ouyang, 2000).

For over 2000 years, Chinese attitudes towards education were strongly influenced by Confucian philosophy. This philosophy placed the scholar in a position of prominence and prestige (Chen, 2001; Barringer, Gardner & Levin, 1993; Wong, 1980). In the ancient Chinese society, learning is regarded as the only pathway toward the highest goal of life: self perfection. According to an old proverb, "The worth of other pursuits is small, the study of books excels them all". Consequently, education was considered an important route to success. The seeking of self perfection and contribution to society are related to the ideas of social status, because learning is seen not only as an individual process but also as a social process (Lee, 1996; Li, 2002; Tu, 1979; Yu, 1996). Chinese achieve high levels of education because they may perceive that education is objectively measurable and valued in certain careers and that they may face disadvantages in pursuing careers that do not depend on educational achievement (Xie & Goyette, 2003). Similarly, Chinese consciously plan and pursue educational paths that yield high financial and social returns (Xie & Goyette, 2003). Ho
(1962) clearly shows that education facilitated upward mobility for those from poor family origins in pre-modern China. Consequently, the purpose of obtaining education is because of expectations, not because of aspiration.

The cultural position suggests that Chinese value education for its intrinsic value; however, the strategic adaptation perspective asserts that Chinese value education primarily for its instrumental value (Xie & Goyette, 2003). That is, the strategic adaptation perspective predicts that Chinese consciously attain education as a way to achieve high status rather than because they value education for its own sake (Xie & Goyette, 2003). The cultural explanation implies that Chinese primarily value high levels of educational attainment with no obvious preferences for majors. After all, the cultural perspective emphasizes the symbolic meaning of educational attainment as a virtue to oneself and an honor to one’s family and community (Bourne, 1975; Endo, 1980; Hsia, 1988). Thus, the more education the better, regardless of the subject.

Therefore, Chinese immigrants bring their cultural strategies and adapt them into the new society, using family resources to facilitate their children’s movement up educational ladders. Consequently, Chinese students place great emphasis on education not just because some of their parents have resources or value education, but because they have been socialized to think that academic achievement is the surest way to improve the family’s lifestyle (Xie & Goyette, 2003). In this way, education serves as a channel to higher social status and better lifestyle to the Chinese. It is neither just a means of learning nor purely attained for the sake of acquiring knowledge.
CHAPTER TWO

Literature Review

The Emergence of the Research Idea

The planted seed: Experience in a community with no inclusion concept (1979-1997)

One afternoon fifteen years ago, I was at my nanny’s shop in the busiest mall in the city, watching and observing the crowd coming and going. I saw a blind man walking with a stick leading four children and a woman who were all lining up one after another behind him. Surprisingly, all of them were blind. I recalled vividly when I asked my granny: “Why are they all blind?” My granny said to me in a soft voice, “The blind men in the blind home on the Blind Road could only marry the blind women who lived in there too and sometimes they have blind children. They are out today because today is a special day.”

The Blind Road was well known in my city. Everyone knew that was where the people with handicaps were institutionalized. That was ‘their area’, where they ‘belong to’ and ‘the only place’ you can see them. The institutions along the Blind Road opened once a year for fund raising. That was the day ‘we do our charity works’ because we as the more fortunate ‘should help’ the less fortunate.

As a child, I had many questions about people with special needs that I never dared to ask openly to the adults around me. To me and to the community, people who have special needs inspired fear and revulsion. As a young child, I learnt to recoil from visible differences, albeit by indirection. That was why I learnt that special needs, more so for intellectual and mental health disorders, were not only
bad, but were literally unspeakable. However, my curiosity in knowing how such people live their lives never left me.

Traditional and spiritual beliefs.
The feeling of fear of forthcoming disasters is still a common reaction nowadays especially among those who practise polytheism, the traditional religion (民間信仰 min jian xin yang), which is most common among Chinese. From many Chinese’ points of view, special needs are associated with the judgment of their gods or spirits with supernatural powers (Chan, 1992). In records dating back to ancient times when the society was scattered into distant small communities mostly dependant on the natural resources for daily provision, the births of children with congenital impairments were used to predict future events for the community. The manifestation of disability was viewed as a means of communication from the supernatural ones (Warkany, 1959). This is why people with special needs often bring on feelings of fear to Chinese. Many parents may blame themselves for somehow offending the spirits and causing the disability through violating some taboos. The widespread taboos for Chinese pregnant women that I have heard from the elderly women in my community include knitting, moving furniture in the room, attending a funeral, attending a wedding, looking at ugly animals, commenting on others’ imperfections and so on. In this concept, traditional beliefs, spiritual beliefs or rituals, and religion play important roles in shaping the meaning of disability for the family (Lowenthal, 1996). Many modern Chinese pregnant women still adhere to these taboos.

Buddhism is the second most common religion among the Chinese community. One of the fundamental believes of Buddhists is '因果報應 yin guo bao ying', which means, you receive what you have accumulated in your past lives. Buddhists believe every happening in one’s present life is dependant on the karma one has collected in the past life. Good karma could be collected through showing kindness to another life including animals,
whereas bad karma is through evil doings. Therefore, the birth of a child with ‘defects’ is seen as the punishment for the transgressions of the parents or the ancestors in the previous life and that the family is under a curse (Chan, 1992). Consequently, feelings of shame and guilt are intense.

There are several other ideas that blend together to form the conception of disability. These include the individual tragedy model and the charity model (Cahill, 1991; Sullivan, 1991). These models are particularly common within Chinese society as they are aligned with traditional moral values. People with special needs are treated as less fortunate ones as though some tragedy has befallen them and that they are unable to survive without the assistance of the able-bodied population (Brightman, 1985). This comes from the concept of benevolence in Confucianism, where showing kindness to the “less fortunate” ones is perceived as something a righteous person should pursue. Consequently, Chinese society recognizes a charitable obligation to people with special needs. In this view, a caring and embracing attitude is encouraged which is different from the feelings that are aroused from the belief that illness is inflicted by an angry supernatural power (Rosen, 1968). These paradoxical ideas reflect the competing ideas towards disability in many Chinese people. Overall, the combination of the feelings of fear and the obligation to show charity resulted in the set up of a societal policy to institutionalised people with special needs.

Ideas about disability became more multifaceted when some of the Chinese community were exposed to the concepts of Christianity. The changing emphasis from legalism in the Old Testament to grace in the New Testament has a significant impact on attitudes towards disability. Documentation of the treatment and life experiences of people with impairment in the Old Testament that influenced the community's conduct is found in Leviticus 19:14, "Thou shalt not curse the deaf nor put a stumbling block before the blind, nor maketh the blind to wonder out of the path" and Deuteronomy 15:11, "there will always be poor people in the land. Therefore, I command you to be open-handed towards your brothers and toward the poor and the needy in your land." The Old Testament
exhorted society to be generous and kind towards individuals with impairments, while also warning that impairment was a mark of God's wrath (Deuteronomy 28:15, 28-29). Shifting from a legalism perspective, writings from the New Testament suggest a paradoxical attitude. The records of a few events offer insights into attitudes towards disability shortly after the time of Christ. Mark records Jesus' healing of a blind man by spitting and laying hands on the man's eyes (Mark 8:22-26). Matthew records Jesus healing of a man with paralysis (Matthew 8:5-13). The healing of Jesus Christ came also upon people with leprosy, epilepsy, mental illness, deafness and so on (Black, 1996). One remarkable event was when the disciples asked Jesus whether it was the blind man's sin or his parents' sin that caused the man's blindness, Jesus replied that it was neither, and he said: "this happened so that the work of God might be displayed in his life" (John 9:3, Black, 1996). This opened a whole new perspective to disability where the value of the individual is upheld.

Perceptions of special needs are intertwined with religious or spiritual beliefs that are generally hard to change. Nevertheless, Groce & Zola (1993) explained that 'traditional belief systems about disability have at times to be quite adaptive, shifting in response to social, economic and educational experiences gained through the acculturation process'"(p. 1054). The extent to which a family holds on to the traditional beliefs is correlated with the level of acculturation and education. According to Zhang & Bennett (2001), generally, the more acculturated or educated families may rely more on the scientific knowledge for the diagnosis and intervention. Nevertheless, traces of traditional beliefs are rooted in each family's daily practice (Zhang & Bennett, 2001). Families may go back to the traditional practices when there is no other source of information on the condition or when the modern approach does not bring a positive outcome (Zhang & Bennett, 2001).

The societal concept of productivity may contribute to the definition of disability within a culture. For example, disabilities related to cognition may carry more stigmas in many cultures including the developed countries, whereas physical impairment is viewed more
negatively in the countries that rely heavily on labour work (Zhang & Bennett, 2001). Compared to Europeans, Chinese have been reported to view moderate to severe disabilities with considerable stigma (Chan, 1992) and are particularly negative in their attitudes toward people with mental disorders (Au, 2002; Cham, Lam, Wong, Leung & Fang, 1988; Chen, Brodwin, Cardoso & Chan, 2002). Having a family member with an intellectual disability or mental disorder is shameful for many Chinese. These phenomena cannot be understood in isolation from the cultural values in which they are rooted; and the cultural values cannot be understood in isolation from the philosophy that it defines and is part of. In the view of social constructionism, no one outward practice makes the culture; no phenomena alone, independent of social context, can occur. In addition, the construction of cultural values is the product of inspiration from the thinking of the philosophers as well as the stimulus from the social background. I feel it is important to outline the relevant social history and Chinese philosophy so that the arguments and findings of this dissertation can be understood within this social historical context.

**Chinese socialization**

Before proceeding any further, I would like to clarify that I am referring to Chinese culture in general here. It is important to emphasize the fact that there is no single, unique Chinese culture since the 19th century when China was opened to outside influence and immigration. Chinese immigrants began to adopt the local cultures into their Chinese values. Consequently, there are many distinctive yet similar sub-cultures within the Chinese population depending on geographical location (Chu, Cheung and Tan, 2001). The characteristics of the sub-cultures will become evident throughout this dissertation as I was fortunate to talk to participants from five different countries. To provide an overview, however, I will focus on the ‘traditional’ Chinese values within which all these sub-cultures are rooted.
Confucius is recognized as being one of the most influential figures in Chinese ideology (Au, 2002; Holroyd, 2003). His contribution to the ethics or moral values in shaping the Chinese culture is undeniable, practically shaping the moral values of the Chinese through his thought and life message. All this thought has seeped into the minds of the Chinese both consciously and sub-consciously (for example, filial piety and proper behaviour), affecting the way they carry out their day-to-day basic responsibilities. Thus, any attempt to understand the Chinese culture would best start with considering the thinking of Confucius, which is recorded in the Analects, the most well known Chinese literature.

Confucian thinking is that in order for a person to be truly human, they have to have 禮 li (ritual) and 仁 ren (benevolence), where 禮 li is ‘imposed on man from outside and 仁 ren is the true human nature which comes from within (Feng, 1953). According to Feng (1953), for Confucius, 禮 li functions as the ‘polisher for the real personality’ of a person in order for that person to become a ‘true human’, or a ‘noble person’. Only through the acquisition of 禮 li can one possess a harmonious relationship with other people in a society and within one’s own family. Therefore, 禮 li (or in the context of this discussion, to behave properly) is the basic requirement for the virtue of a person.

How do Chinese connect 禮 li in their daily living? In the Analects, Confucius said, "恭而無禮則勞，慎而無禮則葸，勇而無禮則亂，直而無禮則绞--Respectfulness uncontrolled by the rules of propriety (禮 li) becomes laboured effort, caution uncontrolled becomes timidity, boldness uncontrolled becomes insubordination and uprightness uncontrolled becomes rudeness (Analects 8:2, trans. 1979). Confucius argued

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2 Analects is a collection of sayings, brief discussions, and observations by and about Confucius, his disciples and his contemporaries. It includes Confucius' teachings on moral living, insights into the human nature and social and political relations.
that only through practicing 禮 li, could one’s conduct be regulated by a socially acceptable norm of behaviour.

Confucius’ teaching of 禮 li is the authentic core thinking of Confucianism (Fingarette, 1972). According to Fingarette, this aspect of teaching has been ignored and neglected for centuries by the Westerners in understanding family dynamics and parenting. The major reason that it has been overlooked is that Westerners tend to emphasize the psychological development of an individual. In this view, the elements of obedience and submissiveness, which are the most fundamental way children practice 禮 li, is not important as 禮 li has nothing to do with the psychological development of an individual.

Confucius said, “不學禮, 無以立--If you do not study the rituals, you will find yourself at a loss how to take your stand” (Analects 16:13, trans. 1938). And, “不知禮, 無以立地--He who does not know the rites cannot take his stand” (Analects 20:3, trans. 1938). Without practicing 禮 li, a person cannot take his stand in all areas in life, where practical, moral and social decisions had to be taken.

In ancient China, ‘religious’ and ‘secular’ activities are inextricably mingled with each other in almost all aspects of daily living and there is no clear line between the dead and the living. Since religious observances can cover such a wide scope (from basic day-to-day living to ancestral worshipping), it is not surprising. The word 禮 li on the most concrete level refers to ‘all those objective’ prescriptions of behaviour, whether involving rite, ceremony, manners, or general deportment, that bind human beings and spirit together in networks of interacting roles within the family, within human society, and with the numinous realm beyond (Schwartz, 1985). Schwartz sees 禮 li in terms of hierarchy and authority. He believes that 禮 li binds together the sociopolitical order of a
society and through 禮 li human beings can perform their roles well in different social contexts.

禮 Li has reinforced the proper networks of hierarchy and authority in Chinese society. According to Confucius, hierarchy and authority are the necessary bases of social order in any type of polity extend over wide territories, and the family is inevitably the foundation of the hierarchy. It is within the family life that 礼 li can be taught and practiced. In a family,礼 li involves proper behaviour of father to son, husband to wife, elder siblings to younger siblings and vice versa. Within the family, it also requires the father to be the living source of authority and power (Schwartz, 1985). Through the practice of 礼 li in the family, the circles of practicing extends to the wider context as all the members of the family interact with the outsiders in all aspects of life, whether in the government services or schools. Although 礼 li is usually translated as ‘ceremonial’, ‘ritual’ or ‘the rules of propriety’, these translations do not fully convey the sense of the Chinese word. The word 礼 li in the earliest Chinese language means “sacrifice”. It actually still retains something of this sense today (Creel, 1949).

*Traditional Chinese education and special needs.*
The traditional values of the Chinese education system have meant that children with special education needs have not been seen as a priority and in many cases have not been recognized as being the responsibility of the system at all. For centuries, there was a strong emphasis on achievement, with only the most able being given any sort of formal education (Ashman, 1995). Yu (1993) has made a similar point about early intervention, which has been recognized as essential in meeting special needs in the Western society for many years, in rhetoric if not always in practice, but which has not been seen as a priority in Chinese society.
The Chinese education system was extremely hierarchical, with a deliberate emphasis on tradition which made any form of change in management very difficult, and also offered no education at all to those with even very mild special needs (Gardner, 1989b).

Some of the traditional ideas about education prevailed even after many revolutions in the education system. One of these is that the purpose of education is to serve the good of society at large, rather than to encourage individual development and promote individual rights (Teng, 1994). This has major implications for the life prospects of children with special needs because it instigated a policy that scarce educational resources should go to the people and institutions that will most likely bring significant contribution to the society rather than to those whose needs are the greatest (Xu, 1993). For example, when Merry and Zhao (1998) compared the management decisions about selection of pupils in the special education system in England and Mainland China, they reported finding significant differences. In England, those who need resources the most are prioritized whereas in China, exactly the opposite maybe true. The special schools in China design rigorous assessments procedures in order to select only those who are most likely to be integrated into society eventually (Merry & Zhao, 1998).

In terms of curriculum, the Chinese education system places great emphasis on moral education, even in the special schools. The moral education includes strong elements of good social behaviour as well as 'political correctness' (Merry & Zhao, 1998). The other characteristic is that classes are much bigger and teachers are expected to keep the whole class together with an emphasis on the collective good, and to use the togetherness of the whole class as the way to help as many individuals as possible to learn alongside their peers (Reynolds, 1996).
Watering the Seed: Revolution from Experience in a New Society (1997-2001)

When I first arrived in Christchurch seven years ago, there were a few things that surprised me, and one of them was the number of people with special needs I saw in public. I naively asked myself, “Why is the population of people with special needs in this place numerous compared to my country of origin?” I soon realized it was not because there weren’t as many people with special needs in my country but it was because this group of people was ‘hidden’ from the community.

Together with my interest in education and children, I have had many opportunities to learn about disabilities within the New Zealand context throughout my undergraduate years.

There is evidence that in developed countries, attitudes towards people with disabilities are becoming less negative (Abberley, 2002; Chen, Brodwin, Cardoso & Chan, 2002). The study by Gething (1986) in Australia indicated that community attitudes have become more accepting and that as a result of such changes people are more willing to identify themselves as having special needs (Australian Bureau of Statistics, 1989). In New Zealand, the social inclusion of people with special needs is greatly emphasized. This societal attitude has a close association with the emergence of the “people with disability’s movement” and the development in academia of disability studies in Britain and the United States (Barnes, Oliver & Barton, 2002).

Prior to the development of the social construction ideology, the connotation of disability, at one level, became beguilingly blatant, that is, not able to do something. In the 1970s, social scientists working within the growing fields of social medicine, social policy and rehabilitation began to make a contribution to researching the social aspects of chronic illness and disability relating to injury. Due to the necessity of working out the prevalence of disability for the research, the lack of clarity of the definition of disability
was acknowledged. Hence the implication of terms such as impairment, disability and handicap was challenged (Williams, 2001). Meanwhile, in the American community, people with special needs began to resist their relegation to residential institutions, their exclusion from the labour market and the opportunity to earn a living wage, and their enforced poverty.

The medical model faced challenges when disability activists presented the fact that throughout human history, disability was not constituted as a social category prior to the eighteenth century, even though impairment was no doubt quite prevalent in the general population (Davis, 2000). The medical model that enlightens the previously dominant approaches to disability takes the presumed biological reality of impairment as its elementary preliminary point. This biological reality is taken for all forms of illness and impairment, whether “mental” or “physical” (William, 2001). In relation to the rehabilitation of people with special needs, the analysis and intervention have been focused on the functional limitations of an individual and the effects of these on activities of daily living (Marks, 1997). Following this belief, the impact on the view of disability which is still recognizable today is: disability is 'individualised' as an individual problem that someone has to cope with (Sullivan, 1991, p. 259). It was then realised that underlying the conceptualisation of disability, there are two preconditioned assumptions: (i) behaviour which deviates in a negative direction from normal is abnormal; (ii) this behaviour needs to be normalised through cure or changes (Reger, 1972, p. 9).

It was true that supporters of the medical model could highlight the improvements in peoples’ health that have emerged from medicine, and people with special needs acknowledged that medical intervention has been useful in terms of recuperating the biological functioning for some. Nonetheless, the problem is the degree to which a medical approach has been presumptuous other areas (Oliver, 1990). The impact of the medical model is that it holds the belief that every individual with special needs requires professional intervention of some kind and is unable to cope without assistance of the
medical world (Summers, 1998). People are viewed in terms of their problems or deficits. They are seen as though their impairment defines who they are. This has been identified as a major factor that contributed to the discrimination and disempowerment of people with special needs (Cahill, 1991).

These political controversies further pushed the birth of radical new ideas about disability. Social constructionism became an important theoretical backdrop for critical theories of disability because it confronts and problematises the essentialist assumptions about the natural body and the able mind (Marks, 1999). Through its cross-cultural and historical sensitivity, social constructionism shows that contemporary assumptions about a specific impairment are not universally applicable. It explains how the limitations of a specific impairment disappear in some cultures when the society accommodates different functioning of the individuals. In this view, it stresses that we should not focus on people with disabilities in abstract but rather on the way in which the labels and limitations are produced and reproduced in social interactions within institutional and cultural contexts (Marks, 1999; Priestley, 2003; Thomas, 2002). This argument leads to discriminating the meaning between disability and impairment, where disability is seen to only exist as it is situated within the larger social context, while impairment is a biological condition. In other words, impairment is a physical fact, but a disability is a social construction (Davis, 2000; Marks, 1999; Williams, 2001). Disability only exists at the intersection between specific demands of a given impairment, society's interpretation of that impairment, and the large political and economic context of disability (Braddock & Parish, 2001).

A major political movement began when disability study activists and writers in Britain declared that the inability of people with impairments to undertake social activities is a consequence of the creation of barriers by the non-disabled majority. These barriers, whether physical or attitudinal, limit the lives of the people with impairment (Oliver, 1996; Barton & Oliver, 1997; Mercer, 2002). In this view, the term 'disability' refers to a kind of social oppression, and 'disablism' entered the vocabulary alongside other
discriminatory practices such as sexism and racism (Thomas, 2002). Consequently, the society began to pay attention to policy and planning to promote the integration of people with special needs into the mainstream community. In New Zealand, the impact of the change of the disability paradigm is evident in the public services and social attitude towards people with special needs, as well as in the education system (Ballard & McDonald, 1999; Donald Beasley Institute, 1997). Inclusion and exclusion experiences of people with disabilities in the New Zealand education system was to a great extent discussed throughout my undergraduate courses.

The social theory has been criticized for ignoring the individuality of the experience of people with special needs due to other socio-cultural factors such as ethnicity, gender, age and socioeconomic status. People with disabilities may characterize themselves as one group within a highly diverse social structure (Barnes, 1997; Marks, 1999). Therefore, since the 1990s there has been an expansion in debate, research and writing that focuses on the way the experience of disability intersects with the experience of membership of other social divisions (Morris, 1996; Shakespeare, 1996). The emphasis of diversity and studies on individuals created a shift in the research paradigm from the quantitative study to qualitative study methodology, which acknowledges the standpoint or social and historical context of the participants, allowing the participants to speak 'in their own voices' and hence acknowledges the individuality (Brown, 2001). The qualitative research paradigm gives people with disability a voice in the research in ways that are not exploitative and that meet with their wishes (Lincoln & Denzin, 1994). Based on this ideology, I have decided to employ a qualitative methodology for this research.


Carrying with me my previous conceptualization about special needs, I found many of the theories and approaches refreshing, motivating, challenging and sometimes contradictory to my former beliefs about disability. While walking in
the process of deconstruction, construction and reconstruction of my personal conceptualization of disability, I also developed the interest in finding out whether the intervention approaches and services provided by the welfare system in New Zealand serve the Chinese immigrants, who very possibly hold the same conflicting beliefs as I had. This growing interest brought about the emergence of this research topic.

Research findings indicated that family members' attitudes, expectations and encouragement influenced the effectiveness of early intervention for children with special needs. In New Zealand, the early intervention programs are based on the professional knowledge derived from European/American beliefs about parents' socialisation goals for their children, and their expectations concerning the skills to be encouraged in early intervention programs. European/American parents desire their children with special needs to develop skills in the domains of emotional-affective areas and skills related to Autonomy, Integrity, Independence and Pre-Academic behaviour (Beena, 2000).

Another assumption in this profession is the concept of "people first and disability second" where the families are more optimistic about achieving a 'satisfactory outcome' and do not underestimate the quality of life of people with disabilities (Batshaw & Cho, 1997). In addition, European/American society emphasizes human rights and individual differences, hence family members tend to see their children as independent individuals and are more open in working with professionals for their needs (Conway, 1991). With my bicultural background, I would expect the attitudes towards disability and expectations of early intervention outcomes in Chinese families to be very different from those of European/American cultural background.
Chinese parenting practices.

Cultural beliefs have been found to impact on behaviour by affecting life viewpoints and goals (Strauss, 1992). Parenting is one area in which cultural influences are apparent and research suggests that significant qualitative differences in parenting styles exist (Chao, 1994; Chiu, 1987). Therefore, parenting values and beliefs is an essential area of inquiry regarding Chinese perceptions of children’s special needs.

One difference between Chinese parenting and the ‘Western’ parenting discussed in the previous literature is that Chinese parents tend to emphasize their children’s relationships with others rather than their children’s psychological attributes (Shek & Chan 1999; Wong, 2002). This orientation is different from the Western view where individuality and personality traits are stressed (Chao, 1995; Chu, 2002). Ho and Kang (1984), based on the intergenerational comparisons of child-rearing attitudes and practices in Chinese societies, found that pre-academic content skills, competence, and achievement were the most important personal characteristics expected of the child. Attributes such as acceptance, autonomy, independence, purpose in life and self-esteem which are central to the developmental tasks for human development as seen in the Western cultures were seldom mentioned by Chinese parents (Ho, 1994). Another well presented trait of Chinese parenting is the focus on parental respect and obedience (Chao, 1995; Ho, 1989). Chinese parents tend to place more emphasis on the family related and academic related attributes than non-Chinese parents do (Chu, 2002; Shek & Chan, 1999).

Many researchers have discussed Chinese parenting in relation to Baumrind’s (1968) conceptualization of authoritarian, authoritative and permissive parenting styles. According to Baumrind (1968),

...an authoritarian parent attempts to shape, control and evaluate the behaviour and attitudes of the child in accordance with a set standard of conduct...she

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values obedience as a virtue and favors punitive, forceful measures to curb self-will at points where child’s actions or beliefs conflict with what she thinks is right conduct (p. 261).

In contrast, an authoritative parent

...directs the child’s activities...in a rational, issue-oriented manner...[and] encourages verbal give and take”, while a permissive parent “allows the child to regulate his own activities as much as possible...and does not encourage him to obey externally-defined standards (p. 261).

Among the literature, Chinese parenting has been commonly described as strict and controlling, meeting the characteristics of the ‘authoritarian’ parenting style as defined above (Chao, 1994; Kelly & Tseng, Chiu, 1987). Chinese parents seldom use praise (Wong, 2002), which is one of the most important parenting strategies the ‘European/Western’ parents practice and is one of the most common elements of behavioural intervention (Church, 1999).

Furthermore, authoritative parenting has been associated with positive developmental outcomes, whereas, authoritarian parenting has been shown to correlate with mixed consequences for child development and functioning, such as psychological health and academic functioning and motivation generally (Chen, Dong & Zhou, 1997; Chen, Liu & Li, 2000; Steinberg, Lamborn, Darling, Mount & Dornbusch, 1994; Maccoby & Martin, 1983).

Nevertheless, the authoritarian parenting style of the Chinese is not associated with poor academic achievement outcomes, rather a high level of success has been found. This
contradicting phenomenon raises doubts on the appropriateness of applying Baumrind’s parenting model (1968) to diverse groups. This is a particularly important issue for Chinese parents living in New Zealand because currently many intervention approaches are developed with the underlying assumptions that authoritative parenting is the best parenting practice. And, most practitioners hold strongly to the principles of authoritative parenting which form the basis of implementing behaviour interventions for children with special needs, including the Chinese children. One example of the conflicting parenting values between Chinese parents and the local community is the use of physical punishment. Some Chinese parents would find using cane sticks as a tool to set limits and boundaries for their children very effective. While to the local society, using cane sticks for punishment is often related to physical abuse; for Chinese parents, it is for the sake of the children’s safety and learning, hence out of love, that they use it.

In a study of Chinese parenting, Chao (1994) suggested that the concept of authoritarian parenting may be ethnocentric and, consequently, does not accurately depict Chinese parenting. She explained that the Chinese concept of parenting is not as much ‘control’ as ‘training’ (教訓 jiao xun and 管 guan). The essence of the Chinese concept of ‘教訓 jiao xun’ and ‘管 guan’ is the use of a standard of conduct out of parental care and concern for their children’s well-being and successful adjustment (Chao, 1994). It reflects the Confucian belief in strict discipline, respect for elders and socially desirable behaviour, taught by parents who are concerned and involved in the lives of their children (Chao, 1994).

Huntsinger, Jose & Larson (1998) reported that Chinese parents are more directive in teaching and scheduling their children’s time, beginning in early childhood, as a way of fostering self-control and high achievement. According to their findings, Chinese children exceed their Caucasian American age mates by nearly tenfold in the daily time spent in focused practice on task (usually math, music or drawing). In addition, the
Chinese parents indicated that they were more likely to set aside daily periods for such practice and taught their children in more formal ways (Huntsinger, Jose & Larson, 1998).

Gorman (1998) conducted a qualitative study and found that Chinese parents have more strict expectations for their children that could be seen as rules or guidelines for behaviour. They perceived the rules for behaviour serving as a protective function for their children from the “negative impact of the Western society”. It is evident that the motivation behind the seemingly strict child rearing practices of the immigrant Chinese are due to their concerns for their children’s welfare, which is more in tune with the notion of ‘training’ (教訓 jiao xun and 管 guan) than the generally identified authoritarian parenting.

But again, these general traits should not be applied to every Chinese parent because there are differences in parenting indicated within subgroups of the Chinese (Berndt, Cheung, Lau, Hau & Lew, 1993).

**Individualistic versus collectivist.**

Chinese and Western cultures are often different in terms of the degree of interconnectedness among individuals. Kitayama, Markus and Matsumoto (1995) and Hsu (1981) distinguished between an emphasis in Western cultures on independence and an Asian emphasis on interdependence or mutual dependence, in which the self is conceived of primarily as part of a relationship. One of the characteristics of a culturally salient “social-orientation” personality is that a Chinese person can sacrifice his/her own interests and suppress his/her own desires to achieve and maintain harmonious relationships with other people (Yang, 1988). The siblings of an individual with special needs are often ready and expected to care for that individual for their whole life. Hence, independence or autonomy of the individual with special needs is not emphasized.
In the New Zealand community, individualism is highly emphasized. The community is taught to value the importance of ‘I’ consciousness, emotional independence, and individual initiative. Consequently, a greater breadth in the self-disclosure of distressing feelings is encouraged compared to highly collectivistic Asian societies. On the other hand, Chinese culture stresses “we” consciousness, collective identity, emotional independence, group decision making, ascribed duties and obligations, reciprocity, and the maintenance of social harmony (Gorman, 1998; Maiter & George, 2003; Markus & Kitayama, 1991). Therefore, self-disclosure of distressing information in Chinese families will be constrained by the need to ‘match’ disclosure behaviour with the social norms governing the interpersonal standards of the society. Chinese link clean genealogy line to social status hence discussion about disabilities is avoided. Chinese families with children with special needs might prefer to stay away from social workers and public services to maintain group harmony and ‘face saving’ (Ow & Katz, 1999). The saying of ‘家醜不可外揚 Jia Chou Bu Ke Wai Yang’ (The ugly issues within the family shall not be spread to outsiders) is very common among Chinese community.

It has long been argued that inability or unwillingness to openly express intense and negative emotions underlie many of the psychological and physical disorders that people develop (Perls, 1969; Derlega, Metts, Petronio & Margulis, 1993). Self disclosure or ‘talking it over with someone’ about intense negative emotions is the most frequently cited way of coping with stressful situations (Parker & Brown, 1982). This is one way of stepping out of one’s own frame of reference and gaining ‘insight’ to the emotions. Furthermore, distress disclosure is a means to instrumental, informational and motivational support (Ow & Katz, 1999). With this understanding, the practitioners would no doubt perceive the ability and/or willingness to express one’s feelings over a stressful event such as the birth of a child with special needs as something important for these parents. However, in the Chinese community, ‘face saving’ is a form of reciprocal affirmation, in which every effort is made to ensure all parties are mutually protected,
including other members of the extended family. Keeping the information within the family or an individual might be a means to self-regulate and to cope with the situation. Therefore, to keep the information secret and not disclose it sometimes functions as a protection of the families. As Chan (1967) explains the place of harmony (和气 he qi) to the Chinese people, “eternal principles are standards; with special situations require expedient measures”. To Chinese, it is standard to be forthright and honest, but in some cases, there are reasons to sacrifice honesty to preserve the greater value of family harmony. This is permissible as an expedient when small issues are involved, so long as the total human values are preserved (Chan, 1967). The ‘art’ of preserving harmony is hard to understand for the professionals who come from European/Western cultural backgrounds.

Filial piety.

While Confucius stresses 禮 li (propriety, rites) in the society, he lays emphasis on filial piety for the family. Filial piety is one of the paramount guiding ethics governing social behaviour in Chinese societies. Confucius also thinks that the way to enhance personal dignity and identity is not to alienate ourselves from the family but to cultivate our genuine feelings for our parents. The first test of self-cultivation is our ability to cultivate meaningful relationships with our family members (Tu, 1998). In order to fulfill the essential requirement of being filial, one needs to submit to 禮 li in serving one’s parents. Confucius believes that filial piety is a way of practicing 禮 li. Confucius says: “弟子, 入則孝, 出則悌, 謹而信, 汝愛眾--A youth should be filial at home and be respectful to his elders abroad, be earnest and truthful, love all people, and be intimate with men of humaneness” (Analects 1:6, trans. 1979).

Zeng Shen, who, among the disciples of Confucius, is always associated with filial piety, also asserts: “Of the services which is the greatest? Service to parents is the greatest” (Mencius, 4A: 19, trans. 1970). The meaning of this statement is not difficult to
understand: Only serving and honouring one’s parents is most important in one’s life; nothing else, be it loving all people with humaneness or learning for its own sake. None of these can surpass or take priority over serving one’s parents (Liu, 2001). Therefore, to behave properly at home and to respect one’s parent becomes especially important.

Mencius also indicates that: “The substance of humaneness consists of serving one’s parents, the substance of righteousness consists of obeying one’s elder brother, the substance of wisdom consists of knowing these two things and not departing from them, and the substance of propriety consists of regulating and adorning these two things” (Mencius 4A:27, trans. 1970). Ho (1994) helps us to understand this by explaining that filial piety goes far beyond the demand of simply obeying, extending to bringing honour and avoiding disgrace to the family name.

One way of relating this cultural value to this research topic is that Chinese parents who have children with special needs would often report feeling shame and guilt for bringing disgrace to the family ancestors because their children with special needs would be assumed to have a lower ability to contribute to the welfare of the society (Chen, Brodwin, Cardoso & Chan, 2002; Holroyd, 2003; Zhang & Bennette, 2001). Another way to look at this is how the parents would perceive their children with special needs in relation to their own roles in the families and hence their expectations of their children with special needs.

The conflicts between the cultural values and the professional practices in early intervention within the Chinese families who have children with special needs are likely to be substantial, although little is known on this topic. Research in understanding how these families adjust between these two discrepancies is essential to effectively address their needs. As a professionally trained child and family psychologist with bicultural background, I believe I have some responsibility to carry out this research. The findings
of this study can inform service providers, including teachers, parent coordinator, special education advisers, early intervention practitioners and other related professionals, about the current attitudes of Chinese parents toward their children with special needs. Most importantly, practitioners can expand their knowledge about how to facilitate family-school/service involvement with parents.

Before I embark the methodology consideration of this research, I would like to sketch the socio history and characteristics of the social context in which this research was carried out.

*The Research Context: New Zealand*

*The Chinese Immigrants Population*
From the 1980s to the 1990s, profound changes in the worldwide economy have encouraged a substantial movement of people between nations, especially from Asian countries to the European countries (Pang, 2002). The New Zealand government changed its immigration policy in 1986 to an 'open door' approach in order to encourage trade with those Asian countries where there has been a phenomenal economic growth (Burke, 1986; Chu, 2002; Pang, 2002). The new policy aimed to attract immigrants with professional skills and/or capital for investment (Bedford, Ho & Lidgard, 2001). Consequently, the contemporary immigrants came mainly from Asia, especially Chinese who are highly educated and have a high economic status (Pang, 2002). Like America and Canada, New Zealand has become one of the countries that is experiencing an unprecedented increase in the ethnic and cultural diversity of its population because of this movement (Chu, 2002; Ip, 1995; Rosenthal & Feldman, 1996). The growth of the Chinese population in New Zealand from 1986 to 2001 is about four-folds, from 26,616 to 105,057 (Chu, 2002; Ho, Au, Bedford & Cooper, 2003). Among the Chinese population, 53% of the recent immigrants were born in China, 18% were born in Taiwan and 14% were born in Hong Kong (Ho, Au, Bedford & Cooper, 2003).
Characteristics of the Chinese Immigrants

It is important to know that the main reasons for Chinese immigrants leaving their home country include political insecurity, over population and not having education opportunities for their children (Chu, 2002). In terms of religious affiliations, 50% of the Chinese population identify themselves as having no religion, 25% as Christians and nearly 14% as Buddhists in the 2001 statistical data (Ho, Au, Bedford & Cooper, 2003). About one in every four recent Chinese immigrants to New Zealand has no English or Maori proficiency (ibid). However, according to the 2001 statistical data, Chinese are twice as likely as all New Zealanders to have a university qualification. As mentioned before, this is associated with the selective immigration policy that favors skilled individuals with university qualifications. Nevertheless, even though the majority of the Chinese population has achieved higher education and qualifications, the unemployment rate is double that of the total New Zealand population (Thomson, 1999; Ho, Au, Bedford & Cooper, 2003). A significant number of Chinese immigrants have no current source of wages or salary income, but are living on savings, interest, or other sources (Friesen & Ip, 1997). Many of the immigrants, especially those who worked as professionals or had well paid jobs when they were in their country of origin, are reluctant to receive financial support from the New Zealand government (Friesen & Ip, 1997; Ho, Au, Bedford & Cooper, 2003; Lidgard, Ho, Chen, Goodwin & Bedford, 1998).

Ho et. al. (2003) reported that the Asian migrant women in New Zealand have experienced multiple challenges including the downward occupational mobility from their professional roles prior to migration, having to take responsibility for the whole family when their husbands return to their countries of origin to work and being isolated due to the language and cultural barriers.
CHAPTER THREE

Starting the Research: Methodological Considerations

There is already a substantial body of quantitative research on Chinese’ attitude towards special needs (for instance, Chan, 1992; Chen, Brodwin, Cardoso & Chan, 2002; Choi & Wynne, 2000; Fatimilehin & Nadirshaw, 1994). This existing literature has a great deal to tell us about the general reactions of Chinese families who have children with special needs, however, there have not been many studies that allow us to hear the what, how and why of the actual day-to-day decisions in bringing up children with special needs in their families. This study pursues a critical examination that goes beyond the traditional single-cause explanation, and aims to explore the sociocultural context and multiple meanings of these families, to depict how Chinese immigrant families living in New Zealand with children with special needs “do things on the basis of their beliefs and desires, striving for goals, meeting obstacles which they best or which best them” (Bruner, 1990, p. 43). A small scale, qualitative approach was seen to be appropriate for this research purpose because it allowed the members of the families to give detailed and personal accounts of some facets of their experiences. It sought their interpretations of experiences which, in some respects at least, reflect the circumstances and experiences of other Chinese families with children with special needs living in this city. The research methodology was facilitated by my ongoing understanding of qualitative research and my application of the social constructionist framework as portrayed in Chapter One.

This exploratory study sought to recruit a small group of Chinese families with children with special needs. To uncover the actual experience, the study was conducted within the accessible social context by the researcher. More specifically, it focused on the local Chinese community in Christchurch. In line with the ecological model, the families should not be seen as existing in a vacuum. In fact, in the view of social constructionists, their experiences are the product of their interactions with the wider community and
environment. Therefore, in this study the wider community of the city was also used for analysis purposes. In addition, I did not consider myself as entering the field as a blank slate, with no preconceived ideas or hypotheses. In this way, the interpretations of the phenomena take into account the subjectivities of the participants as well as mine as the researcher (Creswell, 2003; Taylor & Bogdan, 1998). The meanings and interpretations of my data were constructed through interactions which occurred between myself and the participants, the environment as well as the particular historical and cultural context (Burr, 1995; Denzin & Lincoln, 2000; Guba & Lincoln, 1994). The meaning of the data in this study lies in its specific cultural and personal interpretation of contextually grounded interview narrative data, including values, beliefs, wishes, intentions and feelings. Though the findings cannot be generalised as a guiding principle or a reasoned supposition that applies to every Chinese family with children with special needs living in New Zealand, it can serve as “a valuable lens through which to view the members’ shared thought processes” (Thomas, 2001, p. 4).

The emphasis of my research methodology was to maintain the flexibility and fluidity of the research process, to present the research process as inductive and to prioritise the voice of the participants. The main purpose is to understand what is actually happening among this community; therefore the flexibility of the methodology was very strongly emphasized. The direction of the study has been led by my discoveries made during the research process. I take all the discoveries along the journey as my research data but not just what I gathered during the interviews. In order to present my discussion within its context, my discussion will be integrated throughout every chapter of the dissertation but will not be presented as a separate chapter.

As a result of the ‘open ended’ methodology, this study evolved as four phases. I would like to outline the big picture before I fill in the details because I believe this would help to make sense of the phases.
With a qualitative methodology, multiple data collection methods including networking in the community, in-depth interviews, researcher’s journal and participant observations were employed to gain a rich depth of data and to ensure research trustworthiness. The unstructured interviews were designed to gain information on the parents’ cultural values, parenting attitudes, perception of their child’s special needs and so on. Seven families were included as the primary participants in this study, four from the Group One participant recruitment process and three from Group Two participant recruitment process. As I gradually practiced the alternative ways of thinking by paying “attention to dynamic process rather than static categories” (Gerson & Horowitz, 2002, p. 194), I started to see how this methodology enabled me to extract the richness of my data and helped me to better understand the phenomena I had witnessed throughout my study.

The four phases of the study:

Phase One: Surveying the relevance of this study: the contemporary issues among the professionals

Phase Two: Working on the connotation of special needs in Chinese language: the challenge of translating the advertisements

Phase Three: Group One participant recruitment: Targeting those outside the ‘service system’ using informal sources

Phase Four: Group Two participant recruitment: Targeting those already in the ‘service system’ through a special school

Definitions
In order to clarify the meaning of various terms I refer to throughout the study, a number of definitions need to be clarified at the outset. The “Chinese Immigrants” are defined as the families whose parents are first generation Chinese immigrants. Some of the children were born in New Zealand. The “Children” refers to the offspring of these first
generation Chinese immigrants who are younger than 18 years. The word “Family” includes the nuclear family as well as the extended family. The phrase “Special Needs” takes in all physical impairments as well as all the diagnoses that are listed under the Diagnostic and Statistical Manual of Mental Disorders IV (DSM IV), whether the condition is physically noticeable or not.

**Phase One**

Where I come from in terms of training has a very close association to the beginning of this research. As I have explained in Chapter Two, it was during my learning about the early intervention approaches in New Zealand that I started to question the appropriateness of these approaches in serving the Chinese families. A second reason for wanting to conduct this research came from the academic staff’s reaction when I talked to them about my intention to do the Child and Family Psychology Programme. This research idea was enthusiastically embraced by many of them. Many had commented on my Chinese background and multi-lingual assets. They also made comments about the importance for the service providers in New Zealand to be culturally appropriate. These comments further encouraged my interest in knowing what was happening out there. Nevertheless, my enthusiasm was distracted when my Chinese friends questioned the necessity of my research because they believed there were no first generation Chinese immigrant children with special needs because of the strictly selective immigration policy. It is harder for families to attain residency if they have children with special needs. After encountering the same responses from various Chinese associates, I began to doubt the relevance of my research topic in the New Zealand context.

One day in November 2002, I expressed my research ideas as well as my lack of confidence on the relevance of my research topic to my course co-ordinator. Like many academic staff, her response towards my research topic was entirely positive and
fascinated. Her reaction made me realised that there were contradicting views even just on the relevance of this research topic. This recognition led me to find out what the practitioners had to say about this topic, and what was actually happening out in the community.

This directed the beginning of phase one, which was to carry out a survey on the early intervention practitioners, investigating their responses towards this research. Four paediatricians and two nurses from two main hospitals in Christchurch and the managers of two well established local early intervention institutes were included in this survey. The survey was conducted through phone calls or e-mails. I approached every participant by introducing my research idea and explaining that my purpose of approaching them was to investigate the relevance of my research topic. The questions I asked each of them included:

1. Have you ever encountered Chinese children with special needs? If yes, how many and over how many years of practice?

2. What do you think about my research topic?

3. How was your experience working with Chinese families with children with special needs?

4. What specific issues about Chinese families with children with special needs would you like to know more about?

The findings of this survey will be discussed in the next chapter. In general, all practitioners commented on having a very limited number of Chinese children with special needs in their client lists. However, in their view, this research was not only relevant but it was actually necessary because almost every one of them had some queries from their previous experiences working with the Chinese parents with children with
special needs. Their responses confirmed the relevance of my research topic for me and prompted me to proceed with a research plan. Subsequently, I embarked on defining ethical considerations for carrying out this research.

**Ethical Considerations**

After the continuing consultations with my supervisors to refine my research area, I started to apply for ethical consent from the University of Canterbury Human Ethics Committee. The process of this application brought about a more precise working of my research process.

I was aware of the complexities of approaching these families due to the sensitivity of this issue within the Chinese community. I knew that there would be a possible intention to avoid ‘the academics/professionals’, and also that there is a low momentum in the Chinese culture to participate in research. Therefore, I discussed with great care my recruitment approach with my supervisors and a Chinese PhD student who had just completed a study on the general Chinese community in New Zealand.

I aimed to make my first contact as engaging as possible. Learning from the art of undertaking a qualitative research, I began by establishing what I have in common with these families (Taylor & Bogdan, 1998). Therefore, I would build a relationship with my participants as a member of the Chinese immigrant community. For those whom I took the initiative to ring, being humble was also important to me. This is because my participants could be offended if they feel that they have been ‘picked on’ because of their children’s condition. In addition, I wanted my participants to be able to express themselves without fear of disclosure or negative evaluation (Taylor & Bogdan, 1998). From all of these points, presenting the consent form and lengthy information sheet became inappropriate during my first contact with my participants. Therefore, I took a great deal of time working on designing the research into two phases. In Phase One, I
requested verbal consent to cover my ethical ground for engaging them in general conversation for the purpose of participating in this research. Only in Phase Two did I present the written consent form for carrying out in-depth interviews. My initial hypothesis was that my advertisements and notices would yield responses from both those who met and did not meet the special needs definition in this research. Hence I had to ‘sift’ the responses and would only follow through the appropriate participants into Phase Two. My other ethical standing ground was to not contact any participant unless I was given permission or only if they took the initiative to contact me. In addition, I would not ask personal questions in Phase One. Without needing to go through major revisions, my Human Ethics application was approved. Please refer to Appendix Two and Appendix Four for the consent form and the information sheet.

Problems encountered.
Firstly, consent issues arose when some of the participants rang and said that they would be very happy to share with me their experiences as long as they could remain unidentified even to me. These parents wanted to talk to me on phone but were not prepared to see me or for me to know their contact details. Consequently, I could only obtain verbal consent.

Secondly, many participants were uneasy about the formality of signing a written consent form and would prefer to base our relationship on trust.
Phase Two

The Connotation of Special Needs in Mandarin: Generating Chinese Words that Related to Special Needs

When I decided to commit myself to the profession of child psychology, I believed my attitude towards people with special needs had already undergone a change from what I used to believe. I thought I no longer have a negative reaction towards them but only see them as a person just like anyone else. However, today I discovered a hidden assumption within myself. I could not answer (my supervisor) when she asked me: “What kind of special needs are you referring to in your advertisements? Would you expect gifted children or children with a slightly different personality? That could be interpreted by the parents as having special needs too, right?”

To me, having ‘special need’ means when one is blind, deaf etc., all the ‘common handicaps’. I had never thought that individual differences could actually also be seen as special needs. Also, I never thought my short-sightedness is a kind of special need, just that spectacles became so common that the ‘label’ of this special need has been taken off.

(Journal Entry, 9 April 2003)

One of the objectives of my study was to approach the Chinese families who might be isolated from society due to a language barrier. Therefore, everything in this study was written in both English and Mandarin where necessary. Unaware of my preconceived assumptions about special needs, without any hesitation, I translated the term ‘special needs’ to a Mandarin phrase that means ‘handicap’, which carries a negative connotation. This hidden assumption was exposed when I was challenged by my supervisor as illustrated above.
Like the other three phases, different experiences occurred simultaneously during the second phase of my study. One of them is my increasing understanding of social constructionism and the importance of language as a means to understanding the perspective of my participants.

Many social constructionists challenge the view that a person cannot pre-date language because it is language which brings the person into being in the first place. As Burr (1996) puts it “language itself provides us with a way of structuring our experience of ourselves and the world, and that the concepts we use do not pre-date language but are made possible by it” (p. 33). This suggests that our experience of the world, and especially of our inner self is indistinguishable and indefinable without the framework of language to give it structure and meaning. Also, that when we represent our experiences to ourselves and to others, we can only do it through using the concepts embedded in our language. Hence, our thoughts and how we represent our behaviour are all ‘pre-packaged’ by language. In view of this, I also keep in mind that language is fundamentally a social phenomenon. This includes the language my participants use when responding to my research topic. It is important for me to clarify that the term language here means any kind of communication that occurs in any kind of interaction between people, whether verbal or non-verbal. Therefore, this is inclusive of those who are non-verbal.

In keeping with this realisation, I started to reflect on the alternative translations for the term ‘special needs’. Consequently, finding the appropriate Mandarin words that convey the meaning of special needs became the next focus of my study. To my amazement, there is no direct translation found in the Chinese language for the term ‘special needs’. In view of that, a research phase aiming to investigate the connotation of special needs using various terms in Mandarin was added to my recruitment process through my advertisements and notices. My purpose was to use the language as a tool in
understanding values and beliefs of the Chinese people in Christchurch. In my opinion, this understanding and knowledge is essential to developing more accurate research questions and measures in future.

To generate a list of special needs terms in Mandarin, I asked three native speakers to brainstorm common Mandarin words and phrases denoting aspects of special needs. This step resulted in an initial list of ten Mandarin terms conveying the different aspects of special needs. The ten terms are:

<table>
<thead>
<tr>
<th>Mandarin terms</th>
<th>Nearest English translation</th>
</tr>
</thead>
<tbody>
<tr>
<td>残障 can zhang</td>
<td>Handicap</td>
</tr>
<tr>
<td>特殊條件 te shu tiao jian</td>
<td>Special Condition</td>
</tr>
<tr>
<td>與眾不同 yu zhong bu tong</td>
<td>Different from majority</td>
</tr>
<tr>
<td>非一般 fei yi ban</td>
<td>Abnormal</td>
</tr>
<tr>
<td>不利條件 bu li tiao jian</td>
<td>Disadvantaged</td>
</tr>
<tr>
<td>障礙 Zhang ai</td>
<td>Impaired</td>
</tr>
<tr>
<td>不幸人士 bu xin ren shi</td>
<td>Less fortunate</td>
</tr>
<tr>
<td>弱者 ruo shi</td>
<td>The weaker</td>
</tr>
<tr>
<td>困難 kun nan</td>
<td>Difficult</td>
</tr>
<tr>
<td>非凡 fei fan</td>
<td>Uncommon</td>
</tr>
</tbody>
</table>

Table 1 Mandarin terms conveying different aspects of special need
Ten versions of the notices/advertisements using each of the listed Mandarin term above were printed, and posted in public areas such as churches, grocery shops and restaurants in different areas of the city. Notices using the terms 特殊條件 te shu tiao jian (special condition) and 與眾不同 yu zhong bu tong (different from majority) were advertised twice each in the local fortnightly Chinese newspaper over the period of two months from April to May 2003. For sample notices/advertisements please refer to Appendix One.

During this phase, as a result of working out the various definitions of the term ‘special needs’, I became more conscious of my assumptions regarding whether the potential participants would respond differently depending on how I introduced myself in the advertisements and notices. My assumption was that if I used my professional role, they would respond better because it has been reported in the literature that Chinese prefer to present their problems to the ‘expert’ and those who have more ‘power’ (Lin, 2002). My increasing awareness of this assumption excavated another underlying assumption that these families have ‘problems’. Coming back to my intention to reach those who were hiding away, or who had a different perception compared to the ‘problem focused’ view, I decided to present myself as a community member who wanted to understand and share their experiences. This approach suited my research purpose more appropriately as I aimed to understand their experience and tell their stories in their voices by minimising the impact of my own pre-conceptions.

**Reflection on the recruitment process.**

Although I was using different versions of the advertisements, it is unavoidable for the people to see more than one version of the advertisements, as the mobility of the community is high. This might have created a negative impact on their interest.
There are a few characteristics of the geographical context of this research that I think are essential for me to point out. First, Christchurch City is not the choice for the majority of Chinese immigrants. Compared to Auckland, Christchurch has a smaller population size, the lifestyle is less hectic and the residential area scattered not only in the city centre but along the outskirts of the city where the residents are quite distant from the crowd. These residents are not easily reached through my recruitment methods. The rural area around Christchurch city would be an ideal place for families who intentionally isolate themselves from the community.

**Phase Three**

The common social phenomenon for people with special needs in many Asian countries was that they were institutionalised or kept at home because of social stigma. Linking this experience to this study, my initial assumption was that there would be some Chinese families whose children with special needs were being kept at home and had never been acknowledged by the schools or public service systems. This assumption induced the hypothesis that there were two groups of participants I could approach: One consisted of those who were already in the social services system and the other who were concealed from the service system. I aimed to reach those who were concealed because I believed their perceptions could better reflect the gap between the families and the professionals.

Apart from advertisement and notices, I also started the pre-fieldwork (Taylor & Bogdan, 1998) personally by networking among the Christchurch society, both among the Chinese and the non-Chinese community. I also attended public Chinese occasions such as Chinese singing competitions, festivals, celebrations and traditional exhibitions. While this public approach was maintained throughout the whole recruitment period, I did not
only depend on this as the only source of recruitment because my assumption was that these children would be hidden from the public. For example, I have not seen the children who participated in my study in public but I have seen their parents. In fact, I have not seen any children with special needs so far at any such event. There is a possibility that they are kept at home.

At the same time, I started to gain access into private settings by checking with friends and through personal contacts to see if anyone knows any Chinese family with a child with special needs. My personal contact includes Chinese and non-Chinese people. My recruitment net multiplied as everyone in my personal social network spread by word of mouth through each of their social networks and so on. Word of mouth and mediators became the important means to recruit the first four of the seven families participating in this study. None of these families was from my immediate social network. The initial contact with these families was either that they chose to contact me with my contact details given through a mutual friend, or I was given permission by the families to contact them with their contact details passed to me through a mutual friend.

In all of the four families, only the mothers agreed to participate in the interviews. Among the four children with special needs, there were two teenage boys and two primary age boys. One of the boys was diagnosed with autism and another with visual impairment. Mothers of the other two boys chose not to provide the exact diagnoses however, both disclosed that their children’s special needs were physically noticeable. One of them was reported to have no mobility. As the recruitment process and their responses towards my approach for every participant was unique and interesting, I will present a more detailed account as part of my findings when I introduce my participants in the next chapter.
Phase Four

At this point, I had started my data collection with the first four families. My continuing networking and actively passing the message by word of mouth did not yield anymore participants for two months. Many had come back to me with suggestions but when I traced each of the later recommended families, it was always back to one of the four families I had already included. This could imply the population was exhausted. Nevertheless, as mentioned throughout this dissertation, I had encountered other Chinese families with children with special needs who were not participating in my research. My assumption is that some parents might be denying or perceiving differently the special needs of their children.

In the middle of August, I had an opportunity to visit a special school in Christchurch as part of my placement for the Child and Family Psychology Programme. With my ethnicity and different language proficiency, the school was very excited about my presence and asked if I could talk to their Asian students to find out what languages they speak or could understand because many of them showed little language development as far as the English speaking teachers knew. The school also expressed its difficulty in communicating with the families due to the language barrier. As a result, the speech and language profile had not been completed and the developmental assessment could not be fully administered for some of these children. When I greeted these students using Mandarin or Cantonese, to our amazement, some of the children with autism responded to me. For two of these children, that was the first time the teachers have seen them performing communication intention. Linking this phenomenon to the fact that the majority of the Chinese children in this school were diagnosed with autism, the diagnoses might need to be further investigated using the first language of these children. Another possible explanation for the high proportion of autism diagnosis among this group is because autism is not a well understood developmental disorder to most Chinese parents.
therefore they tend to seek help for rearing children with this particular type of special needs.

I later explained my research to the person in charge and she kindly agreed to write a notice to all the Chinese parents at their school, briefly introducing my research and to ask if they are willing for me to have their contact details. The school wrote a letter in English which I translated to Mandarin (refer to Appendix Three). There were seven Chinese families with children with special needs altogether but the letter was sent to six families because one of them was already in my research. Within two weeks, four had replied and gave permission for me to contact them. The other two families did not reply either to me or to the school.

All the respondents were the mothers and one of them left a note to ensure that I contact only the mother. Among the four families, three were diagnosed with autism and one with intellectual disability. Two of them were females and two males. Their age ranged from 5 to 9 years old. I contacted all four families but did not manage to get in touch with one of these families though I have tried many times. The phone number was correct according to the school, but no one ever answered the phone. Therefore, only three families were interviewed. Two of these mothers, each with one child with special needs, are actually a part of the same extended family.

Data Collection Strategies
The data collection strategies for participants from Phase Three and Phase Four were the same. These included in-depth interviews and observations. The data collection procedure and the length of the procedure were different depending on the responses of each family as illustrated in their stories in the next chapter.
In depth interviews were not mentioned until these mothers started chatting and talking to me. Most of the participants warmed up in a reasonably short time and were ready to talk about themselves in the second contacts. In the initial contact stage, all the families were asked to specify their preferred language or dialect for future discussion and communication so that the interviews were most comfortable and easy for them. I contacted all the families through the phone for a preliminary discussion about the research in order to give them the chance to ask questions and to give some thought in advance to what they might like to discuss in the main interview. Keeping in mind that the hallmark of in-depth interview is “learning how people construct their realities—how they view, define, and experience the world” (Taylor & Bogdan, 1998, p. 101), I avoided over structuring the conversation. In the preliminary exchange, I used open ended and descriptive questions by explaining that I was interested in their views alone and that I would like to talk with them about whatever they felt was important to them. I also encouraged them to identify if they thought there is anything distinctive about Chinese migrants with children with special needs. I emphasised that my research is to voice their point of view and I would be very interested to know whatever they like to share that is relevant to this topic, including the things that they regard as ordinary or unremarkable because they were part and parcel of their lives. When I told these parents that their contributions would be very valuable and respected, most them took the view that ‘my contribution is very little and not relevant to the community’.

As I could not tell beforehand exactly how many interviews I would want to conduct with each family, I made my requirement very small at the beginning, for example one to two sessions to avoid putting off these hard to find participants. As we began to engage in more discussions, I asked if I could come in for more sessions according to the response of each family. I also said to each of them that I would like to hear from the other family members such as the fathers. The majority of the participants referred to their husbands as ‘very busy, need to work and have no time’. I would then add that if they were not available, I would appreciate their point of view, perhaps through their wives.
Four of the participants invited me to their home for interviews. Two chose to respond by telephone and one at a café. The two mothers whom I talked to by telephone were given an information sheet both in English and Mandarin through the mediators. They gave their verbal consent for me to use the information they gave in my write up. One of them refused to take further participation after our first interview by telephone and another wished to remain unidentifiable even to me hence I did not have her contact details. However, this mother was willing to ring me three times for interviews. The rest of the families were given the information sheet in Mandarin during my first visit. I verbally explained my research purpose and design to each of them before I presented the consent forms.

None of these participants gave permission for me to audio-record the conversations. Some of them showed tension and withdrawal when I mentioned about recording. Therefore, I had to reassure them that I would not record because I respected their choice and then slowly regained their trust to talk. Some made it very clear from the beginning that they did not want their conversation to be audio-taped. For four of the seven participants, I had to explain my intentions and motives very clearly and reassured anonymity would be strictly kept in my write up as well as their right to have their final say. I asked for permission to take written notes as we talked by explaining to them the limitation of my memory capacity. Most of them were comfortable with this. However, one constantly checked to ensure that I was taking truthful notes of the conversation.

Five of the seven mothers chose to undertake the interviews in Mandarin so most of the field notes were taken in Chinese. One mother only spoke Cantonese therefore interviews were carried out with my speaking knowledge of Cantonese. As Cantonese language uses Chinese characters, field notes were written directly in Chinese. Several tactics were utilized to produce the most complete field notes as possible since I was not given permission to audio record the interviews. During the interviews, I used probes more than questioning. Probing is to ask for specific descriptions and details of their experiences
and perspectives. I followed the lead of the participants in every interview. I would pay close attention to the participants, looking for and recording key words in the participants’ remarks. On many occasions, I had to ask the participants to give me some time to ‘catch up’ with the notes before we continued the conversations. Each interview was recorded according to the sequence of the conversations. During the visits, I would also keep the scenes and description of the people in mind. For those who were willing for me to go back to them, I would leave the setting as soon as I had as much as I could remember. Immediately after each interview, I would play back remarks and scenes in mind and fill in the details of the conversations and observation comments. I would also add in my own remarks and responses during the interview processes. The field notes were then translated into English.

Reciprocity.

Apart from bringing some food with me during the first visit as a culturally appropriate way of visiting, I did not pay the families concerned for the interviews with them. However, it was possible to come to an agreement, with those who wished, that I would do something in return for them. In a small sample such as this, it is not too difficult to find modest but practical ways of reciprocating. For example, one parent asked for help in finding an English tutor for the child, one asked for me to accompany her to a party for children with special needs in Christchurch and some for translating the information about the local services. For many of them, having a person to listen to their experiences were the major rewards for participating in this study. A few commented that the interviews were helpful for them to talk through the painful experiences that had happened many years ago but were still hurting for them.

Like the experiences of many qualitative researchers, leaving the field for me was not a ‘cut-and-dried’ process (Taylor & Bogdan, 1998; Ellis, 1995; Richardson, 1992). When the interviews were completed, most volunteered that they had enjoyed the experience.
and they hope to keep in touch with me in the future as a friend. They also liked the fact that their experience would be passed on to existing professionals and to me as a prospective professional for the Chinese community who might be able to serve their needs better.

**Power and Positioning.**

In addition to understanding the general experiences of my participants in terms of their perceptions and circumstances, I would like to reflect how my personal characteristics and status might affect the information they chose to share with me and the subsequent interpretation of the data. On the basis of sharing the same cultural background but never having the experience of parenting or having a family member with special needs nor representing the government or the schools, I have been playing both the insider and outsider role during the course of the study.

As a member of the Chinese community, I presented myself to my participants as ‘their people’ and ‘their representative’. I was treated as an insider who shares their concern and interest. Having this common ground helped to build trust with my participants and hence promoted openness during the interviews. On the basis of the created common goal and interest, it helped to engage and encourage communication of the participants in the study. This is particularly important as the local practitioners are having difficulties accessing and retaining the involvement of these families in their services in order to understand their situation.

While studying about my own culture could mean it is very easy for me to overlook some aspects of my data, it provided me a foothold to access the social network and enabled me to be treated naturally within the community. My role as a participant as well as the researcher preserved the unpretentious milieu especially during the recruitment process. This becomes a precious feature of this study because generally people attempt to present
themselves in the best possible light to outsiders (Gofman, 1959). Participants in research tend to share those aspects of their lives and work in which they are seen in a favourable light and hide, or at least downplay, those in which they are not. However, during my interaction as a member of the community within the social network of the participants, I had the opportunity to observe and experience what was actually happening within the network. For example, during my recruitment process, many parents reacted very positively towards the invitation of my research when the mediators were non-Chinese but when they came to me, they responded differently, and some even refused to participate in the study.

When introducing myself to my participants, I assured the participants that I am not from the government services or the schools. As someone not involved in the school or services, I was treated as an outsider with whom they could make criticisms or comments about the services or schools without worrying that they might offend the authority figures. This is particularly crucial for Chinese participants as it is not socially and morally acceptable to offend the authorities. One parent attended the social activity because she was concerned about the school reaction not because she wanted her child to have the social interactions:

I think I should bring Li Mei to this party because I haven't been to any of the activities invited by the school for a long time. I better go this time. Or else, the school might think that Li Mei has not been treated well at home.

(Siew Lan, Original in Mandarin)

Apart from that, for some participants, the authority figures in their country of origin are corrupt, capricious or downright dangerous. Those who live in such circumstances, frequently regard schools or government services as being unwelcome intruders against whom it is necessary to protect oneself, often by
some form of appeasement, or by strenuous denial (Curreen, 1997). My presence as one of ‘their people’ would avoid triggering their defensive mechanism and encouraged them to express their opinions freely.

Presenting myself humbly as a young person with no parenting experience helped me to be culturally appropriate apart from encouraging these parents to give more descriptive and detailed information about what and how they perceive their children. By doing so, I took the ground as an outsider in their parenting experiences so many of these parents understood that they should not assume I was familiar with their situation.

The issue of power is another important reflection that I would like to consider. Before I entered the field, I held the assumption that these parents may be threatened by my educational background and my professional knowledge in the area of special needs. This assumption was further cultivated as the professionals and schools commented that my approach to these families would be helpful for these families. Nevertheless, in the point of view of most of my participants, I was coming to see them to seek for help but not to help. They viewed themselves as the helpers, as one that held the greater power in the research.

_My husband and I are not very keen to partake in this research. I know you need help and this is important for you...after a long thought, I feel sorry for being so unhelpful._

(Anonymous, original in English)

One possible explanation is my young age, as in the highly collective Chinese society, the older community member should ‘look after’ the younger ones. Another explanation is as the result of my purposeful of play down my professional background to avoid anxiety or
distance, I appeared to be a student and learner more than anything else. In these ways, the negative attitude towards researchers was undermined.

In my attempt to address the power imbalance between an able-bodied person and parents of children with special needs, I took no ground to enter these families to ‘fix’ the ‘problems’. I presented and interacted as a person who was willing to listen to their experiences and, when asked, prepared to share with them my experiences as an immigrant and as a member of the Chinese community in New Zealand.

It is evident throughout my recruitment process that the attitudes of Chinese society towards researchers are passive. Generally, the parents became more comfortable and willing to share openly after a few meetings. However, the length of time every participant chose to partake in this study varied. Consequently, the type of information presented in this study is one version of their experiences that they have filtered and chosen to tell based on their perceptions of power and positioning between themselves and me at that particular time. In the view of qualitative study, this should be considered a strength as it allows the space in presenting diverse perspectives of this topic area.

**Data Analysis**

As this was a community with very low interest in participating in research and most of these mothers were extremely busy, the data collection process was opportunistic in nature. I tried to take every opportunity I could to interview these mothers for as many sessions as they were willing. In addition, as I was not permitted to hold any contact details about one of the families, it also meant that it was impossible for me to follow her up unless she rang me. Hence, it was not possible to analyse and code every interview before undertaking the next.
The process of analysis.

Analytic Memos

Listening to the classical music on my way to work, I imagined (one of the children in my study) dancing gracefully to this music. She loves dancing and I believe she is talented. However, her mother never agrees for her to attend dancing classes even though she knows (the child) loves dancing. Why? Her reason was that “she can’t follow instruction obediently.” What about behavioural intervention? Why isn’t this an option for her? To me, what a pity to hinder a talent because of her behaviour. The child’s behaviour is notably important for this parent, more than her talent.

(Journal entry, 10 November 2004)

Today, a Chinese man killed his child in Auckland. Listening to his stories reported in the news, I thought about the stress of being an immigrant, especially in the case of one of my participants. This murderer was a highly paid government officer, governing three provinces in China before he migrated to New Zealand. After his migration, he had to work as a labourer. He wept in front of the judge, poured out the stress he had to face since his migration and his feeling of loss.

I became more understanding of why one of my participants projected her anger when she talked about her husband’s decision to migrate. It was nothing to do with her child at all. I need to be more alert to other stress factors in the family, not just from the point of view of having a child with special needs.

(Journal entry, 15 December 2004)
Throughout the course of my study, I kept a journal recording my observations and comments about ideas I generated at a specific point, including during my daily life activities. I also keep memos of my journey learning about qualitative study and how I make sense of my research data. I also recorded the special events that happened relevant to my research. This journal helps me to reflect on my own frame of mind.

Coding

After organising my field notes into detailed conversations, I undertook coding by categorising the data into different topics, themes and ideas. This is done for every interview. Then, the categories were integrated into major themes across all the participants. Similarities and contrasts were pointed out.

Develop a story line

After reading the interviews over and over again, I began to note some patterns in their descriptions. I find it helpful to outline a story for each of the families telling the main characteristics of their experiences and perceptions. These include things that I found captivating and/or striking. To capture a flowing story line, I had to put aside the detailed conversations with each participant and sketch the story base on my overall impression of the family. Another rationale for developing a story line is to step outside the engaged conversations to see the whole picture. From these stories, I then pointed out the major themes that I would like to analyse in detail.

List all major themes, typologies, concepts and positions

On the basis of my ongoing analysis, I also listed major themes according to my own ideas and insights as well as from coding and the story lines. Under each theme, I then developed the different or similar issues occurring in the data. To make sense of the connections of these themes, I engaged in the process of 'constructing typologies'
(Taylor & Bogdan, 1998) where I began to see the links between the various perceptions under each theme. As it is impractical for me to include every piece of data into this dissertation, during the process of ‘constructing typologies’, some themes were again integrated under a broader heading and those that were not directly related to the story lines were discarded. The connections among the typologies were developed through continuous comparison and reflection. According to Taylor & Bogdan (1998), the exploration of the links brought about the development of concepts.
CHAPTER FOUR

The stories they chose to tell: Seven Chinese Families with children with special needs living in New Zealand

In this study, there are some informative and insightful accounts of the complex experiences of having a child with special needs within a Chinese community living in New Zealand. These accounts illustrated the demands that these families, especially the mothers, have to face. My interest was to explore what they are doing to deal with these demands, how and why they are doing it. The focus of this study is essentially on their explanations for their actions.

It is important that we read these experiences with honesty and respect. This is not a discussion of theories about what Chinese with children with special needs are like. It is a description of how they live. This study includes the vivid insights given by these courageous parents into their sacrificial acts, abilities, satisfactions, disappointments and struggles arising from their common task of being a parent plus having a child with special needs plus being a member of the Chinese community plus being an immigrant in New Zealand in addition to other identities they might see themselves as having. For their children, these parents act as advocates to the society, as defenders to the disabling barriers, as teachers to the schools, as friends for emotional comfort, as servants for their basic needs, as protectors for their vulnerability, as collectors for information and as trainers to the various professionals. This active involvement has provided these parents with a series of significant learning encounters and an increasing ability to parent their children in an informed and skillful way, which should not be disregarded.

Again, I would like to clarify that I do not intend to claim my interpretation for the following experiences as the objective truth. Neither do I claim that I am presenting the full story of these families. In fact, in the viewpoint of a social constructionist, I would like acknowledge my subjectiveness in my interpretation and also that what these parents
chose to tell me during the interviews were contextually specific. Their experiences before joining me for an interview have a part to play in determining what version of their stories they chose to tell. And, my experiences prior to interpreting these stories formed what version of the stories I am going present. The diverse experiences and circumstances these participants shared with me showed that this is not a homogeneous group. In order to preserve the diversity, I would like to introduce each of these participants with a representational theme that I think is unique for each of them. Throughout this dissertation, all my participants would be represented by pseudonyms.

**Introducing Group One: The four families recruited through word of mouth**

**Anonymous: a Defender for Her Child in the Chinese Community**

A Kiwi friend of mine is a mainstream primary school teacher and she had seen a Chinese boy with special needs in the school. I went to the school to meet the principal personally. Then he agreed to ask the family if they were willing to take part in my study. The principal felt very happy about my research because he believed I would be a support for this family. This family had been through an unhappy experience from the previous school so were very upset when they came to this school. The principal became a great support for them because they did not have other people to talk to about the concerns they had for their child. According to the principal, the parents were positive when he gave them the information sheet and my contact details. I waited for two weeks but did not receive any response so I went to talk to the principal again. The principal talked to the family for the second time, and then the mother rang me a few days later.

*We know you are doing a research, which is important, but the sad and cruel reality for us would never change, right? I will still have to face the day-to-day struggles. It is not our natural interest to participate in your*
research because we think it is unnecessary to talk about our situation to a stranger. My husband is definitely not going to participate. We have many concerns that we need to think over. His suggestion to me was that we would not do it. However, after a long though, I feel sorry for being so unhelpful. I have done a Master thesis myself and I know how hard it is to get people to participate. So, I ring you now as I have promised the principal.

Because it is not easy to have a child with special needs and there are many other concerns my husband and I have, we like to keep our names and personal details unidentified. I am sorry but we are not prepared for you to come and visit or to tell you who we actually are. We just want to avoid unnecessary hassles as we are now happy as a family. We do not need others to know what is going on in our family or to know who we are. So I hope you will excuse me for being so secretive. But, if you have other questions, I promise I will ring you back. You do not have to know who I am so you do not have to know my phone number.

It was from the above excerpt that I chose the word ‘weary’ to describe this mother and use Anonymous to represent her throughout this dissertation. Although I did not have her contact details, I was able to talk to Anonymous in three long interviews. Despite her defensiveness during the first contact due to her previous unpleasant experiences, Anonymous was willing, honest and insightful in her sharing as we knew each other better. She actually decided to tell me her name at the end of the last interview. However, Anonymous clearly stated that I did not need to know her child’s special needs as she was still fairly conscientious about being identified.
Zhi Wei: the Runner of an Astronaut Family

Rosemary is my Japanese classmate. Her mother has a high school Chinese student named Hua Chen. Rosemary’s mother asked Hua Chen’s mother, Zhi Wei if she was willing for me to contact her for my research. Zhi Wei gladly gave permission.

Zhi Wei and her three children came to New Zealand while her husband stayed in their country of origin to keep his job in order to support the family. Before coming to New Zealand, Zhi Wei worked as a professional. It was a very hard decision for her to leave her high-paid job.

Welcoming me into their home, Zhi Wei openly told me Hua Chen, who is fifteen years old, is diagnosed with Autism and strongly emphasized that he is high functioning. This household owns a big double-story house. The living room was full of Hua Chen’s airplane models and musical instruments. It was like a professional studio. There were drums, piano, guitar and keyboard. Zhi Wei explained that they do not often have visitors and the whole living area is set up according to Hua Chen’s interests. Hua Chen is allowed to play with the musical instruments any time he likes.

Our first meeting started with Hua Chen playing the piano and singing a song for me. Zhi Wei was proud of Hua Chen’s performance. She took out the world maps Hua Chen had drawn and told me Hua Chen could speak three languages, i.e. English, Mandarin and Japanese. She also showed me the hundreds of sophisticated airplane models Hua Chen has made.

I don’t see myself as migrant because I might leave any time. I don’t feel this is the place where we belong. My whole family came seven years ago and both my daughters attended university in Christchurch. My eldest

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3 Aye & Guerin (2001) define the astronaut family as an arrangement found in migrant Asian households in New Zealand where the head of the household living and working in the country of origin while the remaining family members reside in the host country (New Zealand).
daughter was 19 when she first came. She had already started university in Taiwan when we came but had to come with me because she was too young to be alone. The education system in Taiwan was all in Chinese so both my daughters had very little English when they came. However, they coped well; they had no problem adjusting to the study in New Zealand.

For Zhi Wei, the issue of living in New Zealand as an immigrant seems to be a greater issue than having a child with special needs. Zhi Wei made it very clear that the family does not have a sense of belonging even after seven years of residing in New Zealand. Her description highlighted the impact of having a child with special needs on other siblings, which Zhi Wei emphasized throughout the interviews. Zhi Wei is proud of her two daughters, both in how they had successfully adjusted to the life here and their achievements. A surprising phenomenon is, though both of her daughters adjusted well yet they still did not having a sense of belonging here, which obviously suggested that this sense of belonging comes from more than just getting used to daily living tasks. Zhi Wei further articulated the many challenges an immigrant has to face while living as a member of the minority in this country.

You are a Chinese too but I am not sure whether you feel the same or not. After a few years in New Zealand, both of my daughters choose to leave New Zealand because they do not have a sense of belonging here. They have tried to be part of the society but it is hard. For example, when they had finished their degree and were trying to find a job, the employer would give priority to the local applicants. And also, the government keeps changing the immigration policy to make it harder for the Asians to stay. We came here because of Hua Chen, if it were not for him, we would not choose to stay here since the government is so unwelcoming. As for my daughters, I have to free them to go wherever they want. I want to be open minded. Though we have a child with special needs, I will not let my other children be tied down by this “bao fu” (burden which will pull their lives back). My
daughters are deep thinkers and they are ambitious. I want to free them to pursue their dreams.

**Xiao Lin: an Overburdened Mother**

Xiao Lin works as a professional in New Zealand. She was introduced to me through a Pakeha PhD student in my department. I was given her contact details with her permission. When I rang Xiao Lin, she was unhappy and annoyed. She was reluctant in telling me her personal details and only felt comfortable talking to me through the phone. She gave permission and consent for one short interview but did not want further participation.

*Life is of course much more difficult, so what? Though you are a researcher, you can’t help me much either because I am the one to look after him (the son).*

*With a child like this, I can’t do many things. He needs 24 hours care and I can’t provide that because I need to work. Luckily, I have my mother coming over from China to help look after him. But you know, she is old and we can’t expect her to look after him for a long time. I have wanted to employ a full time nanny from China for my son so that my mother will not have to work so hard. But the immigration department does not allow that.*

*The amount of work in bringing up a child like him is equal to looking after three normal children. I have an elder son, he is studying at the School of Medicine, which is a difficult course, you know. He is only 19. He is bright. We have no problem with him.*
Having interviewed Xiao Lin for only 20 minutes, I did not get much detail from Xiao Lin. However, it was obvious that Xiao Lin's point of view was very different from the other participants. She was the only one who would like her child to be taken into full time respite care.

**Ai Juen: the Hardworking Chinese**

I made an announcement in my English speaking church explaining my research and asked if anyone knew any Chinese family with a child with special needs. A Chinese lady, Emily, gave me the contact details of a family whom she saw in a Chinese church. As Emily does not know Ai Juen and her husband well, she had to talk to another person in the Chinese church whom both Emily and Ai Juen knew well. Through this “mediator”, I was introduced to Ai Juen and her husband. I was first introduced to Ai Juen’s husband because the “mediator” thought he was friendly and sociable. However, when I rang and asked for Ai Juen’s husband, he passed the phone to Ai Juen and asked that I talk to Ai Juen about it. Ai Juen did not ask many questions. She made a time for me to visit. Ai Juen felt uncomfortable talking in the presence of her boarder so we went to a café.

*In our youth days, my husband and I went to many places. We were both born in Taiwan and we spent eight years in Korea after we got married. When we had Zhan Yi, we were not young. Though we did not get married too late, we spent a lot of time working for our financial security. We thought by working in Korea we could make more money for our future benefit so we went. When we were in Korea, we worked extremely hard. Both of us were in highly paid positions. We worked till late at night everyday. We had no life during that few years in Korea. It was not because we were workaholic, it was just the culture. Everyone has the same lifestyle, work, work and work. I was still at work when I was heavily pregnant. I wanted to stop working because I knew the pressure would not be good or healthy for my baby. And, my job was very stressful.*
I was an accountant. I needed to make sure every figure was correct. But I could not quit because the boss was my husband's friend and the company's financial administration depended wholly on me. I felt I should not be irresponsible. And it would be hard for my husband to face his friend if I just quit. So I worked till the week before I gave birth to my son. I guess the work pressure was so intense that it had affected my son's development. Zhen Yi was born with visual difficulty and I believe I am responsible for this handicap.

Ai Juen sees her experience as not exceptional but as highly representative of the lifestyle of the many Chinese couples. In her point of view, she valued the hardworking character cultivated in the Chinese society; however, she also called attention to the importance of family life and expressed that family should not be traded with financial security. Although Ai Juen has no medical evidence for the cause of the impairment, she felt guilty for over committing herself in her career during her pregnancy.

**Introducing Group Two: The three families recruited through a special school**

**Siew Lan : a Wife who Struggles Alone**
Walking into their house, I felt I was back to my home town. There were lots of ornaments hanging on the walls with phrases written in Chinese wishing for good fortune. The most eye-catching thing was an altar with a black and white photograph of the grandmother behind a pot with burnt incense.

This family arrived in Christchurch seven months ago. Li Mei, an eleven year old girl, is the only child in the family and has little language development. She was diagnosed with autism a few months ago by a psychologist in New Zealand.
Meeting me, Siew Lan, the mother, was welcoming and friendly. "It is hard to find a person I can talk openly about my child and who can speak mandarin", Siew Lan commented soon after we started our first conversation. She did not ask any question about my research. The only question she mentioned was, "Do you know much about autism? I really don't know a lot about it and I don't know how I should treat my daughter."

In the middle of our first interview, Siew Lan's husband came out of his room, all dressed up and ready to go out. He briefly greeted me as he walked past but did not ask any questions or show interest in talking to me. He seemed to be a little avoidant.

Seeing her husband rushing out, Siew Lan stopped him to ask if he could take her and Li Mei to the Christmas party for children with special needs. Her husband frowned and did not say anything. We were all quiet for a while. Then, Siew Lan said, "This is a special occasion, I feel I'd like to bring Li Mei there and see what it is like this year." Her husband looked at her for a while, then while putting on his shoes, he said: "But I have to go to work now."

Sensing the disappointment in Siew Lan, I said to her: "I can bring you there if you don't mind." She was very happy and quickly turned to her husband and said: "Winnie offered to take me there if you are busy. But can you go and pick us up when we finish?" Her husband replied: "What time? I might not be able to leave." Siew Lan quickly said: "I think we should be alright. I believe Chui Ming (her sister-in-law) will be there too. I can ask her for a ride home." Her husband turned around at the door, looked at me and said, "Thanks for your help. Sorry to trouble you." Then he left.
Following the above scenario, Siew Lan talked about her role as the primary caregiver to Li Mei.

My husband and I often quarrel because of Li Mei. Her father thinks it is my responsibility to care for her so every time when she is unwell, for example if she is coughing or got a cold, he would blame me. He thinks it is my fault because I have not been careful enough. But, you know, some of these are unavoidable. She is a child, and every child gets sick, especially a child like her, she can’t tell when she feels unwell.

Well, I guess I just have to bear with this because he earns the money. The family is financially dependent on him. It is the same for every family, I think. Wives need to take the responsibilities of taking care of the children and be dependant on the husbands. To me, her father just have to do his part. He earns money to provide for our daily expenses and I am responsible to care for her daily needs.

Yuen Ya: a New Immigrant
Yuen Ya and Wan Yek have a daughter, Hui San, who is seven years old. They came to New Zealand from Hong Kong six months ago. Hui San was born with a mild intellectual disability. Yuen Ya is a full time housewife and wishes to get a part time job to support the family’s expenses. Coming to New Zealand as an immigrant, Wan Yek is required to attend college to gain a locally recognized qualification to be a carpenter and electrician, of which he had more than 20 years of professional working experience in both fields in Hong Kong. The family owns a moderate house in the school area.

Every step is basically self-help. This is my feeling as a migrant with a child with special needs. We had to seek for information or to find a way out all by our own exploration because there is no one to ask from. We made enquiries
and paid the visit personally to find out about a place. If we were in Hong Kong, we would have friends or relatives that have the information. When we were facing the decision of whether a special school would be appropriate for Hui San, we had to go personally to find out what the school is like and we had to base it on our own judgment.

As new immigrants, Yuan Ya and Wan Yek have to adjust to the new lifestyle and the absence of social support which they had before their migration. The family is facing many challenges due to the unfamiliarity of the environment. Yuen Ya showed me the brochure and it was from Intervention Group. Apparently she had been reading them carefully because I could see translation written beside some of the vocabularies. She said to me,

In terms of the services available in Christchurch, we don't actually know what is available and we are unfamiliar with the system here. I have seen many proposals by the government which I think are brilliant if they can really implement them. However, it is not always the case. Implementation is often not as perfect as the proposals. I am happy to have you here because you will be able to explain to me what the pamphlet is about and give me some ideas about which are the relevant services for Hui San. It would take me hours to understand this pamphlet if I do it on my own.

**Chui Min: a mother using professional-traditional intervention approach**

Chui Min and Jie Fei are in their mid thirties. Jie Fei runs a business in Christchurch. The family owns a moderate house near the school. Both Jie Fei and Chui Min have moderate English ability. Chui Min came to New Zealand more than 10 years ago. She met Jie Fei in New Zealand, whose extended family migrated about fifteen years ago. Chui Min and Jie Fei have a son, Wu Bin, who was born in New Zealand. Wu Bin is six years old. Wu
Bin has been diagnosed with autism when he was two. Wu Bin is non-verbal and has self-injurious behaviours.

There have been professionals involved with Wu Bin since he was little. He was under the consultancy of Dr. Robin Ariel, the most well known pediatrician in Christchurch. We saw him very often for a few years. The RTD also provided one hour per week of intervention for a year when he was two years old. When Wu Bin grew older, the challenge became greater because his learning became more and more important. I need professional help in caring for him because the knowledge and skills required to teach him is beyond my ability. Nevertheless, I struggled a lot with the decision of whether to enroll him to school or not because it was hard for me to leave him. But I said to myself, for his benefit, I just have to harden my heart and let him go. It was especially difficult for me when I saw how they carry out some of the intervention. It was pretty cruel. For example, to train him to sit by the table, they would tie him in a special chair, which is like tying a prisoner on an electric chair. He was really stressed and crying and screaming and, oh, it was really hard for me to see that. I was broken hearted to see what he had to suffer. My heart was being torn apart but I just had to constantly say to myself, this has to be done.

Chui Min is the youngest mother among the seven participants. During our interviews, her distress and heartbreak to see Wu Bin hurting himself was expressed through her emotional reactions. The ongoing challenging behaviours of Wu Bin were the biggest concern Chui Min and Jie Fei raised.

I have been learning about the teaching methods at school. I learn them so that I can use them at home with him. I am very happy to follow what the professionals recommended. However, to be honest, the fact is, I am the person who knows what works the best in real life situation. What the
professionals suggest is not always the best way. I have to find the resources and try all the possible ways and come out with a particular way of dealing with my son by myself. It all depends on my own effort because I am the one who is doing things with him and I know him better than anyone else. The western ways are not always the best. Some are good but not all. We have to be flexible and make changes as we learn.

Like many other mothers, Chui Min expressed appreciation as well as outlined the limitations of the input from the professionals. Chui Min tried to integrate the professional advice, the traditional parenting skills she had learnt from her mother and her own knowledge of her child to work out strategies that are helpful specifically for her child. Nevertheless, according to Chui Min, this was not always easy as sometimes her intention might be misinterpreted.

The strategies used by the professional could be harsh sometimes. I totally understand why they need to do that because otherwise they (these children) would never improve. I agree with that. However, if we can accept the ways they treat these children, why can’t they accept some of our own methods?

I know the western people here are doing things that have been well researched. For example, in the school, they have certain strategies to teach my son new skills. Some of them are effective, but from my own experience, I find the most effective teaching method is the traditional methods that my mum used on her children. I use many traditional parenting strategies.

It is obvious that each of these participants had chosen different issues as the focus of their interviews. While there was much diversity, there were some common themes raised by these participants as well. In order to tell the stories in a more systematic way, I would
like to present the experiences in more details by categorizing my findings and discussions into major themes in the next chapter.
CHAPTER FIVE
Findings and Discussion

The Perception of the Professionals: Findings from Phase One

During Phase One of this study, I had the chance to talk to some local practitioners about my research. My research proposal was enthusiastically embraced by these practitioners. For many of them, though the number of Chinese families under their case loads is very limited, they are facing confusion, frustration and misunderstanding with these families and they are unsure of what is the best way to approach them. In the recent literature, many commented that though the issue on special needs have been actively researched in New Zealand, there seems to be a lack of guidelines or study to help them to meet the needs or to better understand the increasing number of families from a multitude of cultural backgrounds (Lim, 2002). The findings from the short survey in Phase One as well as my ongoing observations throughout this study revealed five challenges the local practitioners face when working with Chinese families with children with special needs. These challenges are outlined as below:

Challenge one: managing the initial reaction.
The lead worker for a well established local early intervention centre made the following comment:

We have two Chinese families referred to us at the beginning of this year but I think we are going to lose both of them. One never turns up though we have been trying hard to contact the parents and explaining to them what our role is. But, we get funny reactions towards our initiative, I think they might think
we are there to intrude the family or perhaps they think we are going to do something scary to their child. We are not very sure what causes their reluctance to take our service. The parents never turn up for meetings or appointments. There seems to be a language difficulty and I think, maybe they don't quite understand us. I mean, we are happy to provide an interpreter but there was not even a starting point for us to introduce that provision to the family.

(Early intervention practitioner, phone conversation, February 2003)

**Challenge two: retention**

The lead worker continued to explain their experiences with another family:

*The other family did come along for a few sessions but is starting to withdraw from our service. It is very hard to keep them actively engaged in the program. We don't know why, they are active and caring parents, not that they are neglectful of their child's needs but we just haven't been able to keep them on board continuously. It seems like we have this communication breakdown and misunderstanding between the parents and us and they are trying to avoid our involvement.*

(Early intervention practitioner, phone conversation, February 2003)

When asked, the lead worker explained that the 'communication breakdown' she referred above was not because of language difficulty. The parents had good English proficiency. It was more about the different concepts and values that created the barrier between the two parties.
During a phone interview, a pediatrician made this comment:

_The parents had an interesting view on this child’s condition. I explained to them the prognosis and what kind of procedures we would follow. They seemed to agree but they never come back again after that session. So I don’t know what is happening to the child now._

(Pediatricians, phone conversation, February 2003)

**Challenge three: language barrier.**

In July, I had an opportunity to work in another government funded early intervention service centre for two weeks as part of my placement. On the first day of my placement, I was told that there was a case on hold specially for me to investigate. I was given the profile which identified the family as Mandarin speakers with a five year old child who showed no language. However, I later found out through meeting the family that it was actually a Cantonese speaking family. According to the manager, this child was referred to their service one year ago but the team had been having difficulty assessing the development of this child because the profiles given by the parents and grandmother were very different from the special education teacher’s observations. There had been unresolved issues mostly due to communication barriers in terms of language as well as concepts of development between the parents and the service provider.

**Challenge four: understanding the family’s concerns.**

My further discussion with the case worker informed me of the difficulty to get the family to take up the intervention plan for this child. The case worker said to me,
This is a lovely family. They are kind and polite. I have close relationship with them now after one year of regular visits and building trust with them. It wasn’t as easy in the beginning but now they know me well and they welcome me as a family friend. However, it is still not working well regarding doing something for Zhen Li. I mean, he is functioning like...like way below his age and we know if we don’t do something as soon as, like...immediately; this boy is going to miss out even more. The grandmother is the primary care giver and she is looking after all the three grandchildren. I communicate with her through body language and sometimes using drawings. I sometimes bring an interpreter with me. She is always happy to see me visiting Zhen Li and her, but we are still working on explaining to her that we would like to do some intervention with Zhen Li. You know, it took me one year to convince them that Zhen Li needs to go to school. I don’t know what concerns they have about Zhen Li going to school. I have assured them many times that he will be very carefully looked after.

(Special Education Case Worker, February 2003)

Challenge five: the clash between different perspectives on child development. Zhen Li’s case worker expressed her confusion with how the parents viewed the development of Zhen Li. Not long after that, another early intervention teacher mentioned to me she was surprised to know a Chinese mother still bathed her nine year-old child who was doing extremely well academically, which is not uncommon in Chinese families.

Apart from the phenomena illustrated above, I would like to give a detailed account of another case I had encountered through my personal socialization because it would explain how my assumption based on the ‘problem-oriented’ model was confronted
during the course of the study. Subsequently, it would explain the significance of the clashes between parental perceptions and the 'professional' perceptions of a child who might be developmentally delayed. This seemed to be a big issue happening in the community.

“Miao Qin is fine, we are happy for her to take her time”

Something interesting happened today and it made me wonder...

A Chinese mother attend the church crèche with a 3-year-old girl today. They were new immigrants, just arrived in Christchurch three months ago. I was attracted to this family because the eagerness to find participants for my research follows me everywhere I go. There was something ‘not very right’ with this girl. She wasn’t talking or vocalizing. She wasn’t showing joint attention. She wasn’t showing curiosity towards the surrounding. Her fine motor skill seemed immature for her age... I was pretty sure that she was developmentally delayed.

My first thought was: they might be my first research participant. (Huh, how selfish I am!)

I took up the courage to talk to the mother hoping to have a chance to tell her about my research. This was a well educated mother who knew very well the development of a child. She told me she used to work as a preschool teacher. I thought that would make it easier for me to ask questions about what kind of early intervention she had sought for her child and to discuss about her concerns regarding her child’s development. So I did.

Her response surprised me. In all her description about her dear little daughter, there was not even a hint of delay or special needs. To her and
her husband, their child was absolutely alright and fine. She said to me:
“She might be a little slower in her learning. But that is okay, we can wait
for her. Life is not a race. She just needs more time than the other children
to learn. I have stopped working now so I will have more time to teach her
more. So, she will get there and I am not very worried about it. Miao Qin is
fine, we are happy for her to take her time.

(Journal, 26 January 2003)

Bearing these two cases in mind, I could identify similar reactions from another family
with preschool children who were severely developmental delayed that I have met during
my placement at another organization. The response of this family was identical. To this
family, despite the eagerness of the special education advisor in engaging the family in
the early intervention, their child was not seen as deficient. Instead, the parents attribute
his delay as a personality difference and they emphasized that the children should be
allowed the space to develop in their own pace and time. Furthermore, the condition does
not seem problematic to the family. Rather, in the parents’ point of view, letting the child
function at his current abilities allows also the parents to enjoy their role and place in
nurturing their child. With this view point, it is unlikely that they would respond
favorably to the notion of treatment or to relate their children to the phrase ‘special
needs’.

Confronting the ‘problem-oriented’ model

Even though I am a Chinese, these parents’ reactions contradicted my expectations. It did
not make sense to me until I started to confront, reflect and admit my theoretical
framework at that stage. Surprisingly to myself, my underlying ideology was the medical
model which I thought I had been strongly against through emphasizing ‘positive
approach’ in working with children and their families. I realized that being in the
professional system itself has gradually constructed in me a ‘problem-oriented’ mindset
and that I have been taking for granted the need to identify interventions to help fix the ‘problems’. In other words, though my rationality agreed with the social theory of disability, my practice was still directed by the medical tenets. The ideology of the disability theories that I have been exposed in my previous courses serve to elucidate my supposition.

_The Recruitment Process: Findings from Phase Two_

_The Connotation about Special Needs among Chinese in Mandarin_

My initial assumption was that I would receive responses through the advertisements and notices I posted during Phase Two. From these responses I could then work out the connotations about special needs in Mandarin. However, the active publication of advertisements and notices from March to July 2003 yielded no response. Therefore, there are no findings to be discussed from the initial response. Nevertheless, from interviewing the seven participants, I was able to follow up this research question by looking at the terms they used when referring to their children with special needs. Interestingly, none of the ten Mandarin terms was used to refer to their child directly. In fact, a phrase that is close to the meaning of ‘different from majority’ (gen yi ban bu yi yang de), was used to describe disability throughout the whole research. In Mandarin, this phrase is used as a general description for something that is different whether positive or negative.

Among the seven participants, one mother spoke English in the interviews. She was the only participant who used the term ‘special needs’, which did not have a direct translation in Mandarin. This term was most probably acquired through her involvement with the professionals or from reading my research information sheet. Another mother who spoke to me in Cantonese used the term ‘low intellectual functioning’ once when
describing her child to me. One mother used the term ‘abnormal’ and another used ‘mental disability’ when referring to other children with special needs. For those who have children with autism, they mentioned the specific diagnosis. However, almost every time a specific diagnosis was mentioned, it was spoken in English. This shows that these terms were probably learnt from the professionals. Furthermore, one mother who repeatedly referred to her child with this diagnosis asked me about the characteristics of the diagnosis. This phenomenon suggests that these parents might have accepted the nominal labels without taking in the conceptual meaning of the diagnosis. It is possible that the labels were adapted for the use of conversing with the professionals. This supports the idea that the conceptual category is harder to assimilate by a different culture group compared to the nominal category because going through a conceptual change with the diagnosis involves personal association to the meaning of the diagnosis.

In addition, the specific diagnosis was only used when they first described their child’s condition to me in response to my inquiry. Otherwise, the most frequent and comfortable way for these mothers to refer their child with special needs was to use the phrase ‘children like this’. A lower tone of voice or gesture pointing to the child was observed constantly when they mentioned their children with special needs. This suggests the possibility of attempting to distance themselves emotionally from the child by vaguely describing them. In this way, the existence of the child becomes a subject of conversation rather than personal. In sharing his personal experience, Robert Murphy (1990) described disability as “disease of social relations” (p. 4). He felt a “profound sense of removal” from society, friends even his family. Social distancing between individuals with special needs and without special needs is intensified when the disability involves emotional status or if the individual with special needs is perceived as contributing to one’s own misfortune (Esses & Beaufoy, 1994). The parents in this research omitted the individuality of the child by referring to them with the phrase ‘children like this’. This prompted critical questions relating to the loss of identity and social roles of individuals with special needs (Davis, 1961). Murphy (1990) described how acquiring a disability
typically precipitated nonperson status and other ascribed identities such as social burden, object of charity, perpetual dependent, or quasi human. The disturbance in the intimate relationships is very damaging especially for the self-identity of the individual with special needs because family is meant to symbolize refuge and support (Li & Moore, 1998). Unfortunately, one possible reason for the use of non-personal terms in some of the families who participated in this research was to emotionally estrange from their child with special needs. However, another explanation could be these mothers wanted to protect their children by avoiding using negative descriptions in front of their children.

There are some issues I have learnt from going through this phase such as the importance of construct equivalence or linguistic equivalence when adapting disability studies of other cultures into the Chinese community. Apart from the considerations discussed above, I believe the phenomenon of having so many related but not exact terms for special needs in Mandarin would increase the awareness of the possible mismatches between the professional knowledge about special needs and how Chinese view special needs. The knowledge derived from the Western sample might not be applicable to another culture.

Reactions to me as the Researcher
With the feedback from the non-Chinese local professionals in Phase One, it is important for me to outline the reactions I have encountered while approaching the Chinese families as a Chinese researcher. First of all, the reactions were different for every family. Generally, Group One demonstrated more variety in their reactions than Group Two. My explanation for this difference is, because Group Two was recruited through the school, where invitations were sent to every Chinese family in the school and not just one family, the invitation might be seen as related to school. On the contrary, my recruitment of Group One was individual and the invitation was given in a more personal way. Hence, the invitation for Group One might have been perceived as more 'intrusive' or it could
generate the feeling of being 'targeted'. In addition to this, receiving an unexpected invitation from somebody they do not know might have also created a feeling that the presence of their child with special needs is very apparent to the public.

It is possible that my research is at the cost of the comfort of these families in the society because by advertising and spreading my research, I have drawn the public's attention to Chinese children with special needs and they are a very small population in Christchurch. This thought came to me because many people I had talked to during the course of the study knew about my research before I introduced it to them. Therefore, it was very likely that a contemporary issue of 'finding' Chinese families with children with special needs resulted from my active networking in the community. This phenomenon tells us of the interconnectedness of the Chinese community and the effectiveness of spreading information through word of mouth. In addition, even though the Chinese families with children with special needs had reported keeping themselves away from the public, they were still aware of what was happening in the general community and thus my research. In other words, what they mean by staying away from the general community is to conceal family information but not to isolate themselves. If the family perceives having a child with special needs as a distressful event and for some even as a shame to the family, the purpose of keeping information within the family unit may serve the purpose of preserving group harmony as well as face saving (Ow & Katz, 1999). Nevertheless, for most of the parents in this study, the notion of shame has never been mentioned or implied. In fact, most of them were open and welcoming. Even for the two families who reacted negatively towards my invitations, Xiao Lin was reluctant to take part because of her busyness whereas for Anonymous, it was for the protection of the family from the outsiders. One obvious point Anonymous laid emphasis on was her perception on her family as a whole unit and to her, it was to be protected and kept away from the wider community and external interruption. Later in the interviews, Anonymous hinted that her family has actually had an unpleasant experience where she and her husband were betrayed by a friend and got into legal complications. Therefore, her reaction towards
outsiders was not entirely related to her child with special needs. Even when she chose to remain secretive, Anonymous expressed sadness, disappointment and feelings of vulnerability from having a child with special needs but she did not associate feelings of shame.

Reflecting on the comments made by Anonymous in the previous chapter, the contrasting reactions from the principal and Anonymous were interesting. The principal was very confident that the family would contact me. In addition, from his point of view, I would be a support and helper to this family. However, Anonymous saw me as someone who was going into her family to get some help. The reason she rang was because she felt bad for being so unhelpful. From the description given, it was a big struggle for her to contact me. She did that only after a considerable careful discussion with her husband. However, she did not choose to let the principal know their concerns but responded positively to the principal. Possibly, they ‘think’ the principal could not understand their concerns anyway, so she did not bother to tell. Or, to shut off one’s own cultural value and consideration is a natural reaction when facing a local person. Or, it was because they did not want to say ‘no’ to the principal because he is seen as the authority.

In terms of how the other parents see me, there were different responses. Meeting me, Siew Lan commented soon after we started our first conversation that she found it very hard to find a person she could talk openly to about her child in mandarin. In my first meeting with her, she did not ask any question about my research except to request for advice in how to better understand her child. In contrast, Anonymous and others thought of me as someone with whom they could share their experiences and befriend.

**Combining the Two Groups**

The initial purpose to recruit participants through word of mouth in Group One was to reach the families who were ‘hiding away’ from the services. My hypothesis was that
Group One and Group Two would have very different experiences and perceptions. Nevertheless, the hypothesis was not true when I compared the responses between these two groups. The reason was because the participants in Group One were actually already involved in the services and all the four children were attending schools. Therefore, like families in Group Two, I could have reached these families through their schools. In other words, the division between the two groups was artificial. Since the division is fake, I will combine Group One and Group Two in the following discussion.

Despite my attempts to network and advertise among the community, this research did not reach those who were not yet involved in the system such as Miao Qin and her family, whom I met through personal contact. There was no response yielded from the advertisements. Consequently, the research question remains: What is the perception of Chinese immigrant families who are not in the system towards having a child with special needs? In addition, the effective way to reach these families is yet to be explored.

**What Do the Parents Have To Say: Findings from Phase Three and Phase Four**

As expected, there is no straightforward answer to the research questions. The parents had offered details and insights into what, why and how their perceptions are on being immigrants with children with special needs living in Christchurch from the in-depth interviews. Several themes emerged from the data I have collected. In order to present the findings and discussions in a more systematic and coherent way, I will classify the themes into two parts, namely ‘the primacy of family unit’ and ‘support’.
The Primacy of the Family Unit

More than a decade ago, Fergusson & Asch began a review of published narrative written by parents and persons with special needs and wrote the following:

The most important thing that happens when a child with disabilities is born is that a child is born. The most important thing that happens when a couple becomes parents of a child with disabilities is that couple becomes parents (Fergusson and Asch, 1989, p. 108).

The focus of this research was initially to look at how the Chinese families with special needs responded differently in terms of their behaviours, as well as how the cognitive interpretations that these families place on those behaviours shape their responses. However, in the accounts given by these seven mothers, nene had expressed their views of their child's special needs independent from their roles in relation to the child or without seeing the child as part of the family. Just as the existence of special needs is a social construction, their reactions towards the child with special needs could not pertain without the simultaneous presence of their roles as the parents. Accordingly, the perception of these parents strongly evolved around the family as a unit. Therefore, to understand the Chinese parents' perception towards their children with special needs, this research has actually focused on the general functions of the family unit rather than the parents or the children with special needs separately.

Parenting practices.

Only when these mothers shared with me their values, I started to better understand their explicit attitude towards having a child with special needs. A theme that six of the seven mothers spoke about in unison is the different perception of parental responsibility and societal responsibility for the children with special needs between Chinese and New Zealand parents. This is an important finding in explaining why it is difficult to retain these mothers actively involved in the services. Zhi Wei has a great deal to share because
she has many opportunities to meet the local parents with children with special needs from her volunteer work experiences at the local disability centre.

*Chinese parents have very different perception towards how much we should use the services provided by the government. I agree that the society and social welfare for people with children like these in New Zealand is much better compare to our own country. In fact, the reason we migrate from Taiwan to New Zealand is because of Hua Chen. However, you can't rely on others to look after your child.*

*Often when I talked to the local people, the first thing they ask when they know I have a child with disorder is, whether I have applied for funding or services to care for my child. In my opinion, we should not rely on the government to look after our child just because he has disorder. On the other hand, in my opinion, I as the parent should work harder so that I am able to take the responsibility of raising a child who is not like normal children, which is much challenging.*

(Zhi Wei, Original in Mandarin)

*I have attended a support group twice but I decided not to join this group anymore. The reason is that I couldn't enjoy myself at the meeting at all. The purposes of the meetings did not interest me. In the first meeting, the focus of the parents was to fight for more services and to demand more materialistic provision from the government. That is not my interest. I think we should be content with what we are given. In my opinion, the government has done a lot for us already. We should not rely totally on the government because we have the responsibility as well. We should do what we can for our own child too. I am very grateful to the government*
for what I have been given and I do not see why I should ask for more. So, I felt the meeting was unpleasant for me. In the second meeting, the purpose was for the parents to have a day off from their children. They went for a cup of coffee, to relax and to enjoy while the children were left to the caregivers. I have a different attitude towards parenting. I would not feel all right to get someone to care for my child while I, the parent, go and enjoy myself. Enjoyment is not my interest, my child is.

(Chui Min, Original in Mandarin)

The concept of not relying on the government is coherent with the living practice of these Chinese parents. Chinese are usually described as very hard workers. They work long hours for the future financial security. It will be interesting to investigate whether the working culture is this related to their concept of family or because to be independent and hardworking is one of the virtues within the Chinese community.

One thing I found about the New Zealand society which I could not fit in very well with is that the parenting attitudes are very different from Chinese parents, that is, most of them are satisfied with what the children have learnt from school. But for me, I do everything I possibly can to help my child learn more. I am my child’s teacher. I read many books about the special needs.

I have been introduced to the public services such as ABC but I never want to use them because I don’t know who will be with my child and I don’t know what kind of care my child would have. I admit that we as Chinese parents are very protective. We do not trust others to look after our child. And I am not like most Kiwi parents, I am very happy to be with my child 24 hours a day. My life is my child, and I am totally happy with
that. My husband and I are happy to take turns looking after our son and we are very happy to be with him. We like to be independent. If we can manage well why should we depend on the government so much? We also have been given the privilege to have a cleaner do the housework for me once a week but I never use that service too. I just think this is my responsibility and I should do it myself. I guess this is because Chinese are hard workers. Though I hate the 'Asianness' in me, I think we should keep the good values from our culture.

(Anonymous, original in English)

From an excerpt quoted earlier, we know that Anonymous was regretted not getting intervention from the specialists for her child earlier. However, these specialists are actually accessible from ABC. When Anonymous made the comment of not wanting to be dependent on the government so much, she used the cleaner service as an example. It was not clear in her comment above whether she perceives ABC as a domestic care provider or if she was aware also of the specialist services that might be able to enhance the development of her child.

The government is really kind and very caring. However, to me, some of the services are not crucial. We can handle things all right now. For example, I am given 24 days of respite care a year. I was told that I could apply for extra days if I like. I didn’t apply for extra because I think we shouldn’t be greedy. We should be content with what we are given. We shouldn’t abuse the services just because we are allowed to. I am very happy and grateful for what I had been given already.

(Siew Lan, original in Mandarin)
In a comparative study on the special needs provision in Mainland China and England, Merry & Zhao (1998) reported in the traditional values in China, children with special needs are not being perceived as the responsibility of the Chinese educational system at all. Coming from this background, these parents may have already absorbed the society’s expectation to be independently responsible for their children with special needs. Chao (1994) illustrated Chinese child rearing practice as being grounded in Confucian’s social philosophies and traditions where there is a deep belief in the alterability of human achievement through hard work and effort (Munro, 1977). Another aspect of this philosophy is the importance of the linear hierarchies, especially the parent-child hierarchy. When these two aspects are put together, an extremely serious responsibility for parents to affect their children’s achievement is established (Goldin-Meadow & Saltzman, 2000). The illustrations above clearly demonstrated the discussed traditional child rearing practices of these Chinese parents with children with special needs. Some even see their responsibilities as greater than the general mothers because it requires more effort to change the achievement of children with special needs. The ideology of seeing the parents to be totally responsible for the outcome of the children with special needs might be hard for the local parents or practitioners to understand because in contrast, the Western oriented society emphasizes egalitarian relationships between parent and child, and individual rights where a child is seen as an independent individual, as mentioned in my Literature Review, to whom the general society also has responsibility for his or her quality of life (Pan, Chaffee, Chu & Ju, 1984; Stevenson & Stigler, 1992). In this sense, the responsibility to rear a child with special needs in the Western oriented community becomes collectivistic whereas in Chinese society, it becomes more individualistic with the family as the basic unit. This seems contradictory to the widespread notion of Chinese community as collectivistic and Western society as individualistic (Markus & Kitayama, 1991). However, by viewing these excerpts from another perspective, the attitude of not wanting to rely totally on the government but contributing to the society are the expressions of the collectivistic ideology among these Chinese parents. The self-sacrificial and hardworking attitudes are in harmony with Confucian’s social philosophy as explained in my Literature Review.
One recurring theme from these excerpts is the importance of physical proximity with their children in the parenting practices of these mothers. This is supported by findings from an earlier pilot study (Rothbaum, Morelli & Pott, 1995) using interviews with 17 immigrant-Chinese parents and 13 Euro-American parents of young children. Rothbaum, Morelli & Pott (1995) pointed out that immigrant-Chinese parents had more physical proximity with their children, and saw closeness as meeting their children's nonpsychological needs such as safety. They see this as more important than meeting their psychological needs.

The role relationships within the family.

Another strong and recurring theme in this study is the seemingly 'imbalance' role between the mothers and the fathers in care giving. In most of the households, it tended to be the mothers who had the central responsibility for the care and upbringing of the child with special needs. The account given by Siew Lan in Chapter Four and the first hand account of the father's responses towards the request captured the distribution of labor in child rearing among these Chinese couples.

While acknowledging the contribution of her husband in rearing their child, Yuen Ya was quite clear that it fell onto her to provide the direct and ongoing personal care, support and assistance. She highlighted further ways in which the roles differed:

Though my husband and I are involved with Hui San, I would say my involvement is 98% of the time. This is because I know Hui San very well and I know how to teach her but her father does not. So, it became hard for him to teach her. Another reason is, her father has always been busy
with his career. He works very long hours. In the past ten years, he had been attending night school in Hong Kong. So, he was hardly home.

(Yuen Ya, original in Cantonese)

To some families, the characteristics of the child with special needs further amplify the one-sidedness of parental involvement. For example, the excerpt below further portrays how Siew Lan feels she is on her own in parenting Li Mei.

*Her father does not know her very well. In fact, they are far away from each other. She is not like others who can call ‘daddy’ and ‘mummy’. She just lives in her own world. So they (Li Mei and her father) seldom interact. She never allows her father to touch her.*

(Siew Lan, original in Mandarin)

Being an astronaut spouse⁴, Zhi Wei takes the full responsibility of her family since seven years ago. Psychological literature on astronaut families suggested that such arrangement produces extra stress for the families and can be the cause of mental and physical illness (Abbott, Wong, Williams, Au & Young, 1999). This is because the parent who comes with the children to the host country not only has to adjust to the new culture but also is expected to fulfill the dual role of both father and mother, without having anyone to share their problems with (Lam, 1994; Lidgard, 1996; Pe-Pua, 1996). Many astronaut families develop coping strategies by having the elder siblings share household chores, to look after siblings or contribute to family decisions to share the burden of the astronaut spouse. However, in Zhi Wei’s family, although she has two adult daughters, who in most Chinese families would be expected to be good domestic

⁴ Astronaut spouses are generally the women who are left in the host country with the children while their husbands continue to earn a living in the home country (Aye & Guerin, 2001).
helpers, the daughters could not and were not expected to play a role in caring for the younger sibling because of the special needs of the child.

_Hua Chen needs full supervision especially in the morning before he goes to school because he often gets distressed and often is unwilling to go to school. One morning, I was not feeling well so I had no choice except to ask my daughter to do me a favor. I left Hua Chen with my daughter. Within five minutes, I heard a loud noise of broken glass. Hua Chen was irritated by his sister’s words so he punched the window and broke it. You see, even his sister could not read his emotions. If I were there, I would be able to tell he was not happy before his outburst._

(Zhi Wei, original in Mandarin)

This incident depicts the art of caring for the children with special needs which often only the mothers master. For these children, it is not just a matter of caring for their physical needs but you have to know how to read the child’s mind. Apart from the issue of competency, another factor that determines the labor distribution among the family members is Zhi Wei’s expectation for herself in relation to her responsibility as the person who gave birth to this child and as the mother:

_Usually, I do not ask my daughters to share the work in looking after Hua Chen because that is my responsibility. I gave birth to him so it is my responsibility, not my daughters, and my perception is, they should be free to do what they want and should not bear this burden._

(Zhi Wei, original in Mandarin)
To get a picture of the actual disruption in the astronaut family for a child with special needs, I need to give more explanations to the above account by illustrating the further challenges Zhi Wei has to go through. The family came to New Zealand primarily because they wanted Hua Chen to have a better environment. However, when Zhi Wei’s two daughters finished their studies, they found it hard to settle down in New Zealand so they decided to leave this country leaving Zhi Wei and Hua Chen in New Zealand. Usually, the purpose of this involuntary separation between the couple for a typical astronaut family is for the sake of their children’s education or the long term settlement of the family (Boyer, 1996; Lidgard, 1996). However, in Zhi Wei’s case, the family came to New Zealand only for the sake of Hua Chen. The interests of her other children may not have been met. Consequently, when the other children decided to leave New Zealand, Zhi Wei had to go through the pain of separating again with them, which is uncommon in Chinese families. Consequently, this family is geographically ‘fragmented’ and Zhi Wei often misses her other children and husband.

The above phenomenon is not unusual in Chinese culture. An old and well known saying that has been embedded in family practices is 男主外女主内 ‘nan zhu wai, nu zhu nei’, meaning men are responsible to go out to earn a living while females are to be responsible for the household within. Siew Lan’s referring herself as ‘financially dependent’ on her husband and her acceptance to this role division flawlessly correspond with this cultural value. Nevertheless, from the experiences of these mothers, moving from the conventional child rearing responsibility, they were also the ones who took most responsibility for keeping track, organizing and dealing with the outsiders regarding the child’s needs and information. For example, all the representatives of the families participating in this research are the mothers. It was the mothers who responded to me when I approached the family as an outsider, not the fathers. One family even made a note on the consent form that I could only contact the mother. There are many possible explanations for this occurrence; one is that the fathers find it harder to talk about this topic because they are the ‘head’ of the family hence carrying the responsibility for the
honor of the family. Secondly, they might think it is easier for their wives to associate with me since I am a female. Thirdly, as anonymous had explained before, her husband has other considerations (which might include face saving) and for the protection of the family he chose not to partake in this research and fourthly, which is the most common reasons given, the husbands are too busy with their job, which is consistent with the aforementioned old saying.

Chui Min’s experience is rather different from the others whose husbands are not actively involved in childrearing roles. She explained that Jie Fei (her husband) tends to undertake practical jobs, physical tasks or leisure activities or to become involved for particular reasons when the occasions seemed to demand it. According to Jie Fei, he has cut down his working hours so that he can share some caregiving responsibility with Chui Min because Chui Min at one point was overexhausted and emotionally unstable. While Jie Fei is willingly trying his best to lighten Chui Min’s load, Chui Min on the other hand, is also trying her best to be thoughtful of her husband’s needs as illustrated below:

I share a room with Wu Bin so that I can toilet train him. My husband sleeps in another room because he has to work so he shouldn’t be disturbed during the night. He needs to sleep well. He works very hard, his working hours are much longer compare to Kiwis. So I don’t want him to be tired because of lacking sleep. I have to sleep with Wu Bin because he needs close supervision as he is quite unpredictable.

(Chui Min, original in Mandarin)

Other than describing the self sacrificial will of Chui Min in maintaining stability for the family, this excerpt reveals the complexity of the challenges this young couple has to deal with to find a workable balance. Most literature study on families with children with
special needs tend to focus on factors around the child as the stressors for the family while disregarding other basic yet crucial factors that could contribute to family breakdown such as financial difficulties (Shapiro, 1990; Trachtenberg & Batshaw, 1997). In Chui Min’s case, it is obvious that there are other issues apart from the challenges in caring for a child with special needs that the family needs to put efforts into handling such as financial security, health of the parents and so on. Having to work extra hours is a common lifestyle for the Chinese immigrants. For some, this is the necessary survival mechanism as a minority in a host country. For others, it is for financial security of the family and the children’s future. As we can see throughout the study, some Chinese parents with children with special needs use financial and material provision as one of the compensations for their child’s dependency and needs.

In a comparative study focusing on family relatedness between Euro-American families and immigrant-Chinese families, Rothbaum, Morelli, Pott and Liu-Constant (2000) illustrated that the overarching theme which organizes the Euro-American families’ beliefs and practices related to family relationships is romance, which is related to the concepts of eros or passion. On the other hand, emphasizing harmony, where adapting one’s own needs to the needs of others, is the overarching theme that organizes the practices and beliefs of the immigrant-Chinese families (Rothbaum, Morelli, Pott & Liu-Constant, 2000). The findings from an earlier study carried out by Rothbaum, Morelli and Pott (1995) also stressed that the immigrant-Chinese parents were less likely to emphasize the importance of the spousal relationships. In a more recent study, Rothbaum, Morelli and Liu-Constant (2000) found that relatedness in immigrant-Chinese families was defined in terms of the family unit rather than the spousal unit. Schweder, Jensen and Goldstein (1995) reported the different ways couples from different cultures protect their marital bonds. While the “sacred-couple” principle was valued in many middle-class American families through maintaining privacy by sleeping separately from their infants, in the immigrant-Chinese family, an emphasis on the couple is seen to be incompatible with an emphasis on the family as a whole. To have the child sleep with
One parent or both parents as in the case of Chui Min is common even for families with no children with special needs.

One notable fact which I nearly overlooked but which fascinated my peer supervisor was, there was not one single parent family in my study. Working as a Child and Family Psychology intern in Christchurch, I have now become aware of the diversity of household relationships. I am very aware that the families today are structured in many different ways including single parent families, adoptive families and step families (Boyce, Miller & White, 1995). However, during the course of this study focusing on Chinese families, without hesitation, I took for granted the two parents households. My ignorance of this phenomenon portrayed the importance and presumed necessity to maintain a marital relationship to some extent in the Chinese culture. This is supported by circumstances illustrated by some of the participants. Although there were many accounts given on how the stress of having a child with special needs impacted on the marital relationship but none of these couples ever considered or mentioned divorce. For some of them, the stress further motivated the couples to closely bear each others’ burden, as in the case of Chui Min and Anonymous, whereas for others, one or both parties are willing to sacrifice self pleasure to keep the unity of the family, as with Zhi Wei and Siew Lan. As mentioned before, having a child with special needs is not always the greatest stressor for these families. Like the general Chinese families, living in a host country as an immigrant can very stressful and many couples have to develop resiliency to walk through these challenges. For example, Yuan Ya and Wan Yek (her husband) faced tremendous stress as illustrated below:

"Coming here as an immigrant, we are facing financial pressure and many other challenges. Settling in a new country costs us a large sum. Unfortunately we have been having difficulty finding a job because many Kiwis prefer to employ local people. Besides, I studied accounting under the Hong Kong system and I am unfamiliar with the local taxation system."
which makes me even less privileged for job hunting. Wan Yek is under great pressure too. Although he has worked as a carpentry designer for more than 20 years, his expertise is not recognized here because they (New Zealand government) require hands-on carpentry skills in order to work in this area. My husband lost his confidence when he was told he has to obtain a qualification before his expertise is recognized. So he has to study from the basic hands-on skills. He is slowly building his confidence through his practices. He knows that because he made the initiative to move our family here so he needs to be responsible for our well being. He is doing two courses at the same time because he believes that will give him better working opportunities. We are under great pressure because we currently have no income. We are spending our savings and it is getting low. That is why I am looking for a part time job too. I can do any job as long as the time fits in with Hui San’s school time. Due to all these stresses, Wan Yek and I quarrel quite often.

(Yuen Ya, original in Cantonese)

What is important for the child with special needs?
While much agreement is present among the women in this study about what are the distinctive things that mothers with children with special needs did, there were also variations in their individual experiences. These included matters related to the characteristics of their children’s special needs.

The biggest concern I have is the safety issue. I spend all my time and energy, whether physical or emotional, teaching him to keep himself away from dangers. He has no concepts of risk or danger. He is never aware of the consequences of his behaviour, because he does not know. So I need to
watch him very very closely and carefully. I often have to run after him. This does not only take physical energy, it drains my emotional energy too because it is always stressful and worrying. Sometimes, you get really angry and frustrated.

(Chui Min, original in Mandarin)

In a brief conversation, Jie Fei expressed openly his concern about Wu Bin’s self-injurious behaviour. He told me he had done everything he could but it never improves. He felt helpless and frustrated. He was quite eager to seek advice to help Wu Bin stop this behaviour.

They have some dancing class at school sometimes. Though I know she loves dancing, I think that is the furthest we would let her go because she can’t learn in an ordinary dancing class. She has no patience. She could not wait and take turn. Her behaviours are not acceptable for an ordinary class. To behave well is the first criteria in all classes, if she can’t pass that, how can she be part of the class? No, she can’t. She can only learn that at school because all the staff are well trained and they understand what is Autism.

The most common attitude I have experience from people is curiosity. I sometimes experience it here in New Zealand too. They would look at her and you can see they are curious. The unpleasant feeling comes when Li Mei shows her behaviours, like what she is doing now. People would laugh at her. Sometimes I don’t care how they see us. I don’t know them anyway. If that is what they choose to do, that’s fine. I’ll just let them do what they like. It’s none of my business. In fact, that is one of the reasons why I do not bring her out sometimes. Her behaviour is obviously different.
from other children and it is very distinctive. She needs longer time to learn how to behave properly. I think I would feel more motivated to bring her out if she behaves herself. Teaching her to behave properly is a lot harder. I need to force her to stop doing what normal children do not do. Because if you do what others do not do and don’t do what others do, you will not be accepted. And she won’t be able to learn social skills. Her behaviour is much better now. It only works through forcing.

(Siew Lan, original in Mandarin)

Siew Lan reported she liked to ignore the public reactions towards Li Mei’s stereotypical behaviours. Nevertheless, the public reactions had actually discouraged her to bring Li Mei to the public.

The principle and meaning of 禮 (lì) in the teaching of Confucius and its significance to Chinese socialization has to be understood in order to make sense of Siew Lan’s rationale in emphasizing on having a proper and right behaviour. A detailed explanation of 禮 (lì) and its relatedness to proper behaviour can be found in Chapter One. Nevertheless, it is noticeable that for this mother, the dilemma of trying to ‘normalize’ the child is unresolved.

I spend much time teaching her social skills because I know that is very important for her psychological development. However, it is the most challenging and tiring task. Sometimes I get angry and impatient with her. But I have to tell myself that I need to accept her.

She has difficulty getting on with other kids. She often feels upset and rejected by other kids as she could not play together with them because
they can't understand her. In my opinion, the most important skill for my child is communication. Communication is the basis for daily life interaction. It is the most important skill when you are with another person.

The children at church do not play with her because they can't speak Cantonese. I think friendship is fate; it depends on who you meet. In Hong Kong, there was a center specifically for parents to bring their children for playmates. That was very helpful for us who have a child who is longing to have a friend to play with but is often rejected by the majority. My best friend has a daughter who is of similar age as Hui San. She refuses to play with Hui San because she has no sympathy for her. That has been very hurtful for Hui San.

I don't think we will access every service available. My priority is that Hui San learns practical skills, those which help with her daily living. I very much emphasize the importance of life skills more than academic skills.

(Yuen Ya, original in Cantonese)

For me, the reason for sending her to school is to give her the social contacts. This is very important for her psychological well-being. She needs to mingle with other children and also with the adults at school, you know. Honestly, that is all I wanted from her going to school. I see her learning outcome as my own responsibility, not the school. When we send her to school, it is our responsibility whether she learns from school or not.
I believe the teaching method in the Western countries is better, she has improved a lot. Perhaps another important reason for her improvement is that I have more time to teach her since I came. I worked most of the time when we were in our own country. But now, I do not work and I have nowhere to go, nothing much to do. So, I spend most of my time teaching her new things. I only came to know her better since we came. She was not under my care before, but now she is.

(Siew Lan, Original in Mandarin)

From what Siew Lan said, we can see again that Chinese parents carry with them the impact of the exclusive Chinese educational system towards individuals with special needs, as mentioned in Merry & Zhao (1998)'s study. Consequently, the concept of sharing the responsibility of educating their children with the local educational system is foreign to them.

He knows a lot but yet little. He challenges me, he knows how to rebel and he knows how to get what he wants. He misbehaves, he is stubborn and he does weird things that others could not understand and think you are a poor parent. I believe if he is a low functioning boy, he would be more compliant and easier to control. Having said that, it is hard to have a child with mental retardation, like one of my friends. So, I don't know, it is hard either way. Hua Chen is not stupid, he knows a lot. He can speak three languages. He can play sports.

As he grows older, he is becoming more and more challenging. I have to understand him by reading his emotions or else he could get very violent. This is the challenge working with children with Autism because they do not know how to communicate their feelings. I know the staff are well
trained and they are good, but no one knows your child better than yourself. So, I never put high expectation on the school. I know they cannot do much for Hua Chen because he is very hard to understand. I am not too concerned about his academic performance. What I am more concerned is his ability to be independent. I hate to think what will happen after I die. I am fearful of the future.

(Zhi Wei, original in Mandarin)

One reason given by these mothers for putting so much effort in their children’s learning is because they have a higher expectation for the achievement of their children. Research findings has indicated that Chinese parents regarded academic achievement as one of the most important characteristics of an ideal child and tend to put less emphasis on attributes such as autonomy (Shek & Chan, 1999). However, this assumption does not fit with the perception of these mothers. Although Zhi Wei and Yuan Ya expect their children to learn, they do not consider academic achievement more important than achievement in life skills or the child’s psychological well being. On the other hand, to emphasise the psychological well being of a child is a more common attribute of the Western oriented parents (Beena, 2000; Newman & Newman, 1991), as mentioned earlier in the Literature Review. However, even though most literature on Chinese versus Western parenting concluded that Chinese parents tend not to prioritize their children’s psychological needs, this is not true in Yuen Ya’s case. She put much effort into developing Hui San’s psychological well-being by teaching her social skills so she can interact with others. It is important for me to indicate again that this is not the attitude of every parent in this study. For Ai Juen, she identified with the traditional Chinese parenting attributes:

As I have said before, we are responsible for Zhan Yi’s visual problem. Because of his visual difficulties, he needs to work harder in his studies. I have been doing after-school tutoring for him before he came to New
Zealand but since he started learning in English, I couldn’t helping him at all because I don’t know English too. So, what we can do now is to get tutors to help him. He is not doing very well at school and I am concerned about that. I always feel like helping him but I am not able to. I know the biggest barrier in his learning now is his English too. He needs an English tutor and I am looking for one. He had an English tutor for a few years and she just left for Germany. She was very good with Zhan Yi and only charged $10 per hour. I really would like to get a new tutor for him as soon as possible at this pay rate because we can only effort this amount. I think this is an urgent need because he is starting to become slack and I do not want him to develop this habit.

(Ai Juen, Original in Mandarin)

**Parental emotional reactions towards the child with special needs.**

Under the pressure of having huge responsibilities for their children with special needs, it is interesting to see what these mothers know about their children’s condition and their reactions towards having a child with special needs. The bulk of existing literature on parenting children with special needs has been quantitative in nature. In quantitative studies, the researchers choose a theory or set of measures and approaches the phenomenon from a certain perspective. This reductionistic research strategy may limit the outcome of the study because rather than seeking to understand the experience as a whole, the quantitative approach tends to focus on certain parts of the phenomenon. For example, there may be no one way parents react to their children with special needs, but rather a spectrum of responses (Akerly, 1984; Byrne & Cunningham, 1985; Morgan, 1988). The way one mother illustrated how she felt and thought about having a child with special needs conveys the complexity of the emotional and cognitive reactions one can have:
Before I had my son, my life was 100%. I have a good husband, a good career. Everything in my life was perfect. It was like, perfect. But then having a child with special needs changed my life entirely. My life is no longer perfect, but I guess I have learnt a lot from my son. Before having him, my life was very rigid in many ways. Through having a child with special needs, I have learnt to be flexible, especially with the special grace we have from God. We are lucky that we have this environment. The New Zealand society is very helpful and the government services are very supportive. My son is in the mainstream school. He has 12 hours of teacher aid each week. The school works on his areas of strengths and weaknesses which I am very happy about.

When I was pregnant with my son, I did not know he has special needs until the day he was born. It was extremely shocking and sorrowful news for me. I really thought that was the end of the world. However, along the journey with him thus far, he has surprised me a lot. He could do much more than I thought. And now that we are in this society where he is more accepted, I hope he will do well.

…but the sad and cruel reality for us would never change, right? I will still have to face the day to day struggles.

The hard fact of my life is, my child can never do as well as the other children. All parents talk about hoping their children to become a doctor, or a lawyer, or an engineer. But, I can’t. I know my child will only do lowly jobs.
Anyway, I just have to learn to put in much more. I love my son as he is. He is my only child. He means a lot to me, more than anyone could understand. And, he is not just a person with special needs; he is more than his special needs.

We have attended the Child Intervention Centre. Though my child has special needs, he is high functioning compared to other children with the same condition. He is not mentally retarded, he can achieve many things. He still can achieve many things. We just do not want to compare him with other children because the hard reality is, we have a child with special needs and he is different.

(Anonymous, original in English)

Anonymous actually reported the benefits and positive outcomes for her to associate with raising a child with special needs. These include coping skills, flexibility, family cohesiveness and spiritual growth. This is not to say that having a child with special needs is not a stressful event. The positive and negative emotions are intertwined and they exist simultaneously. For Anonymous, in between the sorrow and disappointment, there were also hope and perseverance. Similarly, in between the joy of seeing the child progressing, there were also the struggles to accept the reality of having a child who is different from her expectation.

I was not sure what was wrong with her. The only thing I knew was something was not normal with her. When she was about three years old, she was not talking at all. Like many others, I asked the elderly for their opinion because they have the experience of bringing up many children,
and most of them told me that it was just because her development was slower compared to other children and they asked me not to worry about it. So I waited patiently, believing that she was just taking it slowly.

No one knows about autism there. It was so uncommon. We know that some children are not the same, they are abnormal but no one talks about autism. The only time I heard about it was from a documentary of a child with severe autism who cannot live in the presence of light. He had to close all the windows and lived in darkness. That was very scary. That was a very severe case. I thought about the possibility of her (Li Mei) having autism but she was not doing that at all. She wasn’t that mad, she wasn’t as severe. It was not until later that I understood there were differences even among children with autism. For her (Li Mei), she is like this, you see. (Pointing at Li Mei who was repeating some behaviours in front of a mirror). She does this again and again, pretending to be a model, dancing in front of a mirror, and pretending to be a teacher teaching in front of the class.

It is hard to find a person I can talk openly about my child and who can speak mandarin. Do you know much about autism? I really don’t know a lot about it and I don’t know how I should treat my daughter.

(Siew Lan, original in Mandarin)

This mother has had this child for eleven years but it was only when she came to New Zealand few months ago that she was told the child is autistic. Although Siew Lan has been confused and distressed about her child’s condition before she knew about the diagnosis, the proclamation of the exact diagnosis is still a very shocking news for her. As a parent who does not have a full picture of what the diagnosis encompasses, the label
of autism could dampen Siew Lan’s confidence in parenting her child. This is exacerbated by her only encounter with a very severe case giving a bias representation of the diagnosis. Nevertheless, one important principle of this diagnosis is, autism is a spectrum disorder where the characteristics of each individual is different and unique and that children with autism should not be categorized into a fixed list of criteria (Trachtenberg & Batshaw, 1997). Therefore, Siew Lan needs to know that there is no uniform way of treating children with a spectrum disorder. Instead of just providing the label, which may create a sense of unfamiliarity and incompetence, the professionals need to assist Siew Lan in better understanding the individualized characteristics of Li Mei. And in the process, building on the skills that she already has.

From another perspective, the appropriate use of diagnosis may help Siew Lan to better understand Li Mei’s functioning and hence will pay attention to the support Li Mei would require. In addition, to have a conceptual explanation for Li Mei’s atypical development may serve to relief Siew Lan from carrying the uncertainties and doubts about Li Mei’s condition and prognosis, which she has been doing for the past eleven years.

Although Siew Lan’s reaction shows that the diagnosis has magnified the fact that there is something different and problematic about Li Mei, she does not dwell in this feelings of helplessness. Instead, she begins to focus on supporting Li Mei by learning more about the diagnosis as well as spending more time assisting Li Mei with her communication skills.

*She is not talking. The reason is that she has not been talking in her last eight years and her tongue has become unresponsive now. So, it would be hard for her to develop good speech. I did not teach her to vocalize or to move her mouth often when she was young. I was not patient enough to sit down and teach her. I was young and had no patience for her. Besides, I*
saw her only once a week. Our carelessness actually hindered her development quite a lot. Her learning is much better now since I spent my time on her. I give all my time to her now.

(Siew Lan original in Mandarin)

Unfortunately, like Ai Juen and Anonymous, there is a voice of guilt from Siew Lan regarding her commitment to her child’s development. Siew Lan believes she had neglected her child due to the high demands of her job and this had caused some unrecoverable delays to Li Mei’s development.

*It is not easy to face the reality, in fact I have been thinking of committing suicide a few times because I can’t face this painful reality. It is hard to have a child with Autism. Many parents think I am lucky because at least my child is high functioning. In some sense this is true because at least he is not an idiot. And, he has some skills that exceed normal people so you can’t really look down on him. But, I face the day to day sufferings which no outsiders would understand. Sometimes I wonder, if he has low intellectual functioning, maybe my life wouldn’t be so hard.*

(Zhi Wei, original in Mandarin)

Zhi Wei’s comment reflects a negative cultural attitude towards intellectual disability, which has been known to be less favorable in the Chinese society than other kinds of disabilities (Chen, Brodwin, Cordoso & Chan, 2002; Yang, Leung, Wang & Shim, 1996). However, the expression of her struggles revealed battles not often understood by the outsiders for parents with children with a developmental disorder such as Autism.
Zhi Wei also has a different way of perceiving what determines parental acceptability towards having a child with special needs which I did not see from the present literature. Despite the fact that they own a big house and live a well-off life, Zhi Wei referred to her family as “poor” and “insignificant”. During one of our conversations, she compared her family to another Chinese family she knew in New Zealand and said:

*I think it is not as hard for me as other parents to accept the fact that my son is autistic because we are a poor and lowly family. We just live a simple life and avoid thinking too far. My friend is not the same, she and her husband are both doctors, they are rich and well educated people. When they knew they had a child with low intellectual functioning, they were so overwhelmed and even until now they still can’t really accept this reality. So they isolated themselves and avoided talking about their son, even to me. I’m one of her best friends, yet still she wouldn’t talk about her son. I have invited her many times to attend some seminars on raising children with special needs but she is often very resistant. I have asked if she is willing to talk to you too but she quickly rejected. I guess it is because both her husband and herself are so bright that it is really hard to face having a mentally retarded child. They have high expectations for life and themselves, you see. And also, both of them are doctors, they do not need other professionals to tell them what they should do. They have all the resources knowledge-wise and financial-wise. They have a real big house with all the equipments that can help their son to learn. They are self-sufficient, they do not need others. They are unlike my family, we are poor and insignificant.*

*(Zhi Wei, original in Mandarin)*

*Before we got married, we planned everything. We saved enough to buy a house. We went for medical checkups to make sure we were both healthy. We planned everything for our future before we got married.*
When Hui San was born, we tried to find the answer for why she was born like this. There was no external factor as far as we could think of. And we couldn’t find anyone who is like this from both sides of the families. We couldn’t trace any genetic defect from our family members.

I feel lucky to have a child with intellectual disability because it is much easier to manage compared with other disorders such as autism. Besides, Hui San is a girl and it is much easier to manage a girl than a boy. Hui San only has a lower IQ compared to an ordinary child. Her thinking is still the same as ordinary people. It is not like children with autism. They have a different way of perceiving the world and it is very hard to teach them, especially in the area of safety. For Hui San, as long as I am patient with her and don’t give up in my teaching, she would understand one day. The only thing is, it takes a lot of energy and effort to teach her because she needs time and guidance for every little step in any task.

Behaviorally, Hui San has no big problems. She is a delightful girl. I have heard this comment from many people including her teachers. In fact, her teacher loves her very much. She is cheerful and happy, you know. Her father too, often comments that she is a very lovable child.

Hui San is a special girl. She knows God since she was very young. For Hui San, her faith is so simple yet so real for her. I believe this is what made her a happy and lovable child despite the impairment and rejection she had been through. Sometimes she would come home with a sad face and said to me, ‘I am not happy today because I did something wrong at school today. I have not been a good girl again.’ Then she would say, ‘I
know I am wrong and I will not do it again. I believe the Lord Jesus will forgive me, right?’ Then she is happy again. When she is rejected by a kid, she sometimes would say to herself, ‘This person doesn’t like me. Never mind, my Lord Jesus loves me.’ So, this is why she is lovable. She is simple. She loves reading the Bible and sharing the Bible stories. She often would sit in front of me telling the Bible stories. She never gets bored watching the animated Bible stories again and again.

I do not mind for you to use our real names. Though Hui San has low intellectual functioning, she has her dignity as a person. There is nothing we should be ashamed of. You are free to address her with her name.

(Yuen Ya, original in Cantonese)

Yuen Ya’s last comment powerfully conveys an undivided and complete acceptance of the individual with special needs, which is often not the attitude reported in the literature. While there have been some studies exploring the actual experience of parenting a child with special needs, existing research has largely focused on its negative effects. Specifically, some have addressed issues and stresses Chinese families face from having children with special needs (Su, Lung & Chang, 2000). Two studies done in Hong Kong (Tsang, Tsang, Chan & Lee, 1992; Shek & Tsang, 1993) reported that parents of children with special needs often had difficulties in child care activities, such as managing the emotional and behavioral problems of their children. Parallel to the domination of the medical model in the disability arena, the majority of the theoretical frameworks of these studies has been influenced by the transactional model introduced by Folkman, Lazarus, Gruen & DeLongis (1986). In conceptualizing parenting children with special needs, the transactional model emphasizes the role of cognitive appraisal and coping in mediating relationship between stress and adjustments. Consequently, the overall focus with families with children with special needs leans towards the psychological domain, which
inevitably resulted in losing sight of how the socio-cultural context shapes parenting, parental investment and family resiliency (Ewart, 2002; Harris, et. al, 1991; Konstantareas, 1990; Tunali & Power, 1993). The common factors discussed include negative parental reactions to the child’s special needs and the multiple stressors that impinge on family development (Ferguson, 2001; Johnson, 2000; Mohr, 2000). Despite the enthusiastic attempt to promote positive or strength focused intervention approaches, there has not been much examination of the more positive aspects of family coping strategies, strength and growth from rearing a child with special needs (Ewart, 2002; Morgan, 1988).

**Parental investments.**

Some children’s conditions challenge the process of parenting. Having a child with special needs violates the expectations of parenthood and the reciprocal nature of parenting. The parents with children with special needs often do not receive the rewards they would expect from parenting their child compared to normal parents when the child’s gift of responsiveness is never capable of being normal. The complexity of the disruption to parenthood is even apparent when the child becomes an adult but does not have the ability to fulfill filieliety to the aged parents. Despite the fact that many of these children are unable to reciprocate, it does not lessen the investment parents put into rearing their children with special needs. On the contrary, many of these couples invest even more in their children to compensate for the special needs.

*My child’s living is totally my responsibility. For his learning, the school has a programme for him, however, most of the skills are taught by me because he needs endless practices and prompts before he can master a skill. My teaching begins from the moment he finishes school through the moment he starts school the second day. I mean, my teaching role goes on even throughout midnight. Every night, I would spend at least one hour in*
the toilet with him before he goes to bed to teach him the procedures of toileting and would do the same in the middle of the night. Because he needs many prompts, it would take at least one hour every time he goes to the toilet. He is improving through this intensive and strict supervision. The most frustrating thing is, I can't be slack even just for a day or two because he would go backward in what he has learnt once I loosen my training with him. Then, I have to repeat some of the lengthy procedures again. Apart from his training program at home, I have been very closely involved in his learning at school too. I read all the information provided by the school, I learnt about the Picture Exchange Communication System and use it with him at home. I also attend conferences about autism. My son is different from ordinary children; he has no self learning ability. It is a very hard work to bring up a child like this. Truly, my parenting requirement is not the same as the general parents. The level of involvement in teaching every, I mean literally every step of self-care skills, is in every moment of time you have. The amount of effort is not apprehensible by an outsider. But we are happy to put all our attention on him. We will not have another child because since Wu Bin needs more, we will concentrate all we have on him.

(Chui Min, original in Mandarin)

I have read about autism and I know some of these children have an extraordinary strength. We are exploring on Wu Bin' strengths. We bought him musical instruments but we haven't seen any evidence of interest or talent. We will keep exploring and wait for the time when we have found his interest. Then, we would focus on his talent and work on that.  

(Chui Min, original in Mandarin)
There was a great deal of common ground among the mothers who took part in the study about the things that distinguished the role of mothers from those played by significant others in the child’s life. However, I was astonished to see what Yuen Ya showed me while she explained to me the extent of her involvement in Hui San’s learning:

I know Hui San needs a longer time to acquire a skill compared to ordinary kids so I started teaching her the skills earlier. Her curriculum is ahead of her peers. I have finished planning all the activities for this coming holiday. I will be doing a holiday program with her. When I showed her teachers what I have designed for Hui San, they were very impressed. I always design my own curriculum and teaching resources. The materials I use include books such as encyclopedia. I also collected articles from the newspapers to teach her general knowledge. Her teachers commented that she knows a lot. Honestly, most of the skills Hui San has are taught by me. The school is not aware of how much time and effort I have put into Hui San’s learning. They do not know I am her teacher. I send her to school because I don’t want her to socialize with her mother only. I know she needs friends.

(Yuen Ya, original in Cantonese)

Apart from being a teacher to Hui San, Yen Ya and Hui San live a sheltered life. Yuen Ya has to assist Hui San in every way. Yuen Ya’s commitment to being a mother is unreserved, as though she is living for her with a fully scheduled life. The lives of the mother and child are so intertwined as we can see from the intensive daily involvement described above. Yuen Ya’s role moves beyond a mother’s role to that of a trainer, a practitioner and the decision maker. She has also taken the role of mediator for her child.
Hui San is very much dependent on me in her learning since she started school. I am like her personal multi-specialist. She would not take the advice from the teachers or her father but only from me. I equipped myself with as much skills as I can to help Hui San with her special condition. I consulted many specialists, attended seminars, joined many intervention centers and read many books. I know quite a lot about Hui San. She has difficulty with her planning so when she is given a task, she would need assistance for planning. So I created many opportunities for her to develop her planning skills. I was the first person to discover she could not differentiate the sounds /f/ and /s/ and she needed a hearing aid. I found that by exploring the reasons for her not being able to concentrate in class. In fact, she has not learnt a lot from attending school. There are too many hindrances that interfere with her learning. She learns better at home through my own teaching and intervention plan.

When Hui San is at school, I spend my time thinking about every relevant skill she needs to learn. I designed pictures or activities to teach her. I started with self care skills, the basic safety knowledge and problem solving. For example, I taught her who to ring if I accidentally became unconscious. I also taught her how to protect herself from strangers from sexual assault. I have also spent 1.5 hours everyday giving her physical training since she was very young. With all these commitments, I have no time to keep in touch with my friends. I have no time to keep my personal social network and I slowly lose it.

(Yuen Ya, original in Cantonese)

As a new immigrant, Yuen Ya does not have people who can take over the care for Hui San even just for a short time. Consequently, Yuen Ya's life revolves around Hui San.
Similarly, Hui San also social interaction becomes very limited because there are no other relatives or family friends that she can associate with, whether adults or children. From a long-term perspective, this might develop over-dependency between this mother-child dyad.

Yuen Ya’s enormous investment in Hui San is not out of the ordinary among these Chinese parents. Many others also have something to say:

_Since we migrated, Li Mei spends most of the time with me at home. Having a child like her takes all my time. I don’t even have time for sports or exercise. She needs my full attention. When she is at school, I have plenty of housework to do. So my life is all around my child and my family._

(Siew Lan, original in Mandarin)

_I am pretty confident that what I know about Autism is not less if not more than the professionals because from the first day we knew he has Autism, I have been reading every book I could find about Autism._

(Zhi Wei, original in Mandarin)

_I love my child. He is my only child. Life is difficult enough for him. My husband and I want to protect him. He is our child. What he gets is what we decide._

(Anonymous, original in English)

Instead of lessening their investments and putting their hope on other children, the majority of these couples decided not to have anymore children so that they can fully
commit themselves to the child with special needs. For those who have more than one child, the fact that Zhi Wei has to ‘free’ her other two children as quoted in the previous chapter opens the window for us to see the complexity of family dynamics and adjustments necessary when diversity between the able-bodied children and the child with special needs increases as they grow older. Usually, when a family needs to move, the parents make the decision for the whole family based more on the needs of the child with special needs while the other able-bodied family members accommodate to the decision. However, at this point, in the case of Zhi Wei, there was no arrangement that could cater for the interests of all the children. Or, more precisely, to accommodate to Hua Chen’s best interest would be at the expense of the other children’s happiness and future prospect. While facing this emotionally challenging decision, Zhi Wei decided to take up the pain of separating from her children for their gain. It is important to note that to leave the parents before a child gets married is very uncommon for Chinese families. The sacrificial love of this mother is shown even greater when instead of giving up on the child with special needs and putting her hope in her daughters; Zhi Wei chose to stay in New Zealand for Hua Chen to invest even more in him. She trusted her able-bodied children to pursue their own happiness with their given abilities.

*Our property belongs to Hua Chen. My other children will have to look after themselves. I have told them since they were young that we will give everything we have to Hua Chen when we die so that they know they have to look after themselves. I have made it very clear to them that we will not pass any of our property to them. But, we will support them in their studies including their tertiary studies so that they will have the skill to earn for their living but all of our property will be saved for Hua Chen because he can’t be independent.*

(Zhi Wei, original in Mandarin)

Despite Hua Chen’s inability to reciprocate to their investment, this couple has worked very hard to do as much as they could before they die to provide for and secure the future
of this child. Furthermore, they have decided to invest more in him than in their other children even though it will most probably be the other able-bodied children that could fulfill their filiality towards their parents. The following excerpt further exemplifies how actively Zhi Wei is preparing for Hua Chen’s lifetime provision:

I do not want to think too far ahead because it is scary. What would Hua Chen’s life be when we die? I have been to the local respite care and what I have found is even more worrying for me. These people do not have quality lives. The respite care centre only provides for the very basic needs. But I want my child to have a comfortable life. I am worried that he would not be able to cope with the limited care provided in the institution after I die because he has always had a luxurious living environment. I am regretful for spoiling him. He has all he wants now and our life is centered around him. I have thought about this for a long time and I think what I might do is bring Hua Chen back to Taiwan because I have found a private institute for people like this which provide high quality care. The respite care service in Taiwan is better compared to New Zealand. I want him to be in good residential care. We are prepared to pay thousands a month as long as he has a better life. We will not send him to the public institute. We have saved enough for the rest of his life. When we go back to Taiwan, we would sell our house in the city and move to a remote area because we want to be far away from the rich and arrogant people. We prefer a less crowded city and a simple life. In fact what attracted us to New Zealand is the simple lifestyle here.

I don’t know, I guess I just live one day at a time.

(Zhi Wei, original in Mandarin)
This excerpt shows the depth of a parent’s heart for their child with special needs. However, it is not clear whether the meaning of "comfortable life" to Zhi Wei goes beyond material wise or not.

A common phenomenon is that Chinese parents would be more willing to let their lives 'center around' their child with special needs and they would provide for the whole lifetime of that child as much as they can. This might be different from the child-rearing attitude of the Europeans who emphasized individuality and rights.

Interestingly, Zhi Wei made comments about wanting to be far away from the rich people to a less crowded simpler life. I wonder having a child with special needs has led them to value different things in life.

**Support**

As with all human endeavors, a child with special needs does not exist in isolation, nor does the concept of special needs exist without its social context. Likewise, a family’s interpretation of the meaning of special needs would undeniably reflect to some degree the larger context of social attitudes and historical realities within which that interpretations emerged. The experience of these Chinese families from having a child with special needs is very much influenced by the support they received from their social contacts. These experiences, whether pleasant or unpleasant, then shape their perceptions towards having a child with special needs. From the accounts given by the seven families, three forms of support emerged from the stories of these seven Chinese families with children with special needs living in New Zealand. These forms of supports are: the familial support, the professional support and the social support.
Familial support: the role of the extended family

The full commitment of these parents is at the cost of their own socialization opportunities. Literature on families with children with special needs reported social isolation and a lack of social support for these families especially for the mothers who have to pay close attention to the child with special needs (Batshaw, 1997, Beckman, 1996; Ferguson, 2001). Among the seven families in this study, on top of having a child with special needs, they are also going through a social network transition as a result of leaving their home countries to reside in a new country where the language and culture are very different. The biggest challenge for quite a few of them was to leave their extended families and to adjust to the absence of support from them. Conversely, for some, leaving the extended family to live as a nuclear family is actually a relief. It is important to keep in mind that like the Maori culture, the family unit in traditional Chinese culture is the extended family, not the nuclear family. I will let these mothers share in their own words the significant roles of the extended families in their lives:

Before Hui San attended primary school, I worked as an accountant. I employed an Indonesian housemaid to look after her. That was very economic because the pay for a maid was low. Her grandmother would bring her to the kindergarten everyday. We were living with the grandmother then. We wanted to bring her grandmother to New Zealand to live with us but she refused to come because her health is deteriorating. And it would be hard for her leave the familiar people and environment. She was not willing to come with us.

When we were back in Hong Kong, we had support from our extended families. That was very important and valuable for us. We felt a sense of security. Living in this foreign country, we feel we have very little support.
My mother-in-law is a wonderful person. She is open-minded and modern. She accepts Hui San fully. My own mother is very supportive too. All the members of our extended family know Hui San’s condition very well. We have been very honest in communicating to them about Hui San. They are very accepting and understanding. They are willing to spend time interacting with her, which is so good for her psychological development. She became lonely since we came.

(Yuen Ya, Original in Cantonese)

Migrating to New Zealand does not only involve change of the environment, it also means a change in lifestyle and parenting responsibility for the parents. Yuen Ya’s role changed from working as a full time accountant to a full time caregiver for Hui San. The emotional and psychological challenges during the adjustment period should not be overlooked. Her feeling of the lack of support needs to be heard.

The primarily caregiver for my son is my mother because she is at home. She came from China specially to look after him. Without my mum’s help, how could I survive? I mean, it’s not an easy task. It’s not just ordinary care. It is a 24 caregiving job and I can’t do that with my job commitment.

(Xiao Lin, original in Mandarin)

Xiao Lin's mother's participation in the care giving of the grandchild is a classic representation of the lifelong parental involvement in Chinese culture. Xiao Lin's mother is in her late sixties and she speaks no English. Xiao Lin explained that coming to a foreign country was a big sacrificial act of her mother because it involved leaving her social networks and familiar environment.
During my first visit at Siew Lan's, she shared freely and openly about her life in New Zealand, her description of her life here is not entirely positive. Siew Lan missed her hometown. She missed her extended family though she has some relatives living in New Zealand too. In between the descriptions of her lifestyle in this new environment, she brought in memories of her home country. Often, she compares them and works out the pros and cons. The place of the extended family in the dynamics of her nuclear family is indispensable as we can see from the excerpt below describing how they share her role in parenting:

*Li Mei was brought up by her grandparents. My husband and I had to work in Kimali so we could only visit her at nanny's place once a month. When she was a little older, her aunty looked after her. We paid her to be her nanny and she lived with her. We were all concerned about her development and often discussed together but we were not sure how delayed she was.*

(Siew Lan, original in Mandarin)

Despite her longing to be with her relatives, Li Mei’s welfare was the central consideration factor for their decision making. They decided to leave their country of origin because there were no resources for them to raise this child. Siew Lan came from a country where services for children with special needs were so scarce that only the population at the top of the social economic status could access them. This country is not an under-developed country; however the welfare of the children with special need has been uncared for by the government. Consequently, the services are delivered only through private practice. This phenomenon once again portrays the society’s exclusive attitude towards individual with special needs.

*But when she was four or five, we knew she was definitely not normal, so we thought about moving from our village to the cities where there were*
institutes and schools for children like these who have problems. The medical services were more advanced in the cities. However, private practitioners run them and the fees were unaffordable for us. My salary was only enough to pay for her school fees, I mean, all of my salary was only enough for that. So we knew that was not going to work.

(Siew Lan, original in Mandarin)

Instead of keeping her child's special circumstances within the family to avoid stigma as suggested in the literature, Siew Lan had the whole community in her village involved in understanding the development of her child, as shown in the excerpt below:

When Li Mei got older, the elderly started to tell me that she was deaf. So we tested her by calling her name from a distance and seeing if she would react, and she did. So, we knew she was not deaf. Then, they started to think that she was dumb. So again they tried to test her by provoking her in various ways to get her to make some noises...

(Siew Lan, original in Mandarin)

Although through sharing her concerns with the community, Siew Lan received some useful suggestions and advices, it did not always lead to positive outcomes. In some occasions, it created much stresses on Siew Lan who knew her child more than anyone else.

Many thought she was dumb, but I had a feeling that she wasn’t. I had quite a few unhappy experiences over this matter because all of them, especially her grandfather insisted that she could not speak but I knew she could. Then one day, when I brought her out for a walk near the railway station, she
suddenly said a sentence: ‘That is a train’. I was shocked and surprised. She never said a word before but she gave me a complete sentence all of a sudden! So I quickly brought her home to show the grandfather, telling him that she could actually talk. He reluctantly believed what I told him. I tried to get her to talk again after that but she never did. That was the one and only time she spoke. She never does it again, frustrating, isn’t it?

(Siew Lan, original in Mandarin)

When the traditional method is unable to make sense of the characteristics of the child’s special needs, the involvement of the extended families, especially the older generations could create confusion for the parents. Like many Chinese young women, Siew Lan was taught to follow and respect the advice of the elderly, which was, in this case, conflicting with her understanding of her child. In another excerpt, Siew Lan mentioned that no one in her village ever heard about Autism, and nobody believed her description of her child. The conflict between Siew Lan’s experience and her father-in-law’s thinking introduces us to the possibility of the intergenerational gap in terms of perception towards special needs. This increases the burden of parents especially the mothers as daughters-in-laws because traditionally, they are expected to submit to their in-laws. In the case of Chui Min, unfortunately, she has even more to deal with. She is related to Siew Lan but they have different in-laws.

We would join the extended family whenever there is a family gathering. My mother-in-law loves grandchildren; she often helps to look after the grandchildren except for Wu Bin because she could not cope with him. When Wu Bin was born, she was very happy because he is the only grandson. My husband has a sister who is married but has no children, and a brother who has three daughters However, as we slowly discovered that he is autistic, his grandmother was terribly disappointed. And she
withdrew from us. I mean, we still see each other sometimes, but she never visits our place or cuddles Wu Bin. She often says to her relatives that her fate is bad because she has no grandson.

Before I gave birth to Wu Bin, my mother-in-law favored me... But her attitude towards me changed when she knew Wu Bin is not like other children. I can feel that very significantly. However, I never talk about her reactions towards me or the hurtful feelings I have with my husband because he would think I am over-sensitive. Besides, that would put him in a very difficult position because she is her mother and he can’t complain to her about her attitude. So, I just keep it to myself.

I believe my extended family has the idea that I am the one who caused our child to have autism because my brother has a child with autism too. So, it is reasonable for them to think that the problematic genes come from me and I am the one to blame, especially with my mother-in-law. When talking to our relatives, she would make comments like 'it is from the female side'.

Once when I was at the restaurant with my mother-in-law and sisters-in-law, I expressed my thinking about my plan for old age during our conversation. I said to them, I would not rely on my son when I am old. Immediately, my mother-in-law became upset and very angry. She said to me ‘so now the young generation would like to be different, huh?! How can you have the idea of not living with your child? You are so young and yet you have this kind of idea already.’ Actually, I am quite open-minded. I think it is worse to insist living with my child when he couldn’t look after me, especially when I am old and when I need domestic care. For me, it
would be more enjoyable and easy to live in an old people's home because I would be provided with all the facilities and care there. But my mother-in-law was offended because I have this idea.

(Chui Min, original in Mandarin)

My husband has an elder brother who is a pediatrician. His wife is a pediatrician too. My parents-in-law put a lot of pressure on them because he is the eldest son and they wanted a grandson from him to continue the 'family root'. Unfortunately, they have no children even though they tried hard. When I gave birth to my two daughters, the competition between my sister-in-law and myself was not as bad because what my parents-in-law wanted was a grandson. But, when I gave birth to Hua Chen, they became very envious. Of course, I did not know Hua Chen was not an ordinary child when he was born. But his behaviours escalated when he was two years old. No one was willing to understand his condition because they did not want to accept the fact that he was not a normal child. It was extremely painful news for my parents-in-law because Hua Chen was the one and only grandson. Hua Chen was not an ordinary child. He did not call mum and dad until he was three. I had to pay extra 50% to the nanny every month because he broke so many things. He loves the noise of broken glass so he would throw glasses and plates whenever he has the chance. My relatives did not show empathy. They did not understand he was not a normal child. Many times, my brother- and sister-in-law sarcastically commented on my parenting skills. They told me what Hua Chen needed was smacking and discipline, and that he has no disorder; it was me who was creating the disorder. I was told I had uterus cancer when Hua Chen was 5 months old. No one understood the hardship I went through. That is why I do not keep in touch with my extended family. What they have to offer are critiques, comments like: I'm a lazy mum, I have
poor parenting skills, I spoil my child etc. Even though they are pediatricians, they would not admit the existence of Autism in Hua Chen.

(Zhi Wei, original in Mandarin)

There are a few cultural values that I tend to take for granted but I believe are important for me to point out to my readers. First, the cultural significance of having a son to carry on the family lineage still prevails in the modern Chinese society. Chinese attach importance to surnames because the surnames relate the individuals to their ‘root’ or ancestors. As a child’s surname would follow after his father’s, it becomes important for a couple to have at least one son to pass on the family lineage. Second, the women are believed to be responsible for the gender of the child. Third, to please the in-laws is one of the virtues of a married woman. Fourth, having many grandchildren is one of the highest honors for a person in his or her old days. Fifth, Chinese children are expected to honor their parents by obeying and respecting their parents even after they are married. All these values are expressions of filial piety (Ho, 1994; Liu, 2001; Tu, 1998).

Having a child with special needs may constrain these mothers to fulfil the expectations of the extended families and hence create disharmony in relationships. Breaking the good relationship with extended families could cause these mothers to lose social, emotional, and for some even financial support. As in the case of Zhi Wei, she had to bear with loneliness during her health trauma.

*When my son was born, my friends, my relatives avoided me. It is like my child’s disability is a contagious disease. They want to get far away from us because they believe we bring ‘bad luck’. My child’s disability for them is ‘bad luck’. It is hurtful whenever I recall these experiences; people can say so much negative things. (she was emotional as she said that)*

(Anonymous, original in English)
Relating the birth of a child with disability to the supernatural is not just an ancient Chinese societal attitude but it is still prevailing at present. According to my literature review, the extent to which a family holds on to the traditional beliefs is correlated to the level of acculturation and education in that family. Also, ‘traditional belief systems on disability are at times quite adaptive, shifting in response to social, economic and educational experiences gained through the acculturation process’ (Groce & Zola, 1993, p. 1054). I would like to explain here that Anonymous came from a well developed society where there are advanced medical services. However, traditional beliefs are still deep rooted in the daily practice of the society as suggested by Zhang & Bennett (2001). Therefore, the influence of the traditional beliefs on the families should not be undermined even though a family might seem considerably acculturated or has received Western education.

**Social support: living in the New Zealand community.**

For a Chinese parent like me, I feel quite lonely living in this community. Though there are now many Chinese migrants in New Zealand, I feel lonely because none of the Chinese families I know has a child with autism. None of my friends have a child with special condition like this. Their children are all normal, they do not have the same experience, so it is hard for them to understand my situation. They can’t understand how I feel. I do not isolate myself. I socialise with people, but I can never bring issues about my child into our conversation. I usually just shut that part of my life off when I go out with my friends. They feel uncomfortable asking about my child too because they don’t know what is going on and they can’t help too. However, that is the biggest part of my life.

(Chui Min, original in Mandarin)
Chui Min uses a multiple self strategies in maintaining her social network.

*I am lucky to have my husband’s extended family here. I sometimes hang out with my sisters-in-law (husband’s sisters). From my own family, I have my brother and his wife living in Christchurch. They have a daughter with autism too. I sometimes meet with his wife for a meal or to go shopping together but we seldom go out together with our children because Wu Bin and Li Mei do not get on well. It becomes difficult when your children do not play together. As a result of this, we see each other less frequently and if I see her, we will not usually talk about our children. So, when I go out with her, I also tend to shut off my feelings about my child.*

(Chui Min, original in Mandarin)

In the previous excerpt, Chui Min’s difficulty associating with other Chinese mothers is because they do not share the same experience. However, having a sister-in-law who shares the same experience did not seem to give Chui Min’s more social support. It is very common for Chinese parents to revolve their lives so much around their children that their lifestyles are governed by their children’s preferences. One possible explanation for this phenomenon is that, one of the basic assumptions of the Confucian scholar is that a child’s disposition can be derived from environmental influences (Chao, 1994; Goldin-Meadow & Saltzman, 2000; Munro, 1977). Often cited and recited for Chinese parents is the exemplary story of Mencius’ mother who sought the best neighborhood for raising Mencius. The story is known as 孟母三遷 (meng mu san qian) which means Mencius’s mother moved three times. Mencius’ mother’s sacrificial act in finding the best environment for her child regardless of the effort it required strongly inspired Chinese parents to sacrifice for their children. Mencius’ mother was mentioned in one of the
classic literature, The Biographies of Virtuous Women in Ancient China (烈女傳, lie nu zhuang), written in 77-76 BC and became an example for Chinese women (Zhang, 1993).

Apart from my sister-in-law, I haven't really known many people. But she is very busy with her son. She stays at home most of the time because no one can look after her son for her. And, it is very tiring to bring children like these for an outing. We both have the same feeling, we don't feel like participating in any activities because it takes a lot of effort to bring a child like this along. We had tried before and thought it was not a good idea, really. They are not like other children who can wait and can cooperate. Their behaviour problems really put us off; it is very troublesome to bring them for any outing. So, she stays at home and I do too. In some way, I think my life is easier because she (pointing at Li Mei) is a girl and girls aren't as active as boys. Though she runs all over the place and she can do dangerous things, but never as bad as my sister-in-law's son. I think my sister-in-law really has a tough time. It is a very hectic job to look after a child like this. You know, she got really exhausted at one point, emotionally and psychologically. She spends most of her time at home and even if she goes somewhere, she likes to be with her own family. They like to stay together as a little family. So I don't feel I should interrupt. I have no car, so we can't go anywhere too. My husband is not home until evening usually. By the time he is home, Li Mei needs to go to bed.

(Siew Lan, original in Mandarin)

With their explanation, we can see that these parents did not seem to deliberately isolate themselves socially, but it is just that circumstances prevailed.
Later, Siew Lan provides more facets of the effects of the children’s behaviour difficulties:

*I have no close friends here. My support is back in my own country. I ring usually. It is good that with the prepaid phone card, it is not too expensive to ring my friends. I always go to them. There is no one I can really talk to here.*

*Well, sometimes I play mahjong with some Chinese women to release my stress. I only know these women because of the game but never can talk to them. They are not good friends, just game mates. They don’t provide emotional support to me. None of them have a child like Li Mei. They are all normal so they can’t really understand my situation. So, I just don’t mention about it because that is meaningless. That is just for me to relax myself.*

(Siew Lan, original in Mandarin)

*I have been very active in attending the meetings for parents with children with special needs. I even work voluntarily for places like CCA (Cripple Child Association). One thing I find interesting is, I have never seen another Chinese parent in all the meetings I have been attending all these six years. It is not easy to be a Chinese family with a child with special needs in New Zealand. I often feel very lonely because no other Chinese parent who shares the same experience is willing to actively involve themselves in the activities. Sometimes I wonder if I am the only Chinese*
parent with a child with special needs in New Zealand apart from another family from Taiwan I know of.

(Zhi Wei, original in Mandarin)

These words provide insight to realizing the extent to which Chinese family with children with special needs is reluctant to actively involve themselves in meetings.

*I have no opportunities to associate with the Kiwis. I had been to a church where there were 50% of Kiwis. However, I seldom socialize with them. I would choose to ask or talk to a Chinese whenever I have a question because it is much easier to communicate.*

* I do not know any Chinese family with a child with special needs. I have only seen one at church but we don’t know each other well. I would think having a support group among the Chinese parents would be good so that we can have some time off. Joining a support group with the local parents is not as desirable for me because it is hard for us (Chinese) to mingle with the Kiwi parents. Our lifestyle and thinking are too different and it is difficult for me to communicate with them.*

(Yuen Ya, original in Cantonese)

Comparing Yuan Ya's comments, there are contradictions in her socialisation preference. On one hand, Yuen Ya would choose to associate with Chinese more than Kiwi, on the other hand, as she said in the last excerpt below, she knows that Chinese parents have a more competitive attitude of comparing their children’s achievements. Nevertheless, even though she is trying to avoid that kind of pressure, and feels more at ease with the less competitive attitude of the local Kiwi parents, she still wishes a Chinese parent
support group could be set up. Probably she thinks that among parents with children with special needs, this kind of attitude would be less if not absent.

In the Chinese society, academic achievement is the most important requirement for every parent, not the child, but the parent. It is almost the one and only thing we care about. When parents talk to each other, the first thing they would talk about is, of course, how bright your child is and how well the child does at school. The whole community thinks highly of education and it becomes the reference point. Parents with bright children are proud, children who do well at school are regard as smart and they often look down on those who are not doing so well. We are a community of ‘kia su’ (fear of being a loser) and ‘kia si’ (fear of death). I have no stand in the conversation among the other parents because the only thing they want to know is my child’s academic achievement. The hard fact of my life is, my child can never do as well as the other children. For a parent like me, I just have to accept this hard reality.

I do not know other Chinese children with special needs. I don’t think it is necessary to have a Chinese parents’ support group because the competitive attitude would be there too. I prefer to stay within my own boundary.

(Anonymous, original in English)

I really think Chinese parents have a very competitive attitude. Among the Chinese elderly community here, they talked about their grandchildren most of the time when they have a gathering. Comparing the number,
gender and achievement of their grandchildren is the most popular topic. The achievement of their children determines whether they themselves have a life with good fate or a bad fate. They will mourn for having a bad life if their children are not as successful as their friends’ or relatives’ children. As for me, I do not think that way. I am quite ‘westernised’. However, it is not easy to associate with Chinese parents without comparing our children. People would do it automatically.

(Chui Min, original in Mandarin)

The attitude of comparing among the parents in New Zealand community is not as rigorous. I only feel it slightly here. This takes the pressure off and it helps me avoid that sort of thinking.

(Yuen Ya, original in Cantonese)

Unfortunately, the competitive attitude is so customary among Chinese community that parents from various countries feel its presence and impact. Many of them relate this attitude directly to their 'Chineseness'. For example, when expressing her objection towards this competitive attitude, Chui Min described her difference in attitude as due to her being more "westernised". And, Anonymous refers it as "the Asianness" which she dislikes. Obviously, this is a major factor that keeps these parents away from supporting each other. However, the change in attitude of Anonymous towards me as a Chinese practitioner brightens the hope of the possibility to overcome this hindrance. From hearing how these mothers feel about their children, we know that at least the efforts of these parents in caring for their children should be reassured.
Professional support: experiences and perceptions towards the professionals.

I think since it is my child who has the disorder, I should be responsible for his upbringing. I need to study about the disorder and to equip myself to be a competent and resourceful caregiver for my child. I don't think the high teacher to student ratio teaching is enough for my child. To me, the most effective intervention is provided by the mother. I have been to the early intervention program too to observe the quality of the service. I know it is important to praise your child but I don’t think you should praise when their work is not up to their potential. If you say ‘wonderful’ to every little thing they do, they will remain satisfied with the achievement they have and will not be motivated to do better. The parent must be the educator if you want your child to do his best. I think it is just because we come from a different cultural background so we have different standards for our children. I agree that there are many sound policy and plan drawn by the government, but there is a gap between policy and implementation.

(Zhi Wei, original in Mandarin)

The first professional we saw when we first came to New Zealand was a Chinese therapist from Auckland. My sister-in-law told me she is an expert for children with autism so we went to see her. She told me Li Mei is autistic. She confirmed it to me. We also brought her to the room where they play all kinds of games with her, playing like children going wild, just playing. We brought her there 2 or 3 times a week for quite a while. These professionals were very patient. They gave Li Mei presents or gifts every time she did something good and they said good things to encourage her very frequently. I think that is a good method because they told me when I praise her, she would become more interested in improving herself and
would feel that she was doing something good. I used that too in the beginning. But I can’t keep on doing that because I think she learns faster through constant reminder and close supervision. I spend all my time when she is at home teaching her how to write and the basic self-care skills. She is starting to master some of them.

I had also been to the school and talked to the therapists on how to help her improve her learning. However, the strategies we use at home are different, you see. I am the person who looks after her daily and knows her very well. She needs pushes so that she learns faster and better. I know she has the potential to do certain things. I follow what I have learnt from my experience with her to see what methods work the best. Besides, I can’t let her waste her time. She is growing everyday. She can’t remain like a baby. She needs to learn.

(Siew Lan, original in Mandarin)

Instead of expecting the services to provide better quality services, Zhi Wei equips herself with the competencies to take up the role of a trainer in order to make sure Hua Chen receives one-on-one teaching opportunities. On the other hand, Siew Lan assimilates the traditional Chinese parenting to work out a strategy that works with Li Mei. The common ground of these two parents is, when the services offered are not as compatible, they adopted a variety of strategies to improve the situations. These parents got to know their own children and to formulate ideas about what is the most effective way in meeting their children’s needs in particular areas. The conservative viewpoint is that Chinese parenting focuses on respect and obedience and hence Chinese parents seldom praise their children (Gorman, 1998; Shek & Chan, 1999; Wong 2002). This is commonly interpreted to be negative. The use of praise could be important, however, as these parents explained, they were aware that the misuse of praise could create a teaching
approach that is bound to restrict their children's potential. Similarly, Siew Lan's last comment could have been interpreted as being impatient. Nevertheless, from another perspective, it shows the emotional attachment of a mother towards her child which the professionals do not have. This emotional attachment is often the source of motivation for these parents to walk the extra miles with these children, while not many professionals would go as far. Therefore, it is important that professionals do not judge parents' reaction but be more thoughtful about how this emotional attachment might effect their decisions and attitudes.

It is important to acknowledge, on the other hand, that some mothers did point out pleasant experiences with professionals and appreciated their contribution.

_Sometimes the descriptions for a therapy or for the professionals make it sound like the professionals are scary...like they are some kind of monsters. But once we have personal contact with the professionals, it is usually not the case. Most of the professionals are friendly. They do not put pressure on the parents or the child. Only sometimes, the professionals who do the assessments treat us harshly and have bad attitude. This upsets us._

_Often I am not sure whether my approach is appropriate or not. So I wish to have a professional whom I can learn from. I would really appreciate it if a professional can give me some advice on how to improve my approach with my child. Parent training would be helpful too because then I will have someone I can consult and discuss my queries with._

(Yuen Ya, original in Cantonese)
His teachers tried to help us (parents) by explaining the possible reasons for Wu Bin to have self harming behaviour and they encouraged me to be patient and to bear with the process. That was very helpful for me because it sustained me and gave me the support needed to endure heart-breaking times. I know I need to endure the pain and let him go through the hard times because I believe this is good for him.

(Chui Min, original in Mandarin)

I never heard of the Child Intervention Centre until I attended the session. Later I went to look in the internet for more information and realized that it is well known around the world for early intervention. So, I feel very lucky to be in the Child Intervention Centre. The director of this centre is a person whom many people look up to.

(Anonymous, original in English)

Anonymous' comment reveals the importance of the reputation of a service and how the expertise of the practitioners is one factor that could influence parental attitude towards the services.

Literature on children with special needs stresses the importance of families as a family plays an important role in determining the developmental outcome of the child. In addition, contextualizing the symptoms within a specific social context, such as the family, helps the professionals understand the reciprocal interaction between the child’s symptoms and family members (Ma, Lai & Pun, 2002). In the experiences of the mothers in this study, Yuen Ya sees the role of a professional as providing advices and services to
her, the parent, more than directly to the child. This once again shows her profound level of involvement in the intervention for her child. Like Zhi Wei, she is taking the role of a practitioner for the child. Chui Min's experience reminds us that to provide parental emotional support is as important as working with the child at school. More specifically, by providing information on the rationale behind an intervention to the parents, the school helps Chui Min to hang on in the intervention and to be willing to work with the school when things are not going very well. It is vital to note that if Chui Min was not supported enough to continue with the intervention program, Wu Bin's access to the services would be automatically terminated regardless. All these support the expansion of the intervention approach for children with special needs from focusing on the child as the 'identified patient' to the 'family as a client' perspective (Mohr, 2000).

*Please excuse my honesty, I do not mean to put you down. But, actually if I want to find a therapist for my child, I would never choose a Chinese therapist. I would only go to European therapists for my child.*

*I think it is impossible for a Chinese to have a neutral or accepting attitude towards special needs regardless of the openness and the willingness to accept the special needs. I am sorry; I don't mean to discourage you or to say that you will not be a good therapist. But we need to be honest to ourselves. I mean, the negative concept about special needs is so deeply rooted in us. It has been cultivated within the Chinese community and it is in our mindset regardless of what profession we are in. Even as a parent, we have very negative attitude towards special needs too.*

(Anonymous, original in English)
Cultural compatibility of the practitioners has been mentioned in almost every study on mental health and special needs services (Choi & Wynne, 2000; Harry, 2002; Kung, 2001; Zhang & Bennett, 2001). In practice, many practitioners including myself perceive my culture background as something that helps me to promote the engagement of these parents. Nevertheless, for this mother, it is actually a barrier for me to build trust with her. Her statement might seem confusing if we only compare it with the literature; however, it is easily comprehensible and logical when it is put into its context. Coming from a society where her son with special needs was not respected and accepted, the reason for this family to migrate was to escape from the attitude that was believed to be deeply rooted in the culture. Having made so much effort to get away from it, it is very natural to keep away from the unpleasant attitude. Therefore, it is very clear that for families with children with special needs, cultural compatibility of practitioners should not be taken for granted as something positive as what is commonly suggested in the literature. Anonymous’ reaction towards the cultural attitude was more explicable from her honest sharing of her struggles as a parent with a child with special needs with a Chinese background. Furthermore, the change in her perception of me being a practitioner serving the Chinese families later in the conversation clearly shows that it was the cultural attitude that was putting her off.

*I encourage you to set up an organization for Chinese family with children with special needs. I would think you will be one of the pioneer workers for Chinese children with special needs because you have adapted the very valuable concepts from the European towards special needs.*

(Anonymous, original in English)

Moving from seeing the cultural from the profession’s point of view, here is an excerpt that reflects the view on the profession from the cultural perspective to explain why some of the services are not enthusiastically embraced by these parents.
Why do you choose to study this course? Isn’t it true that Chinese would normally avoid courses like this because they believe this is not a practical occupation? A child psychologist is not a proper profession.

(Chui Min, original in Mandarin)

In terms of social welfare, the government of Hong Kong provides good services for children like these too, so I don’t see much different from this point of view. The services in Hong Kong are quite sufficient. Every resident can access to free visual and auditory tests and there are multidisciplinary teams working for the government to provide assessment for every student once a year. Based on the results of this assessment, referral will be made to specific intervention centre.

In fact, I prefer the service system in Hong Kong because the information from the screening assessment is handled by a department under the government who knows every specialized centre available in the whole country. They provide all the information relevant to a child’s condition including the name and venue of the specialists, the date for detailed assessment and follow up and also courses and seminars for the parents.

The multidisciplinary team in Hong Kong gets involve with the mainstream schools and if they find any problems with the children, they will get the parents to keep in contact with the specialists directly. Comparatively, the mainstream schools in New Zealand pretty much depend on the Teacher’s Aide for their learning. And intervention is
carried out through the school. The actual hours available for a student to access the specialists such as Speech Language Therapists, Physiotherapists or Occupational Therapists are not clearly understood by parents.

(Yuen Ya, original in Cantonese)

In the light of the literature, we tend to assume the Chinese families are from countries where there was no sufficient service and support for children with special needs. While this is true for most of the cases, it is not for Yuen Ya. Yuen Ya clarified that in Hong Kong, there was a well-established referral system, which she found very helpful. Her description above projects how she sees herself as part of the intervention and her enthusiasm to equip herself with professional skills in order to improve her capability to bring up Hui San.

Although Chinese immigrants in New Zealand are a heterogeneous group and the subcultures are very distinctive, very few studies on Chinese pinpoint the differences among the subcultures. We need to be aware that Chinese immigrants come from many different countries where the societal values and beliefs could be very different from one another.

**Professional support: barrier to services.**

Although every family in this research is accessing the professional services, there are some specific barriers that hinder the utilization of the services as these mothers have disclosed through words or reactions. I will start with Ai Juen’s reaction to me when I told her I would like to send her the information sheet of my research. Before I finished my sentence, Ai Juen said:
No, no... I can’t read it. Though I have been here a while but I have very limited English. It is no point for you to send it to me because I can’t read it.

(Ai Juen, origin in Mandarin)

Ai Juen’s immediate reaction was ‘I can’t’. Given that I was actually communicating with her in Mandarin and did not mention anything in English, her instant consciousness of her inability to understand English indicated that the extent of the language barrier might have impacted on her attitude towards her environment. The possibility of Ai Juen intentionally avoiding the hassle to read all this information was disproved in the change of her tone of voice when I later explained that the information sheet was written in Mandarin as well as English. When I shared with her one of the reasons I was carrying out this research was because I wished to provide the Chinese parents the opportunities to speak of their experiences without having to worry about their English proficiency, she said to me:

That is good. I can’t understand most of the things in the society because I don’t understand the language. Often, we are isolated from what is happening in the community. I would like to know more about the services available actually. I have very little information because I can’t understand the papers and the ads. We have never used any of the services because I have no idea what is available out there. I would like to know more about them if someone could translate the information for me. Perhaps you can tell us more since you can speak Mandarin.

(Ai Juen, origin in Mandarin)

It is important to note that this family is not a new migrant but has actually been residing in New Zealand for seven years. Many New Zealanders assume a migrant’s length of stay is a determining factor of his/her English language proficiency, but that is often not true
(Merlin, 1997). In fact, many Chinese immigrants are able to earn for living expenses or even run a business but understand or speak little English.

In the view of a social constructionist, language is the fundamental means of constructing meanings (Burr, 1996). In this light, it is interesting to explore how acculturation\(^5\) develops when there is no language exchange between the individual and the host community. In Ai Juen’s term, she described herself to be involuntarily isolated from the community. The family’s lifestyle was very much in keeping with the Chinese customs. Interestingly, Ai Juen acquired fluent Korean when she spent eight years working in Korea but was never motivated to learn English after seven years in this English speaking country. From her enthusiastic response wanting to know more about the services from me, it is evident that it was not because of lack of interest that she kept away from the services. Putting together Ai Juen’s information, one possible reason for her passive attitude towards learning English is that apart from helping Zhan Yi with his studies, there was no need for her to acquire English as she was content with her own social network which consisted of Chinese and Korean. In fact, she later explained that in her ‘sub-communities’ in this English speaking country, speaking English would actually create a language barrier because the majority of them do not speak English.

It is even more puzzling to think about how Zhan Yi, who is a high school student with learning difficulties, copes with the different languages at home and at school. Moreover, when Ai Juen gave a detailed account of Zhan Yi’s extra developmental challenges due to frequent change of environment, the necessity for every practitioner to understand the background and previous life experiences of the child was magnified:

\(^5\)“Acculturation refers to the process of cultural change that results when two (or more) cultural group come into contact as well as the psychological changes that individual experience as a result of being members of cultural groups that are undergoing acculturation at the group or collective level” (Berry, 1998).
I am concerned with Zhan Yi’s learning. I am responsible for Zhan Yi’s learning difficulties because I have been insensitive towards his developmental needs. We had been over emphasizing our career and financial security. We moved from Korea to Taiwan when Zhan Yi was four, which was the time children start schooling in Taiwan. Zhan Yi knew only Korean but no Mandarin. So, I was very worried about his learning at school and how he would cope in social interactions. I sent him to intensive language tuition and put a lot of pressure on him. Two years later, his father and I decided we would move to New Zealand. That was the time children start their primary school in New Zealand, so again, he faced language challenge. This time he needed to start learning English from basically nothing. Consequently, his language is very limited.

(Ai Juen, origin in Mandarin)

The experience of Yuen Ya when enrolling Hui San in a mainstream school provides us a different dimension on language barrier:

Initially, we planned to enroll Hui San in a mainstream school. We went into the school for a visit and talked to the principal. Hui San was accepted and enrolled. However, as she was very new in New Zealand and she had no English background, she could not understand hence became restless in the class. The school agreed to find her a Teacher Aide however there is no Teacher Aide who can speak Cantonese. So, language became a problem. I offered myself to be the Teacher Aide for Hui San but the principal strongly disagreed because she was concerned that my presence would interrupt the class’ learning. So, at that point, we needed to choose either of the two
options, that is, to get an English speaking Teacher Aide or to transfer Hui San to a special school.

(Yuen Ya, Original in Cantonese)

Another child who has to struggle with language confusion is Li Mei. I think the following excerpt shared by Siew Lan, the mother, is rather informative on the practical difficulties due to language barrier.

It's funny how Li Mei gets confused with the language because of my limited English. Ever since Li Mei started attending this school, she would bring one book home every week from the school library and gets me to read to her everyday. Every time I get a new book, I get nervous. I have to read it through first to see if I can pronounce every word in the book. Honestly, it is just like I am learning with her because I only know a few English words like apple, is, and,...so on. So you can imagine how nervous I am when I get a new book, (laugh) often the level is too high for me. I can only read at a kindy level. The problem is she would not let me go if I don’t read the book to her. So, often I just have to pretend I know the words and read them phonetically. That keeps her happy but many times she learns the wrong pronunciations from me and the teacher has to take a long time to unlearn the mistakes. And it confuses her.

(Siew Lan, original in Mandarin)

With her level English proficiency, it is not surprising that Siew Lan would face barrier in engaging in the services.
I know very little English, this is the biggest difficulty for me. I seldom participate in the activities at Li Mei’s school. I know they have meetings regularly and the school is very enthusiastic in involving the parents in their work with the children. They even accommodate the parents’ need by having meeting at 7 to 8 in the evening because that is the time when parents are off work. However, I need to get Chui Min (her sister-in-law) to go with me every time I attend a meeting because I can’t communicate with the teachers. Chui Min has a busy life with her own child. It is very troublesome for her to come with me. So far, I only attended once and the reason I could make it that time was because Chui Min had an appointment with the school for her child on the same evening. So she was there and she could translate what the teachers said to me. Other than that, to save the hassles, I just do not go.

(Siew Lan, original in Mandarin)

It is obvious that Siew Lan appreciates the school’s effort to meet with the parents regularly. But due to the language barrier, she has to rely on her sister-in-law who is extremely busy with her own child with special needs. As mentioned by one of the practitioners earlier in this chapter, most of the services are prepared to provide translators. Furthermore, in Christchurch there is an established working relationship between the mental health and education services and the translator services. Therefore, this should not be an unsolvable problem. However, much needs to be explored around the issues of language barrier. For example, when I followed the above comment by asking how she felt about the school appointing a translator during the meeting, her response opens the window for us to re-consider the effectiveness of translators in some occasions.
I had experience with translator when I attended a meeting specially for Chinese families at the school. There were four families altogether. However, there wasn’t a lot to say. Hmm...you know, it’s very annoying. Sometimes the teachers talked so much but when it came to the translation, it seemed like there were only two words. It is not easy to communicate through someone you don’t know. You never know whether they have said it accurately or not.

(Siew Lan, original in Mandarin)

There are at least three issues around using translators Siew Lan has pointed out above: client-translator relationship, translator compatibility to the expertise and client’s trust. Siew Lan was feeling comfortable for Chui Min to be the translator but was reluctant to have meetings with the translators she does not know personally. In Curren’s (1997) suggestions to practitioners working with Asian families, she mentioned care must be taken to ensure that the integrity of the interpreter and that the privacy and confidentiality of the client are respected as much as possible as the presence of interpreters as the third party can further increase the dimensions impacting on trust and privacy. Some practitioners suggested pre-session procedures such as letting the client to have an input in suggesting what will be included in a session (Curreen, 1997).

As I continued to explore why she has not accepted the services introduced by the school, Siew Lan disclosed another dimension of language barrier. This is particularly significant to Siew Lan because of her literacy level:
I know there are a lot of good services, but I never apply for it. You have to fill in many forms to apply for any service. That is very troublesome. Especially for me...

(Siew Lan, original in Mandarin)

The lengthy application procedure put a stop to Siew Lan’s desire to take any new services. However, the complexity of Siew Lan’s passive and avoiding attitude towards the services is certainly beyond her lack of English proficiency. Siew Lan added later in our conversation the following concern:

It is quite troublesome. I don’t want to have many people coming and asking many questions. You know, before they approve your application, they would send people to ask many questions. I think that is very...very...you know, very bothersome.

(Siew Lan, original in Mandarin)

Siew Lan’s uneasiness to provide information to many people is not unusual. Many others in this study have the same feelings. There have been a lot of studies discussing the effect of prolonged and lengthy assessments on the family of children with special needs. From my experiences working as a psychologist intern, I have heard many parents with children with special needs, including English speaking parents, expressing their frustration with lengthy application process for resources such as the ORRS funding6. Often, these parents need assistance from case workers to complete the application forms. The matter of language is not the only issue but also the time-consuming effort from these usually worn out parents.

6 ORRS stands for Ongoing Reviewable Resources Scheme which is a funding provided by the Ministry of Education for children with high needs.
Other than the barriers above, a basic yet crucial factor should not be overlooked. Siew Lan explained the practical issues for her access to the services:

_The other difficulty we have is transportation. We have only one car. When her father uses the car, I can only stay at home. This is very inconvenient. I can’t always ask Chui Min to take me there because she has her own life and I don’t want to trouble her._

(Siew Lan, original in Mandarin)

The principal who introduced me to Anonymous has become a great support for these parents because they did not have other people to talk to about their concerns they had for their children. He described to me that when the parents found out about services such as Occupational Therapist and Physiotherapist available at the current school, they became very guilty of not bringing the child to the school earlier. They felt that the child had lost opportunities to do better because of their bad decision. I would like to point out that these parents have good English proficiency. However, there was still a lack of information regarding the services available and the concept of early intervention. For this family, it is not that they think the services are unimportant but that they believe if they had brought their child to the services earlier, their child would be much better than what he was at that point.

The experience of another mother, Zhi Wei, shows that the conceptualization of the attitude towards services does not happened in a one-way interaction. How the local community reacted to her actually played a big role in constructing how she reacted to the services.
I know there are more services available for people like these in New Zealand and we appreciate that very much. And the public attitude towards these children is so different from (the society in) Taiwan. That is indeed a credit to this country. But, I am not here just to take advantage of the government. I know we would use some of the public resources here for Hua Chen, so we brought a lot of money from Taiwan to invest in New Zealand because we want to repay the society. I have also been doing many volunteer jobs for organizations for children with problems such as IHC and CCA. I am not here to compete for the resources; I am willing to contribute to the society too. However, many of the local people I know reacted negatively to me when they knew I came with a child with problems. They think I am here just to take. When I signed up for volunteer work, the workers thought my purpose was to compete for the jobs, which I did not need at all.

(Zhi Wei, original in Mandarin)

To Zhi Wei, the factor that affects her decision of whether or not to access the services is not just the child’s condition or needs. Zhi Wei’s experience strikes a chord on the issues of racism in this country and how Chinese parents with children with special needs might have to put up with extra critical attitudes of those who show racism. Furthermore, to an individual who valued the importance of reciprocating to the provision of the host country and was already doing so, the accusing comments could be taken as humiliation, hence unsurprisingly leading to hostility.

My son was in a different school before and he was there for four years. My experience with that primary school in the first two years was good because my son had a very good teacher aid. She was very helpful and so
my son loved going school. However, by the end of the second year, this
teacher aid was promoted to fill a vacancy for a teacher. Then, the school
appointed some parents as teacher aids. They were not qualified or
trained...I am not sure whether it was because my son is a Chinese or
there were other reasons, the new teacher aid in many occasions made
very negative comments about my son...which often upset me.

(Anonymous, Original in English)

I struggled a lot with the decision of whether to enrol him to school or not
because it was hard for me to leave him. But I said to myself, for his
benefit, I just have to harden my heart and let him go. It was especially
difficult for me when I saw how they carry out some of the intervention. It
was pretty cruel. For example, to train him to sit by the table, they would
tie him in a special chair, which is like tying a prisoner on an electric
chair. He was really stressed and crying and screaming and, oh, it was
really hard for me to see that, you know. I was broken hearted to see what
he had to suffer. And because he had self-injurious behaviour where he
would bang his head on the wall or hit his face with his hands really really
hard, what I had to endure was to see his swollen head and face every day.
I felt the pain for him, you know. My heart was being torn apart but I just
had to constantly say to myself, this has to be done.

(Chui Min, original in Mandarin)

For Chui Min, the emotional challenge for her as a mother to see her child going through
tough intervention could have dissuaded her from taking up the service provided if she
was not given the information and support.
So far, the presented portions of the stories might have drawn an erroneous picture of the availability of the services for children with special needs in New Zealand. From my working experiences in a government funded special education organization, usually lengthy negotiation and active initiative are required to access the services due to limited resources. On top of the stress of caring for their children with special needs, these parents do not just receive the services but actually they often have to fight for the supports or assistance for their children. Anonymous provided insightful information on how this process might have put off many Chinese parents especially with their cultural beliefs and values.

Another difference between me and the local parents is, they are more assertive and they make what they want very clear to the service providers. They would make sure they fight for as much as they can and they are very vocal. I guess it is because we respect our authorities very much that we are not as good in fighting for the services. We are more submissive towards our authority and are frightened to speak out for our rights. I have been told to learn to be more assertive.

(Anonymous, Original in English)

I never ask about that. You know, I am concerned that if I request many things from the school and add many extra works for them, they would be unhappy. I don’t want to offend them.

(Siew Lan, original in Mandarin)

As explained in Chapter Two, the concept and conduct of 禮 (li) is the overarching guidelines for Chinese socialization. 禮 (li) directs attention to proper conduct and maintenance of the relationships between individuals (Fingarette, 1972). The expressions
of 礼 (li) on the social conduct level include: to be self-disciplined, to restrain lust and greed and to submit to hierarchy and authority structure (Schwartz, 1985), which are somewhat opposite to the characteristics that are required to fight for the services.

There is no service in New Zealand that can provide 24 hours care for my child. There is also no such nanny in New Zealand like what I can get from China. I can ‘buy’ a nanny for my child from China and bring her here to live with me. That will provide 24 hours care, and it is affordable.

I really like the government to approve a working visa for a full time nanny from China. That will make my life much easier. If they are not prepared to do that, then they should provide more respite care. I wish my child to be placed into full-time respite care once he is 18-yr-old. My mother is getting older and it is impossible for her to look after him all the time. I would like him to be independent and do not have to rely on our care once he turns 18.

(Xiao Ling, Original in Mandarin)

During her one twenty minutes interview session, Xiao Lin’s emphasis was very much on having a full time nanny for her child, which she could get from her country of origin but was not offered by the local services. In her opinion, the barrier to services is the mismatch between her needs and what is being offered.

It would be very helpful if there is a department working especially to provide information for the parents about where they should go according to the child’s diagnosis, like what we had in Hong Kong. If there is a team
that provides parents advices of where to seek for relevant services, that would be good.

(Yuen Ya, Original in Cantonese)

As a new migrant, Yuen Ya is facing language barrier as well as adjusting to the new place. She and her husband need some time to be familiar with the environment and to know more about what is available. Coming from a country with sufficient service providing system, Yuen Ya’s preference provides a suggestion to improve the accessibility of services to the parents with special needs who tend to have limited time to collect information from the general community:

Yuen Ya’s perception towards the services such as interventions and consultations from the professionals is entirely positive and welcoming. Nevertheless, when we discussed using the respite care services, she has the following to say:

I appreciate the provision of respite care. However, I am the person who knows Hui San (the child) best. It is very hard for others to understand Hui San. When the communicate breaks down, for Hui San, she would feel discouraged and has a sense of failure. That is not constructive for her. So, I would not let her go for respite care.

(Yuen Ya, Original in Cantonese)

In spite of how important the professionals view respite care and how needed it is, as numerous studies have indicated that providing daily, hands on care to a child with special needs over a long duration poses threats to the well-being of the caregiver (Garwick, Kohnman, Wolman & Blum, 1998; Penning, 1995; Shu, Lung & Huang, 2002), Yuen Ya has never used the respite care offered but is coping amazingly well.
Although the majority of the comments presented above are fairly negative, it is important to acknowledge, however, that these mothers went out of their way to mention services they were using and were helpful to them. To these mothers, they choose not to partake in some of the services did not mean they perceived the professional services to be useless, but in fact it was just because there were mismatches between the services and their parenting practices which was embedded within their culture.

Concluding the Stories: Settling Down
After listening to their stories, we know that being a Chinese immigrant with a child with special needs living in New Zealand is no doubt very challenging. So far, we understood that the stress is often not just from having the child with special needs but also from other factors such as being a new migrant, being part of the Chinese community with negative views on disability or being a member of the extended family needing to consider their child’s needs in view of traditional customs and values. Despite these challenges, these mothers have found their coping strategies and are managing their lives very well. During last interviews, many parents opened their hearts and shared their feelings about choosing to come to New Zealand. I would like to let them conclude their stories by sharing what they have in mind about their future with their children with special needs.

After talking to you, I thought about my family and I realized I should be more positive. Though life is still the same, I should not dwell on the negative side of it. My family is fortunate compared with many others. The support we received is much better compared with many other families. I am in a prayer group with three other mothers with children with special needs. One of the ladies’ son is now studying at the Polytechnic. That is something very good for me to know because it gives me hope. It is
comforting to know that the educational system is starting to allow flexibility for people with special needs. Time is slowly changing the attitude towards special needs. I strongly believe this is the way for my son, that he can be free from the expectation in mainstream education system. I am very grateful for the grace of God because my family was accepted by the Immigration Department for migration even though my son has special needs.

I would not go back to my country of origin. It is true to say that NZ is not my place of belonging, it is not our 'home', but I believe if we stay longer, we can fully adjusted to the lifestyle here. We still keep close contact with my extended family back in my hometown. In fact, they take turns to come and visit us which is great.

For me, moving to NZ is a right choice. But it is not the same for everyone. Some people find it hard to accept the lifestyle here. They think it is 'lifeless'. Life is too simple. But for me, I feel 'this is the right place' for me. It is the best place for my son. We go out quite a lot, not to the malls but to visit our friends. We are happy here.

It is good to have a person like you doing what is right. The attitude is very important. Our life as a family is different here. We are accepted and my son can be respected. We just like to start our life here. I feel at home the first moment I arrived in Christchurch. We are happy as long as we don’t think about the future. It’s a fearful thought because we don’t know what will happen to him. I just don’t want to think about the future.
I dislike the “Asianness” in me. We are so critical towards special needs. In New Zealand, it is so different. The whole society is very positive towards special needs. People are compassionate and they help in practical ways. They see my son as a whole person, not just seeing his special needs. You know, before we came to New Zealand, whenever we go out, people would look strangely at my child, what they see is only the special needs. Some even mention the word ‘idiot’. That is really hard for a parent. As for me, I love my child. He brings so much joy to our family. He brings us happiness. He is 10 years old and is a lovely boy. I love my child. Yes, it is right that he needs a lot of help, but he can talk, he can walk, he can do many things. He started walking when he was 2 years-old which is much later than other children, but at least he can walk. I often have great dreams about my child. I dream that he would be able to stand in front of many people, telling his testimony. I have these dreams you know.

(Anonymous, original in English)

My husband and I have been to many places. When we were young, we thought the best place to live is where the economy and technology is very advanced. We thought a ‘modern’ lifestyle was what we wanted. But after experiencing it personally and in many different places, we finally and truly realized the essence of life is simplicity. We longed to escape from the high-pressure and tensed lifestyle and were trying hard to find a better place to go. After chasing after material prosperity for a while, we wanted a place to rest and for us to spend some time with Zhan Yi. My husband came to New Zealand for a visit while we were applying for migration to America. The moment he arrived in New Zealand, he decided this was the place we were looking for, so within a very short period of time we declined the permanent residency offer from America and moved here to
New Zealand. I think the peaceful and relaxed lifestyle is the reason we came. My husband and I have been to many places, almost every country in the world and we think this is the best place to live.

I have been a fulltime housewife since we came to New Zealand. However, I have no free time. My home is an open home. People come in and out all the time. I have a Taiwanese cooking class for Korean women. I don’t really know how it started. I guess it’s because I have been in Korea and Taiwan long enough and know the preferences of both nationalities so I know how to modify the dishes to suit the Korean’s taste. I did not intend to start a cooking class but they requested for it so I am doing it as a favour for them. Sometimes, I also make some Taiwanese confections for sale in the Chinese shop. And now, I am busy with this young home-stay girl too. She is very hard to look after. In fact, her parents send her here because they could not handle her. I am starting to be concerned about the negative impact she gives to Zhan Yi. Zhan Yi is a protected child. He is very soft hearted and simple. But this girl is very intelligent. She is skilled in manipulating others and often challenges me. She has taught Zhan Yi many ‘cunning’ ways. I realize that it is much easier to discipline your own child because you have the authority to set the limits and to punish. Anyway, I have no chance of getting bored. I enjoy the lifestyle here.

(Ai Juen, original in Mandarin)

Unlike the other participants, the decision for Siew Lan’s family to come was not clear-cut. To Siew Lan, it was very obvious that the main reason for the family to migrate was merely for this child.
I did not think about migration until my sister-in-law mentioned it to me. She has a son with autism too. That was why she understood our difficulty with Li Mei. She was willing to be our sponsor person to apply for us to come here. To be honest, I didn’t even know how I got here. She completed the application for us and did everything for us. What I knew was when they told me it was approved, I just got ready and I came. I did not know about the migration procedures.

We are physically as well as financially exhausted from rearing Li Mei. Well, at least we don’t have to worry about her future as much now because she is learning and has a standing ground. When we were in our country, we felt overwhelmed whenever we thought about the cost of bringing her up. My salary was enough only for her school fees. Besides, there was no flexibility at work. No one works part-time. You would loose your job immediately if you can’t commit fully to your job. That was how harsh life used to be. The lifestyle here is much relaxed. I feel less stressful now. I am very happy that I could come. I don’t worry as much now. I have no high expectations for her. As long as she could take care of herself, I am happy and satisfied.

The public is used to seeing people like these in New Zealand. They are free to go anywhere they like. The facilities are good and enable these people to participate in many normal activities. I think they are all well looked after by the government. In the state where I originally came from, there was no school, no services, nothing for people like these. And you won’t see people like these on the street. Perhaps, they can just stay at home, like her. When I brought her to school, her teacher asked me to take her home. This was because we were in a rural city. If we had moved to the bigger cities, there would be schools and better medical services
available. But as I said, they are all private practitioners and are very expensive.

(Siew Lan, original in Mandarin)

The first reason was that Hui San was less and less accepted by the school. We received more and more complains from the school. The second reason was the amount of homework she was given. She spent four hours a day doing her homework because she could only do it very slowly. As she has hand-eye coordination difficulty, writing for her is very hard, especially writing the very complicated Chinese characters. I am her fulltime tutor. I sat with her for four hours everyday supervising her work. The workload just kept increasing. And that happened to a point where it was impossible for her to finish her homework. She became very tired and was worn out. In the end, I sometimes completed her work for her because I knew it was too much for her and I knew she would be punished if she did not complete them.

I used to worry a lot for Hui San. We can’t foresee her future. I was terribly worried. I couldn’t sleep at night. Once a friend shared with me that we shouldn’t over-worry about our children because they do not belong to us. They are from God and they belong to God. Our responsibility is to care for them but not to own them. Pondering on this for a long time, I can be more trusting now though I am not yet a Christian. When I feel down or upset, I often say to myself, God has a plan for Hui San, He will provide for her and He will look after her.
The more I think with this perspective, the more I see the pointlessness of worry. Many parents have children with high intellectual ability, they are bright and talented, but an accident can take away their lives. In the end, there is no difference too, right? Having a good brain but losing one's life is meaningless. So, I started to realize that it is all in God's hand. He is the One who provides and plans. I trust that God will arrange Hui San's future.

Wan Yek used to attend a church but he stopped going because I was not going. Recently, he started attending church again. I observed that he has become more and more responsive to his family's needs since he started going to church again. I am glad to see his changes.

Although we are facing many difficulties, I do not regret my decision to migrate because I believe Hui San will have a better future living in New Zealand. In Hong Kong, it will be impossible for her to find a job because there is no tolerance, consideration or acceptance for people with intellectual disability. Also, her IQ is between 70 and 80, which is above the cut off for disability benefit. Only those with IQ below 60 will be given allowance and social welfare. She could probably find a very lowly job like working in a factory in Hong Kong. However, the working hours would be during the night, which would be very inconvenient.

Sometimes, I would wake up in the middle of the night thinking, 'what would happen if we (Yuen Ya and Wan Yek) die in an accident?'. Now that we are living in New Zealand, I feel less anxious about that because we know the government would look after and support Hui San.

(Yuen Ya, original in Cantonese)
I would like to share with you two significant incidents which are particularly hurtful for me. I will never forget them. The first one happened when we were in Taiwan. Hua Chen loves flags. One day while we walked pass the embassy, Hua Chen ran to the flag post and lowered the national flag because he wanted to have the flag. Before I could stop him, a policeman ran towards us from the embassy and accused us of cursing the president of Taiwan. We know that when the flag is lowered it means an important person has just died. I explained to him about Hua Chen’s condition but he is determined that I write a letter of apology and put it on the newspaper. I begged the policeman and there were many people gathering around me. I was very embarrassed and ashamed. But the really hurtful thing is, before the policeman left, he said, "if you have an idiot son, don’t take him out to create troubles!"

The second incident also happened in Taiwan. Hua Chen loves coins because he likes listening to the noise they make when they hit the concrete. To keep Hua Chen happy and quiet, I gave him a gold coin to play with while I brought him out. Coincidentally, an elderly lady dropped her coins when she walked passed us. As Hua Chen so liked the noises, he was immediately attracted to catch the coins and was very happy. One of his characteristics is when he is happy, he laughed loudly and that could be very weird to those who do not know him. I quickly stopped Hua Chen from taking the elderly lady’s coins and tried to move him away but the elderly lady saw the gold coin in his hand and thought that was hers. So she loudly accused Hua Chen as a stealer. I explained to her that it was a gold coin I gave him but she would not believe me. Hua Chen was still laughing and his loud voice and the elderly lady’s accusation attracted a lot of people to see what was going on. I was very embarrassed. I knew I
would not be able to convince her so I quickly hopped in a taxi with Hua Chen. While I was escaping from the crowd, I heard the lady yelled at me saying, ‘Your son steals and you are helping him, shame on you!’

Another incident happened in the arrival hall at Los Angeles. We went for a holiday. I was in the queue waiting for the officer to check our passports. Hua Chen was tired so he sat on the seat not far away from me. When I handed over Hua Chen’s passport to the officer, he asked me where was Hua Chen. I pointed to him so the officer walked towards him. When Hua Chen saw the officer, he ran away. The officer ran after Hua Chen and I ran after them too because I did not know what to do and I did not want to lose my child. So, we were like playing a circus show. The officers thought we were illegal passengers. Anyway, after chasing for a while we finally got Hua Chen and I had to tell them he is a handicapped child while many were watching me. The officers apologised when they understood the situation so that was not too bad. You see, the attitude is very different. At least the officers respected Hua Chen’s disorder but the two incidents in Taiwan were truly heart-breaking for me.

I felt that it is too hurtful for me to live in my own society. That is why I gave up my well-respected and high-paid job and left Taiwan. My employers tried hard to convince me to stay but I did not. I like my child to be in a place where he is accepted and where his humanity is respected. However, I wonder such a place exists or not. I appreciate the more accepting societal attitude in New Zealand. However, in fact, I have had a few unpleasant experiences in New Zealand too. For example, one day I brought Hua Chen to a mall. I gave him some money to buy an ice-cream because I wanted to teach him how to purchase food. As he liked the noise of the coins, he threw them on the table instead of putting them in the
cashier's hand. The cashier got very angry and said to him, 'we will not sell you any ice-cream because you are a rude child.' I felt hurtful and did not even feel like explaining anything. Since then, I never buy from that particular shop. It used to be one of Hua Chen's favourite places.

(Zhi Wei, original in Mandarin)

**Conclusion**

The existing literature has a great deal to tell us about disability within the Chinese community. However, not many have provided detailed accounts on the uniqueness and individuality of each family. This small-scale qualitative study allowed me to obtain detailed personal accounts of some facets of the social world of my participants. This was done through discussions around the cultural factors that influence Chinese parents perceptions towards services for their children with special needs. The philosophy of social coconstructionism and narrative inquiry encouraged me to allow the participants’ stories to be told in their own voices so that the reader could be provided with the opportunity to make first hand interpretations of the stories. The most exhilarating aspect of this study is the combination of the shared family narrative and the flexible research process. This bought forth wonderful first-hand accounts, which are rich in detail and capture the subtlety and complexity of the lived perceptions and attitudes of these Chinese parents. This phenomena raised a wealth of issues on which to reflect upon and explore more seriously.

With the awareness of how culture influences parents’ attitudes and decisions (Vygotsky, 1978), I chose to situated my participants’ stories within their relevant socio-historical
context. The reasons behind the decisions and attitudes of these parents became more comprehensible when cultural values such as the importance of proper behaviour and the meaning of education for Chinese socialization were taken into consideration. I understand that the commonly held ways of seeing the world and the categories and concepts we use to define it, are historically and culturally specific. From this view, I need to focus not on what the participants do but on why they do it. I also become aware that I should not view the disability of my participants in the abstract, but through consideration of the way in which the labels are produced and reproduced in social interactions within institutional and cultural contexts. For instance, for some families, developmental delay seemed to be non-existent.

Much discussion has been inserted in between the excerpts presented above. However, I would like to re-emphasized a few points that were particularly thought provoking for me. One significant reflection from the stories of these families is the likely isolation they face as a consequence of their difficulty fitting into either culture. Almost every family in this study has expressed a mismatch between their parenting values and that of the New Zealand culture. On the other hand, they are also avoiding associating with other Chinese immigrants, who most probably hold similar cultural values.

On top of their strong commitment to caring for their child, some families also face difficulty when it comes to adjusting to the New Zealand lifestyle. Many of these immigrant families came to New Zealand primarily for the welfare of their child with special needs. The cost of this decision included the sacrificing their social support network, career, spousal company and so on. Furthermore, for Chinese parents, following the advice of professionals in New Zealand might conflict with the expectations of their extended family members. Practitioners need to be aware of the pressure the parents face from their extended families, especially the grandparents of the child with special needs.
The individual stories collected in this study are demonstrative of the heterogeneity of Chinese families living in New Zealand. The conventional beliefs about Chinese parents and Chinese attitude towards children with special needs should not be taken for granted and each family should be treated individually. From this study, the diversity of the parents' professional knowledge about their children's special needs, their parenting approach, the involvement of the extended families, their previous experiences, their perception towards services and their reactions towards having a child with special needs were evident. We should not assume that all Chinese parents have the same expectations and perceptions towards their children. Most parents in this study prioritize the psychological wellbeing of their child over their academic achievement and not every parent has high expectations for his or her child. Those who do place expectations on their child are also willing to put in the effort to walk the child through the learning process.

Although many of the parents perceptions towards professionals and services provided were not entirely positive, it is important to note that these parents are, to various degrees, actually engaging in the intervention services. In addition, their responses to me as a Child and Family Psychology student and their appreciation of the services they are currently receiving clearly shows that they do hold an open door to the services provided by professionals. Furthermore, when I took a closer look at the responses of the families and the professionals, I observed many mutual goals between the two parties. Nevertheless, the resourcefulness and readiness of parents, to invest their time and effort is seldom recognized in the conventional literature. This is a vital strength on which to draw. One of the possible reasons for this phenomenon is the lack of communication between the families and the professionals. For example, Chui Min’s experience with Wu Bin’s school is demonstrative of the possible lack of communication between school and family. In Chapter Four, Chui Min shared how she has been using a cane as the tool to teach Wu Bin. She honestly expressed that she never dared to let the school know about this strategy because she was concerned that the school might misinterpret her intentions. Later, when expressing her feelings about watching the teacher tied Wu Bin in a special
chair like a prisoner, Chui Min did not voice her feelings to the school nor did she question whether this intervention strategy was empirically based or not. This lack of communication led to disengagement between home and school in relation to these two particular matters. One disadvantage of this disengagement is that the two parties become shut off from one another, restricting the possibility of a give-and-take dialogue whereby each party can learn and borrow from the other for the best interest of the child.

One challenge is for service providers in New Zealand to work collaboratively alongside Chinese families by building trust, respect, and open communication with them. This partnership should focus on shared skills, knowledge and experiences in order to develop competence and confidence in key people such as the parents. This is only possible when the emphasis is shifted from 'the kind of services provided' to 'the parent-professional relationship', and makes the link to the next level in the ecology of the family receiving this service (Rush, 2000). In other words, the services need to be conducted in a way that de-emphasises professional services and emphasises the support that professionals can provide (Campbell, 1997).

Most parents participating in this research perceived themselves and not the professionals to be, responsible for their child. This is actually in line with the value of the professionals also. Families need to be informed that professionals do not actually intend to take over the responsibility nor do they claim that their interaction with the child is the key to changes. On the contrary, professionals see the family as the pivotal factor in determining the child's development outcome. It is also important to clarify that the major purpose of intervention for children with special needs is to enhance the competence and confidence of the caregiver so that the children will have the greatest likelihood of developing to their maximum potential (Watkins, 1999). Contemporary practice promotes that “therapists view themselves as advisors, counselors, and purveyors of information to families...rather than as direct care providers and that they need to maintain a long-term perspective” (Campbell, 1997, p. 13). Since the child spends a considerable bulk of their time with parents/caregivers, the more knowledgeable the caregiver is about the child’s
developmental strategies and activities, the greater is the impact of intervention. If the focus of services is to increase the child’s learning opportunities in existing or desired settings, the goal of intervention should be targeting on effective parenting, not as providing therapy. Therefore, the role of the professional is more akin to a coach or personal trainer than a hands-on provider. The aim of the professional is to increase independence within the family.

Collaborative consultation encourages different interdisciplinary perspectives to develop congruent programs and delegate appropriate roles to other team members. The interdisciplinary approach has been promoted in the literature as the preferred model of team interaction in intervention services in order to provide co-ordinated and comprehensive services to children with special needs and their families (O'Neil & Palisano, 2000). When collaborative consultation is used effectively, the parents/care providers are the true facilitator of change or improvement in the child's skills and development (Coufal, 1993).

Apart from increasing the quality of services through joint accountability, the information shared could avoid the exhaustive and time-consuming assessment procedures, which has been one of the factors that de-motivated some of these Chinese families from taking up a service.

The high level of commitment and resourcefulness of these Chinese parents actually provides a very sound foundation for family-centered intervention. Family centered service means families are not just consumers of services but guide practices as well (Shelton & Stepanek, 1994). Parents or care givers are to be regarded as important decision makers in the planning of intervention programs and must function as equal members of the team. Since the development of culturally appropriate services among professionals in New Zealand is at its initial stages, it would be wise to use these parents as resources for the development of practice guidelines. This strategy is also very
culturally appropriate because by letting parents reciprocate to the welfare of the services, professionals are also meeting the expectations of 礼 li (the rules of propriety).

It is true that in the past, state-of-the-art services have been defined by clinical settings with the latest therapy equipment and private therapy rooms which inhibit distractibility. However, the current trend of intervention services is to promote learning opportunities across environments with typical caregivers and ordinary objects. In other words, professionals are happy to visit children and their parents at their home and provide services in their homes. In this case, the transportation Siew Lan has would not be a barrier for her in access to the services anymore. The accounts given by these mothers however, have demonstrated that they are not aware of the high value that professional attribute to naturalistic interventions.

Another possible reason for Chinese parents’ low involvement within professional services is simply because of their lack of information about the range of services available to them. This comment is made based on the fact that when asked to give an example of the services they have been offered, almost every parent mentioned respite care, which is not directly related to therapeutic interventions. With little experience with professional services, these families may have found it difficult to identify areas in their live which professionals could contribute. In response to this, a routine based assessment (McWilliam, 1992) could be employed where parents are asked to think about their family’s daily routines and how satisfied they are with each routine. In this way, the family’s concerns become the service plan’s goals. Then professional and parents would have something to work on together. I believe this is an effective way of building a relationship between families and professionals because the goals become tangible and practical.

Thanks to the accounts given by these parents, they are now some practical ways in which professionals can contribute to the needs of Chinese families with children with special needs. First, many of these parents voiced their lack of information about the city.
For example, Ai Juen and Yuen Ya were very enthusiastic to know more about the services available in the city, and Zhi Wei would like to know whether there are Chinese support groups available in Christchurch. This basic information support should not be overlooked but should be used as an opportunity for professionals to commence a working relationship with these families.

Some parents, like Siew Lan and Anonymous would appreciate information about the special needs of their child. Instead of focusing merely on the child, professionals could provide consultations or education for these parents to help them to better understand their children. In relation to the information about special needs, these Chinese parents would value information about child development and intervention strategies. However, this does not necessarily mean that these parents will follow these methods. The role of the professional nevertheless is to convey the principles and rationales underlying a strategy so that these parents are equipped with the knowledge to later adapt to their practices. Some obvious open doors to the seven families for the professionals to provide strategies are: to teach social skills to Yuen Ya, to suggest alternative program for toilet training for Chui Min, to provide guidelines for Siew Lan to assist Li Mei with her communication skills and so on.

Supporting the parents in learning English is also an essential service because as the children continue to receive education in English, many parents will not be able to keep up with the children’s learning. This is very crucial in the case of these Chinese parents because losing the parents’ involvement in following up the intervention at home means losing the most significant partnership of the intervention programme.

Professionals often underscore the importance of material support, although it is unlikely that these families will require assistance for basic needs since most of them are reasonably well off financially. However, material support in terms of finding specialized equipment and adapting materials appropriate for the child’s special needs will most probably be embraced by these parents. For example, in Xiao Lin’s circumstances,
provision of equipment such as an adjustable chair that can improve the child's independence would mean less burden on the grandmother. Another example is to help Siew Lan in selecting English story books that are compatible to Li Mei's development, which Siew Lan reported to be a challenge for her due to her limited English proficiency.

Last but foremost, to each of these families, the professionals could offer emotional support through responding to the parents, talking to them in a friendly way and being positive about the parents and the children. Emotional support has been found to reduce stress (Meadow-Orlans, 1994), promote well being and positive parent child interaction (Hadadian, Merbler, 1996).

It is also important for us to understand the strength and the functional strategies that have been used and are working for these parents. This is because in many cases, the underlying principles of the so-called traditional strategies are actually aligning with the empirically proven and evidence based intervention. The beliefs and perceptions of disability are important for professionals to respect, so that a true understanding of this concept and the potential positive outcomes of working more effectively with families utilizing a family-centered philosophy can be achieved.
CHAPTER SIX
From Hearing the Stories: Implications

Societal understanding of Chinese families with children with special needs and professional's practices and approaches are very much guided by the literature. When comparing individual accounts given by these mothers to the general findings in the present literature, I realized that the generalization made by large-scale research articles are appropriate in representing the research population as a whole but are very limited in their applicability to individual cases. Having engaged in extensive interviews with the families in this study, I would now like to present some implications. I will do so by comparing these personal accounts to what I believe to be general beliefs commonly held by professionals towards Chinese families with children with special needs. I hope that by refuting these commonly held false beliefs, I may also provide the public professionals with a better understanding of Chinese parents with children with special needs. Before clarifying these false beliefs, “Myths”, I will sound some cautionary notes about my study. Finally, I will propose some recommendations for ongoing research in the area of Chinese perceptions towards special needs, and I will conclude with my reflections on the attitudes of professionals who are working with these families.
Myth about Chinese Families

Myth One: the Child’s Special Needs is the Major Cause of Stress for Every Family with Children with Special Needs
Research on families with children with special needs are often designed to measure the stress on the families as a result of having a child with special needs. Consequently, parents of children with atypical development are often asked to describe their distress in dealing with their children’s special needs. However, these parents are not necessarily asked to report on other stressful factors at play in their lives. Interestingly, in this study, some parents found that the stress of being a new migrant could be greater than having a child with special needs. No family functions in the presence of only one stress factor. Having a child with special needs is often one of many other challenges a family may be dealing with, although it could be a major challenge. Therefore, future research on the functioning of families with children with special needs would benefit from broadening the variables it uses to measure these families by.

Myth Two: Chinese Parents Would Prefer to Have a Chinese Practitioner Working with Their Family
The importance of cultural compatibility between practitioner and client is a very well-documented topic. However, when working with Chinese families with children with special needs, the practitioner’s Chinese background may be seen as a barrier rather than an asset to the service. As discussed in previous chapters, this is because having a child with special needs is a very sensitive issue especially when considered within the context of Chinese culture. Knowing that a professional comes from a cultural background deeply rooted in negative attitudes towards disability, leads to Chinese parents taking extra-
precautious in allowing this professional to treat their child. Therefore, professionals with a Chinese background may need to carefully explain their viewpoint in order to gain the trust of parents prior to engaging in a professional relationship with them.

This finding suggests that the attitude of the practitioner, whether Chinese or non-Chinese, is a determinant that, in importance, overrides the cultural background of the therapists when it comes to building working relationships with Chinese families with children with special needs. Barriers such as language difficulties are unavoidable hindrances for any Western therapist working with a Chinese family. However, the therapist can remain confident in knowing that by showing empathy and sensitivity, a trusting, working relationship remains a viable option.

Myth Three: the Academic Achievement of a Child is Most Important for Chinese Parents
Another well-believed concept is that Chinese parents prioritise the academic achievement of their children over their life skills or psychological wellbeing. Some parents in this study were explicit in commenting on how they preceded their children's feelings and self-concept beyond their academic performance. These parents demonstrated this by focusing the intervention goals of their children on self-care skills, social skills, and other such non-academic skills. However, being the parent of the child with special needs may alter one's values in terms of what is important in life and this may explain the different focus that we saw in these parents.
**Myth Four: The English Proficiency of Immigrants Improves Over Time**

Some practitioners might assume that Chinese clients who have been residing in New Zealand for a long period of time will have higher English language proficiency than those Chinese who have been in New Zealand for shorter periods. However, many Chinese immigrants remain in their sub-communities where English-speaking is not required at all. In this case, acquiring proficiency in English is not necessary and therefore may not increase no matter how long they remain in New Zealand.

**Myth Five: The Availability of Services in Another Country is the Main Reason that Chinese Families with Children with Special Needs Chose to Migrate**

It is true that at least three of the families in this study migrated to New Zealand because of their child with special needs. It is easy to assume that the main purpose of migration was to access the intervention services because, for many of them, there are no good services for their child in their country of origin. Nevertheless, many parents in this study reported choosing to come to New Zealand because of the cleaner environment, the more accepting social attitude and the more stress-free lifestyle. Therefore, access to professional services may be one of, but not necessarily the main reason behind the families decision to migrate to New Zealand.

**Myth Six: Chinese Children with Special Needs are commonly Mistreated by Their Families**

Current literature has focused dominantly on the negative implications of having a child with special needs. In research studying specifically Chinese families, Chinese parents are often portrayed as placing a high value on the ability of their children to reciprocate
parental investments and to meet societal expectations. In this study, I found that instead of securing their future provisions by having more children or investing more in their able-bodied children, most of these parents totally put aside encouraging individual thought or increase the child’s ability to reciprocate. On the contrary, they invested even more in the child with special needs in order to guarantee his or her future security.

Myth Seven: A Chinese Parent’s Support Group would be a Good Support for these Parents
Among the participants, there are conflicting views about the benefits of belonging to a Chinese parents support group. One mother clearly stated that she avoids associating with other Chinese parents including those with children with special needs because of her desire to avoid the competitive attitude so prevalent among Chinese parents. The competing attitude among parents is a common concern the participants raised whenever a support group was mentioned. Therefore, a support group would only be helpful to support these families if the possible negative impacts are well addressed.

Myth Eight: the Involvement of the Extended Family is Crucial
It is true, that for five of the families, the extended family unit plays a significant role in supporting the couples with children with special needs. However, apart from the positive contributions provided by the extended families, there were also negative impacts reported. Each family should be considered individually especially when it comes to the issues of having a child with special needs. Some extended family members reacted negatively, for instance, staying away from the couples because they believe them to be
under a curse. Others reacted by blaming the couples for bringing shame to the family. In these cases, extended family involvement only contributed to the couples, burden. It is important for practitioners working with Chinese families of children with a disability to collect information regarding their experiences with the extended families, providing, of course, that the influence of the extended family is one of significance in their lives.

**Myth Nine: Chinese is a homogeneous ethnicity**
Chinese living in New Zealand come from many different countries including Malaysia, Singapore, Taiwan, Hong Kong, Indonesia and Mainland China. These countries have very different political backgrounds, social backgrounds and even cultural values. Among the Chinese community in Christchurch, there are many sub-cultures and each has its own distinctive characteristics.

**Myth Ten: Chinese Parents Show a Lack of Knowledge and Understanding of the Diagnosis of Their Child**
Generally, the Chinese community in New Zealand consists of those who are of higher socioeconomic status and educational attainment. In this study, quite a few of the parents reported conducting personal research through reading books and attending seminars in order to understand the diagnosis of their child. They showed comprehensive knowledge about their child’s impairments and are adapting the principles of evidence-based intervention in their day-to-day interaction with their child.
Cautionary Caveats

Firstly, since only mothers participated in my study, it is quite possible that research from the perspective of other family members may yield a different account of their perceptions towards living in New Zealand as members of a family with a child with special needs. As noted in the literature, the father in a Chinese family is regarded as the decision maker and the financial provider but not usually as the caregiver for the children. Hence, the experiences and perspectives of the fathers in particular might be different. Studies investigating ways of approaching these fathers would be worth carrying out as they would lead to more discoveries about various dynamics in these families.

In addition, in spite of my attempts to recruit families through various methods and sources most of the participants were from a school for children with special needs. That meant that these families were from the same residential area and had similar socioeconomic status and values, despite representing different homelands. Further, some of the participants stated that their aim for taking part in this study was to gain information about their children’s special needs, rather than sharing their experiences. This reflected a conscious acceptance of their children’s condition.

It is also important to bear in mind that my focus was on the Chinese families in Christchurch city. It is plausible that immigrant families who chose to live in Christchurch instead of other cities in New Zealand might have some common
characteristics and values. This is particularly relevant when considering that the majority of Chinese immigrants choose to settle in Auckland rather than Christchurch, because Auckland is perceived to be more ‘advanced’ whereas Christchurch is known to be a ‘quiet and peaceful’ land among the Asian population.

**Future Research**

I have raised a number of broad areas in this dissertation, which should be further explored. They include, but are not restricted to investigation on the connotation of special needs in Mandarin. This topic can lead to further understanding of the cultural perception on special needs. Research with a specific focus on the effective ways to reach the Chinese families if there is any, who do not involve in the intervention service system. The perceptions towards special needs of these families would be invaluable information for understanding the meaning and social construction of disability. In response to one of the limitations of this study, future study needs to include the other family members as well as the children with special needs, if possible, in the in-depth interviews so that a more complete shared family narrative could be obtained. Finally, studies that aim to gain further insights into how the Chinese families develop resiliency over their circumstances would not only be important but necessarily.
I would like to conclude my dissertation with another challenge I have encountered as a Child and Family Psychology Intern near the end of this journey.

What one commends is not always what one would do in the daily life. Once, a professor working with children with Autism honestly and cleverly convicted my unreasonable expectation towards others. I think it applies very well to the rigidity of professionals which unfortunately is not uncommon. Pointing to her own over weight body, she said: “I had a biscuit during the break not because I was hungry but because it was put in front of me! Well, you do not have to tell me I don’t need it. I know that very well. But, it is so natural for me to grab one and put it in my mouth. I just do it, it has become my habit. We cannot expect the parents to change their habits just because we have told them what is good for their children. They know very well what is good for their children. But it could be that certain ways of doing or behaving has become a habit. If we can’t change our habits, why expect others to change? Moreover, they are the ones who have to put up with the daily stress.

(Journal entry, 18 October 2003)

Of course, her implication was not that we do not give advice or pass information on to parents. The point is to have flexibility and empathy in understanding and accepting the limitations as parents just as we live our lives with our own shortcomings as a human being. Our focus should be on how we can provide the support needed for these parents
to improve the function of the habits or in this case, the family functioning, and, to allow room for parents to creatively develop effective strategies for their particular circumstances.
REFERENCES


Barnes, C., Oliver, M. & Barton, L. (2002). Disability, the academy and the inclusive society. In C. Barnes, M. Oliver & L. Barton (Eds.), Disability studies today (pp.120-139). USA: Blackwell Publishers.


APPENDICES

Appendix One

Sample Advertisements (I): Chinese Version

您有具有特殊條件的孩子嗎？

本人是教育系碩士學生，很希望透過我的論文將華人父母的心聲向當地政府福利社發表，以為在紐西蘭的華裔同胞爭取更符合我們文化的服務。您願意貢獻您的經歷與見解嗎？您所提供的資訊僅供參考，所有身份將不會被公開。

請聯絡     ： 劉小姐
電話         ： 03-1234567
Sample Advertisements (1): English Version

Do you have a child with special conditions?

I am a Master student in the Education Department. I would like to know more about your experiences living in New Zealand with your child. The aim of my dissertation is to voice out your point of view to the community. Would you like to share your experience with me? All the comments you make will be strictly confidential and neither your name nor your identifiable information will be disclosed.

Please contact: Winnie
Phone : 03-1234567
Sample Advertisements (2): Chinese Version

您有一位與眾不同的孩子嗎？

本人是教育系碩士學生，很希望透過我的論文將華人父母的心聲向當地政府福利社發表，以為在紐西蘭的華裔同胞爭取更符合我們文化的服務。您願意貢獻您的經歷與見解嗎？您所提供的資訊僅供於參考，所有身份將不會被公開。

請聯絡： 劉小姐
電話： 03-1234567
Do you have a child who is different from the majority?

I am a Master student in the Education Department. I would like to know more about your experiences living in New Zealand with your child. The aim of my dissertation is to voice out your point of view to the community. Would you like to share your experience with me? All the comments you make will be strictly confidential and neither your name nor your identifiable information will be disclosed.

Please contact:  Winnie
Phone          :  03-1234567
Appendix Two

Information Sheet to All Participants: Chinese Version

研究諮詢書

紐西蘭華裔移民家庭探討:
特殊條件兒童與其家庭成員的生活經歷與見解

敬愛的_____________________先生/太太

您好。您也許記得我曾經與您通過電話，提到有關我正在進行的研究。我很感謝您願意在百忙中抽出時間來了解這項研究。這封信將與您和您的家人簡單介紹這項研究的目的及過程。

我是劉有寶，是出身於馬來西亞的華籍研究生。六年前，來到紐西蘭就學，從中有機會接觸許多有關兒童與家庭的研討，我對兒童及家庭心理學有深厚的興趣，希望透過了解兒童的思想和經歷以及其家庭在他們的發展過程中所扮演的角色來增進社會對兒童教育的理解。今年，我有機會設立一項研究來深入探討一個主題。我一直深信具特殊條件人士的生活經歷裡有很多寶貴的經驗是值得社會來學習的。所以，我就選擇探討特殊條件兒童的成長經驗。

在過去數月，我開始探討有關特殊條件兒童的理論，發現目前所有理論，均是存西方的觀點，因而未必能切合華人的經驗。作爲一位有文化醒覺的華裔教育工作者，我非常關注運用西方理論去解釋華人觀點所引致不足的可能。這項研究旨在將您和您的家人的經歷和見解透過我的論文向這個西方社會發表，改善目前文獻的不足。也希望藉此研究，華人獨特的文化及觀念將會更廣闊的被發揚。然而，由於這項研究的宗旨和資源是您和您的家人，所以研究的成功將有賴您們的參與。
我恭敬邀請您和您的家人參與這項研究。若您願意參與，您只需要允許我登門拜訪，了解您們的家庭生活方式和從您的角度與我敘說您身為您家庭裡的一份子，在紐西蘭生活的經驗，看法，感受，見解和意義。我們面談的目的是要了解您，我會鼓勵您表達您的想法和經驗，我歡迎您帶入任何有關這項研究的話題。同時，您也絕對有自由在任何時間，任何情況下，選擇不回答某些問題，甚至停止參與。為了讓您更能了解真實的研究過程，我舉出在面談中，所可能談及話題的例子：

- 您養育孩子的經驗
- 您與特殊條件兒童的家庭經驗
- 您在紐西蘭生活的經驗
- 您的經驗中順心的事
- 您的經驗中遇到的困難
- 您對您的家庭和孩子未來的期望
- 您身為家裡一份子的責任和扮演的角色，等

若您願意，我希望可以與願意參與的家庭成員進行單獨面談。然而，若您覺得大家一起同時參與面談會比較適合您，我會依您的決定。我會因應您的方便去安排面談時間。我希望可以在週期三個星期內與您們進行三至四次面談，不過時間與次數的決定還是完全在於您。然而，您的人生經歷是很可貴的，您所有的分享對我們華人同胞來說是重要的貢獻。

若您們許可，我將把我們的面談錄音起來。錄音的目的是為了幫助我能更精簡及正確的來發表從您們的角度所表達的意見。此外，為了加強研究結果的可靠性，如果您願意，我將邀請您審查面談實錄，提供您修改或糾正的機會，以確保內容貼切的表達您的見解。

面談中所有資料將絕對保密，而在任何口頭或書面報告內，絕不會透露你的真實姓名。為確保絕對保密，除非有關係到您的生命安危，在整個研究過程中只有
我本人會知道您的身份，面談後所有的筆記和實錄將用假名來取代真實姓名。所有關於您和您的家庭的資訊也將不會向其他參與的家庭透露。此外，除了我本人和我的督導教授 Dr. Baljit Kaur 和 Dr. Karyn France 以外，任何人均不能接觸面談實錄。所有記錄，面談實錄和錄音帶會存於一個有鎖的文件櫃中。

我將在下週再一次與您聯絡，確定您願意參與這項研究。如果您有興趣進一步了解這項研究或是有任何疑問，歡迎您聯絡我，我附上我的電話號碼和電郵地址。我非常樂意與您們討論任何對於參與這項研究的顧慮及疑問。您也可以聯絡我的督導教授以尋問更多資訊。為確保您的利益，這項研究是經過研究道德原則委員會審查並准的。最後，我重申這項研究的成功將有賴您們的參與。謝謝您們的合作和支持。

於，
劉有寶

兒童與家庭心理學碩士研究生，
劉有寶
電話：03-1122334
電郵：

肯特伯利大學，教育學部門教授，
Dr. Baljit Kaur
電話：03-1234567
電郵：

Dr. Karyn France
電話：03-7654321
電郵：
Information Sheet to All Participants: English Version

Project Title: Living in New Zealand with a child with special needs: The perception and experiences of Chinese Immigrants

Dear Mr. & Mrs. _______________ & family

You may recall talking to me few days ago. I am very grateful for your willingness to find out more about my research. The purpose of this letter is to introduce you to the primary aim as well as briefly outline the procedure of this research.

My name is Winnie Yu Pow LAU and I am a Malaysian Chinese. Six years ago, I came to New Zealand to further my study and found my interest in Educational Psychology. Over these years, I have learnt many things about children and their families. I became very interested in understanding how children feel and think about what is happening around them. This year, I have a chance to choose a topic and find out more about it through carrying out a research. I always think people with special needs have many valuable things they can share with the community so I decided to study about people with special needs.

As a member of the Chinese community, I would like to take this opportunity to set up a research study to gather information about the views and experiences of Chinese families. I hope by doing this, the uniqueness of the experience of Chinese families in regard to our cultural background could be acknowledged to a wider extent. However, I need your participation to carry out this research.

I am writing to invite you and your family to participate in this in depth discussion. With your permission, I would like to spend some time with you in your home to understand how you interact as a family and talk with you about you and your
family's point of view and experiences. Some of the topics which I will be interested to hear about from you are such as:

- Your experiences in raising up your child / children
- Your experiences living in New Zealand as a family with a child with special needs
- What expectation you have about the future of the child with special needs
- What are your role in the child with special need's life and what role does the child play in your life

Such conversation can either occur with the whole family or on an individual basis, whatever suits you best. I would like to come to visit and talk to you once or twice a week for three to four weeks if you allow me to do so. Please be assured that you can stop at any time. You and anyone in the family can choose not to participate in the conversation. However, I truly hope I can have the opportunity to talk to each of you because every contribution will be very valuable.

I would like to audio-tape our conversation if that is alright with you. The reason for doing this is to help me to be more accurate when representing your point of view. However, I will not audio-tape if you do not want me to.

After the conversation, I will send you the transcript to make sure I have written down correctly what you wished to say. You can amend, add or delete any information if you want to before I use it in my dissertation.

You may be assured that all comments you make are confidential unless someone's safety is at risk. I will be the only person who talks to you and who knows your names. The information collected (without the names stated and other identifications) will be used for discussion with my research supervisors, Dr. Baljit Kaur and Dr. Karyn France. Such information will not be released to anyone else. Nothing you say in the
interview will be used in my dissertation without your permission. To ensure anonymity and confidentiality, none of your family member’s identifying information will be mentioned in the write up.

I will be contacting you by phone within the next week to confirm whether you wish to participate. Alternatively, you can contact me at the phone number written below if you have any queries. I will be happy to discuss any concerns you may have about participating this research. You also can contact either of my supervisors if you like. This research has been reviewed and approved by the University of Canterbury Human Ethics Committee.

Thank you for considering taking part. Your contribution will be of great value for the welfare of the Chinese society in New Zealand.

Yours Sincerely,

---------------------
(Winnie Yu Pow LAU)

Master in Education (Child and Family Psychology),
Student:
Winnie Yu Pow LAU
Telephone: 03-1122224
e-mail:

Education Department, University of Canterbury,
Senior lecturers:
Dr. Baljit Kaur
Telephone: 03-1234567
e-mail:

Dr. Karyn France
Telephone: 03-7654321
e-mail:
Appendix Three

Letter from Special School to Parents: Chinese Version

親愛的_________________

劉有寶是馬來西亞的華裔學生，正在坎大就讀兒童家庭心理學碩士。他為華裔同胞的一份子，她希望能藉著她的論文來向這西方社會發表您與您的孩子在紐西蘭的生活經驗，以促使華裔同胞在紐西蘭的福利。為了能更切實際的來了解您的經歷和見解，劉小姐希望能與您見面或通電話。所以，校方懇求您的同意讓劉小姐得知您的聯絡資訊。若您有任何疑惑，請聯絡 Pip (電話：311-1234 轉 123)。

謝謝您的幫助！

治療組主任

_____________________________________________________

我(們)同意讓劉有寶聯絡我(們)，以了解關於我(們)和孩子的生活經歷。

孩子姓名：________________

簽名：_________________ 日期：____________

（家長）
Dear ____________

Winnie Yu Pow LAU is a student from Malaysia. She is currently taking the Child and Family Psychology Programme at the University of Canterbury. As a member of the Chinese community, Winnie would like to take the opportunity to set up a research study to gather information about the views and experiences of Chinese families. She hopes by doing this, the uniqueness of the experiences of Chinese families in regard to their cultural background could be acknowledged to a wider extent.

In order to understand your experience better, Winnie would like to spend some time with you in your home to understand how you interact as a family and talk with you about you and your family’s point of view and experiences. Alternatively, she could also talk to you through the phone.

This letter is to ask for your permission for the school to give Winnie your contact numbers. If you have further enquiries, please contact Pip Baker (Phone: 311-1234 ext.123).

Thank you for your help.

Intervention Coordinator

__________________________

I/ We agree for Winnie Yu Pow LAU to contact me / us to talk about our experiences living in New Zealand with our child / children.

Child’s name: ________________

Signature: ________________ Date: ____________

(Parent)
Appendix Four

Consent Statement: Chinese Version

同意書

紐西蘭華裔移民家庭探討：
特殊條件兒童與其家庭成員的生活經歷與見解

研究員：劉有寶

我已了解關於這項研究的諮詢和其目的。研究員和研究督導教授已給予我機會澄清我對這項研究所有的疑問並明白我在這項研究裡的角色。

我明白:
1. 我將與研究員分享我和我家庭在紐西蘭生活的經歷和發表我的意見。
2. 我有權決定與研究員面談的次數和時間。
3. 我將有機會閱覽面談實錄並在研究員引用在論文以前作任何更改。
4. 研究資料將絕對保密。在任何文獻和討論中，我和我家人的身份將不會被披露。亦只有不會披露我個人資料的原文，才可以在研究報告中引用。
5. 我同意讓這份引用我的意見和見解的文獻被出版。
研究督導教授 Dr. Baijit Kaur 和 Dr. Karyn France 有權接觸面談資料。

我的參與是完全出自於自願。我有權拒絕回答任何問題，或在任何時間不需提供理由就退出這項研究。

我同意此研究以錄音進行，以深入和開放式的訪問，作爲資料搜集的方法。

我願意參與這項研究：

家庭成員：
姓名：____________________
研究員：
姓名：____________________
（請用正楷）
（請用正楷）

與特殊條件者的關係：____________________

簽名：____________________

簽名：____________________

日期：____________________

日期：____________________
Consent Statement: English Version

Research Title: Living in New Zealand with a child with special needs: The perception and experiences of Chinese Immigrants

I have been given and understood the explanation for this project. I have had an opportunity to ask questions and seek clarification on what this research is about and my role in this research.

I understood that:

1. I will be asked to share my point of view and experiences as a member of my family living in New Zealand.

2. I can decide on how many times and how long the researcher meets with me.

3. I will be given a chance to look at the transcript of the interview with me and I can make changes if I want before the material is used for the write-up.

4. The report will be written in such a way that neither myself nor my family can be identified and the information collected is considered confidential.

5. I agreed for the write-up of my point of view to be published.

6. The research supervisors, Dr. Baljit Kaur and Dr. Karyn France of the Education Department of University of Canterbury will assess to the information I provide.
7. My family and I may withdraw from this research at any time, with no obligation to give any reason.

8. I agree / not agree for the interview with me to be audio-taped.

I agree to take part in this research:

Family Member: 

Signed:__________________  

Name:__________________  

(please print clearly)

Relation to the individual with special need: ____________________________

Date:__________________  

Researcher:

Signed:__________________

Name:__________________

(please print clearly)

Date:__________________