### PALACKÝ UNIVERSITY OLOMOUC

Faculty of Education
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# Research on Family Resilience in Families of Children with Hearing Impairment

A dissertation presented in partial fulfillment of the requirement for Ph.D. postgradual study programme of Special Education

by

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This research is activated by those parents who have survived and been resilient while facing the challenge of fostering the children with handicaps by unfailing efforts to dispel the negative impacts imposed on their children by handicaps and to stretch their children's developmental potential. In an age said to be without heroes, they are ordinary but authentic heroes in my eyes.

# **Declaration of Originality**

I, Shenglin LIU (Student number 20044952) declare that this dissertation entitled "Research on Family Resilience in Families of Children with Hearing Impairment" and submitted as partial requirement for Ph.D. postgradual study programme of Special Education is my original work and that all the sources in any form (e.g. ideas, figures, texts, tables, etc.) that I have used or quoted have been indicated and acknowledged in the text as well as in the list of reference. Signature

**Date** 

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#### **Abstract**

Childhood hearing impairment not only impacts on children's development, but also affects all aspects of family life. This research adopted mixed approaches of quantitative research and qualitative research to examine how families from two different social contexts, the People's Republic of China and the Czech Republic, adapted to the risk of childhood hearing impairment in a sample of 160 families and explored the process of Chinese resilient families' positive adaptation despite of risky exposure. Due to substantial variations in definitions and measurement of resilience and family resilience in previous studies, in this study the term family resilience was operationalized as a systematic structure consisting of the impacts of hearing impairment as a significant risk on family life, the transactional process of hearing impairment and protective factors, and outcome of positive adaptation of accepting hearing impairment well, functioning well and expecting well.

Based on this conceptual framework a questionnaire was developed to assess the overall level of family adaptation and to identify its influential factors including impacts of childhood hearing impairment on family life, social stigma, family characteristics in family self-efficacy, family cohesion and open communication, family belief change in fatalism, optimism, altruism and tolerance toward difference, social support, family perception of childhood education and development. The findings of questionnaire survey show that (1) overall, the two groups of families were resilient facing challenges of childhood hearing impairment; (2) the outcome of positive adaptation could be contributed to the interactions of the factors of impact of hearing impairment on family life and social stigma, family characteristics, change in family belief, social support.

The further group comparison suggest that Chinese families and Czech families did not demonstrate significant difference in overall outcome of positive adaptation but displayed apparent differences in adaptive patterns because of the Chinese families showed much higher stress levels and more changes in acceptance and family cohesion than the early days after diagnosis when compared to Czech counterparts. The big gap between the two groups of families in intervention services including using hearing aids, cochlear implants, receiving therapy and other social supports involving information support from professionals, the community supports of free choice in special school and regular schools, the access to self-help parent group which may contribute to the difference in subjective appraisal of stress levels between them; however, despite of adverse impact of childhood hearing impairment and lack of adequate social support, the protective factors including Chinese family's cohesive family relationship, open communication, and positive changes in family beliefs such as becoming more optimistic, altruistic and tolerant toward difference, and feelings of being helped may have contributed to the outcome observed in Chinese families' positive adaptation.

Subsequently, in-depth interviews were conducted to describe the rich experience of eight Chinese families struggling with and adapting to childhood hearing impairment positively. The qualitative analysis of data from semi-structured interview further validated that due to inadequate social support from social security system and professionals, the Chinese families were severely impacted by childhood hearing impairment, specifically manifesting in heavy economic burden, communication difficulty and little possibility to make informed decision in sensory devices, communication mode, and educational placement. However, faced with the risk of having a child with hearing impairments, Chinese families used the strategies of shifting life focus, accepting what can not be changed, mobilizing all potential resources inside and outside family, taking concrete steps towards goal such as educating themselves sign language and working harder to earn more money for their child's future etc. to cope with it and demonstrated that childhood hearing impairment is not obstacle which is insurmountable.

Last but not least, some recommendations for intervention services in China and the limitations of this research were discussed.

Key words: Family resilience Children with hearing impairment China Czech

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#### 1. Introduction

Resilience, simply speaking, represents the manifestation of positive adaptation despite significant life adversity (Luthar, 2003). This phenomenon is highly valued in the developmental science. As one of old sayings in Chinese culture says, "eight or nine of ten things in one's life time can not happen as one wishes." Adversity challenges everyone who is living in the current changing society. Resilience is a valuable and positive concept in understanding why some individuals or families can cope with adversity successfully and be resilient while others can not.

For the overwhelming majority of families, the birth of a child with any kinds of disabilities can create a severe stress which they are difficult to face up. Just as one mother of a child with a handicap stated: "Indeed I never in my wildest dream had planned for any of the experience that we have had a child with disability..... It has changed absolutely every waking moment of our lives." In a sense, such sorrowful and stressful reactions are universal and understandable. Like the meaning expressed in the foreword of Every Child Matters, the green paper of United Kingdom government, "For most parents, our children are everything to us: our hope, our ambitions, our future." (Department for Education and Skills, 2003). For those who have had experience of being a parent, including myself, it is not difficult to understand what having a child with disability in a family may mean. It will violate anyone's deep-rooted expectations associated with having a completely healthy and promising child. It is a life-changing stressor that challenges a family's ability to cope and negatively influences their psychological well-being. Also, the reality of having a child with disability can not be seen as a single event happening at some particular point of time. On the contrary, it is long drawn-out process which may well produce marked effects on family and which may continue to produce substantial effects on

family.

With respect to the birth of a child with hearing impairment or having a hearing-impaired child, it presents special challenges to families. The term hearing-impaired-children is used to describe children who has hearing impairments ranging from a very slight loss to a total loss of hearing in the special education field. In this paper, the term hearing impaired children will be used to describe children with severe or profound hearing loss. Because most cases of hearing impairment are not hereditary, many hearing impaired children will have congenital or early-onset hearing loss that are totally unexpected (and usually unrecognized for some time) by their parents. As a result, most of families are often overwhelmed by helplessness due to lack of experience about the hearing impairment. Furthermore, they are depressed with the children's gloomy future by some common myths and social stigma associated with hearing impairment, such as "profoundly hearing-impaired people have lower IQs than people with normal hearing", "profoundly hearing-impaired are all underachievers", "profoundly hearing-impaired people can not talk" and "profoundly hearing-impaired people can not think in abstraction" (Bishop, 1979).

It is inevitable for parents to worry about the development of their hearing impaired children according to relevant research findings of deaf children. To date, a large amount of researches on deaf children have shown significant developmental differences between them and their hearing peers in cognition, language, social emotion and school achievement. For instance, relative to hearing peers, deaf children have been described as having difficulty in understanding and using abstract relationships, conceptual categorization, mathematics, reading and writing (Marschark, 1993); a variety of investigators have described deaf individuals (and deaf children in particular) as unable to take the affective perspective of others, thus, making them emotionally egocentric, lacking in empathy, being insensitive to the needs of those around them, and of more tendency to withdraw from social participation and responsibilities (e.g. Gregory, 1938); also a well-documented fact in the field of deaf education is that the majority of deaf children achieve lower educational attainment relative to their same-age hearing peers. For example, they often read between third

and fourth grade level when they graduate from high school (Zernovoj, 2007).

However, hearing impairment does not automatically lead to children's developmental lags or delays in cognitive, language, and social areas. On one hand these developmental lags or delays are just meaningful statistically. As in other populations, hearing-impaired individual vary widely in the range of development. In some ways these individuals would be expected to vary more widely than hearing individuals. So it is common that some hearing impaired children are intelligent, some are clumsy; some are sociable, some are unsociable; some are high achievers, some are low achievers. Some are successful, intelligent, and socially well-adjusted children and adults who are hearing-impaired, such as deaf and blind writer Helen Keller, deaf scientist R. H. Weitbrecht, the Gallaudet University deaf president Dr. I. K. Jordan, the Academy-Award winning actress, Marlee Matlin, a famous dancer Tai Lihua in China, to name a few. Today more and more hearing-impaired individuals are completing their higher education, even some of them getting the master, doctoral degrees in academic area, and high social status. These successful examples are testimony to the fact that many factors other than the hearing loss itself are responsible for many children's functioning below their potential. Another important findings need to be mentioned are that children of deaf parents also frequently exhibit academic skills beyond those of same-age deaf peers with hearing parents (Marschark, 1993). These findings suggest that a strong relationship existed between appropriate developmental experiences and the impact of a hearing loss on adult outcomes.

In fact, beyond the direct or primary effects of hearing impairment, those directly relating to hearing and speech, there are a variety of consequences not directly related to the hearing loss, usually being termed as secondary effects. The effect of hearing impairment on the individual's development is accumulative. The primary effects resulted from the hearing loss usually deteriorate the children's interactions with environment. Without appropriate interventions, these interactions, in turn, feed back into other aspects of development, resulting in quantitative as well as qualitative differences in the development histories of hearing and hearing impaired children, especially those deaf children who have hearing parents. Looking back the previous

researches, there really exist observed differences and deficits in hearing-impaired performance relatively to hearing children. However, these differences are more likely caused by the ways in which parents and educators structure deaf children's environment than the hearing loss itself. As a result the secondary effects of hearing impairment may be more responsible for the lags of children with hearing loss. In another words, the overall development of hearing- impaired children depends on the their range and nature of experience, such as early language experience, diversity of experiences, social interactions between children and the social environment around them (Marschark,1993).

In addition to worrying about their children's lag in development and their future, parents of children with hearing impairment are often tortured by extra parenting difficulties. To a larger degree, the world today has become more hazardous with more uncertainties, so raising relatively normal children is tough enough. In addition to normal parenting difficulties and challenges, such as adaptation to the changes in routine, the parental role demand of meeting the children's needs, attempting to balance work and parenting and so on, due to additional challenges to be experienced frequently by hearing impaired children, such as medical conditions related to the cause of hearing loss, barriers to access in the home, school, community, parents of hearing-impaired children also encounter some special difficulties of educational decision-making and often look for answers to some unique questions: How can they accept the reality of child's disability? What does the hearing-impairment mean to the child's future development? Which kind of language experience is the best choice for their hearing-impaired children, sign language, speech or other communication modes? Which kind of educational placement is more appropriate for them, the inclusive education or the special school? Which kind of auditory equipment can be more cost effective and more useful to improve the hearing condition, hearing aids or cochlear implant? Nevertheless, no matter how harsh the situation is, in any social context, there are always some families who can cope with hearing impairment successfully and be resilient, while others not. The history of deaf education is filled with numerous inspiring stories of families who successfully cope with the difficulties

imposed on them by the handicap of hearing loss. These families are often called resilient families or families with resilience. Indeed, as with children with other disabilities, parents can make differences in the education and development of their hearing—impaired children. As Weitbrecht's mother, Winifred M. Weitbrecht (1887-1973), had ever written in her unpublished essay, given that they are provided with early access to the full range of language and other experience, a beneficial climate, every deaf child will prosper and overcome his handicaps, and grow to be a happy, useful member of society as their hearing peers:

It is my hope that some part in this simple story of my son's success may help a worried parent, as the experience of others has helped me. By living one day at a time, with hope and patience and the firm faith that in God, all things work together for good; misery and despair can not prevail—and by unflinching courageous effort, a beneficial climate can be created, in which the deaf child will prosper and overcome his handicap, and grow to be a happy, useful member of society. (quoted in Marschark et al, 2002, p.13)

In line with the recognitions or ideas stated above, another more important question has arisen. That is, how can these families be resilient or resist the negative impact of hearing impairment on their family and push their children to reach their full potential while they are harassed by the various kinds of difficulties resulting from their child's hearing impairment? The answer to this question may be simple. As the United Nations High Commissioner for Human Rights had proposed in Convention on the Right of the Child, the family as the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community (Office of the United Nations High Commissioner for Human Rights, 1989). Following this line thinking, this paper examines how families of children with hearing impairment should be supported by their society so they can be resilient before they can have ability to play their social role. Up to now, this issue and the associated issues, have been

extensively discussed in family stress and coping research. From this theoretical perspective, more recently, a large number of researchers (e.g. Patterson, 2002; Walsh, 2002, 2006) have been concerned with family resilience research. Their researches aim to answer such questions as what gives a family the resilience to work through a crisis and why is it that some families develop good outcome of adaptation or thrive while others fall apart when faced with significant risks or adversities.

Consistent with these theoretical and practical explorations in family research and the health care field, policy-makers, professionals and practitioners in special education from various parts of the world have been increasingly paying more attention to the educational intervention of children with disabilities, including hearing-impairment, to prevent, reduce, or avoid deficits in children at risk for developmental problems and to reduce stress in these families, which they hope enhance resilience in families by increasing support. Since the child is seen as inextricably linked to the family, efforts to support child must simultaneously identify the characteristics of the child's family and serve the needs of child's family. Over decades of development of intervention service, the importance of being family-centered and resilience-oriented when providing services to children with disabilities and their families has gained value in research and practice. The fundamental assumption of family-centered intervention is that the best way to help a troubled individual is to support, strengthen, and empower his or her family (Snyder & Ooms, 1996). More specifically, the family-centered intervention approach is based on the following four crucial beliefs (Dempsey and Keen, 2008). First, the familynot the professional, is the constant in the child's life; second, the family is in the best position to determine the needs and well-being of the child and family; third, the child is best helped by also helping the family, and this help may extend to an understanding of the family's community and to providing information that the family needs; and finally, family choice and decision making in the provisioned services by showing respect and affirming families' strengths, enhancing family control over the services they receive, and partnerships and collaborations with families are emphasized. In essence, by empowering the child with disabilities, including those

with hearing impairments, will lead to a family who is also empowered. This may lead to families who are better equipped to cope with the adversities they face.

Indeed, what affects child affects family and what affects family affects child. Accordingly, children's disabilities, including hearing impairment belong not only to children, but also to families. Nowadays, how to best help children by empowering their family, or how to provide effective family-centered intervention service for children and their families has been becoming a internationally hot-discussed topic in the field of special education. According to previous research, some well-established recognition concerning effectiveness of family-centered intervention service include the following guiding principles: (1) based on family identified needs and desires; (2) maintaining adaptive fit between the family system and service delivery system; (3) family independence and empowerment while providing a stable ongoing support system; (4) fitting the cultural, linguistic and economic niches of families and communities etc. (Thurman, 1991; Odom, et al, 2004).

During the past decade, many changes have occurred in the educational options and provisions available to children with hearing impairment. Among them, technological changes increased the likelihood of early diagnosis of hearing loss and application of hearing aids for children, expanding use of cochlear implants provides an additional technological option for this population. Also, the bilingual-bicultural approach provides another program option in education (Meadow-Orlans, 1997). At the same time, there is increasing concern about family as a major force and primary resource for children with hearing impairment. However, despite these efforts, there is little known about such questions as how families adapt to the reality of having a child with hearing impairment, what the level of adaptation is among them, what protective factors can help families reduce or avoid the negative impact of hearing impairment on families in different social contexts, and what lessons from resilient families who can adapt to the risk of childhood hearing impairment positively can be used with those who are struggling.

Similarly, one of the well-established recognitions is that different families in different part of the world are frequently with different prior needs or desires,

difficulties, and experience diverse path of adapting while struggling with childhood hearing impairment. However, professionals need to know what the differences are, how they are different, how the intervention services are suitable to fit the diverse situations? Up to now few researchers have explored the resilience of families of children with hearing impairment in different social contexts despite the fact that hearing impairment is usually recognized as highly socially constructed and specific-context disability. Keeping these considerations in mind and making use of the convenience of studying in Czech Republic, the author of this dissertation has chosen the research on resilience in the families with hearing-impaired Children as the topic of her PhD dissertation. The purpose of the research is to increase understanding of how families with hearing-impaired children from different social cultural contexts, specifically Chinese and Czech context, which can be regarded as two representative samples of developing and developed countries respectively, adapt to the life challenges of having a child with hearing-impairment successfully, while others do not. It is expected that some lessons can be learned from resilient families across economic and cultural differences which may help future families facing the similar challenges.

More specifically, the research of resilience in families with hearing impaired children attempts to attain the following seven purposes:

- (1) To assess the overall level of adaptation among families experiencing childhood hearing impairment from China and Czech;
  - (2) To seek for influential factors contributing to the overall level of adaptation;
- (3) To compare the difference in level of adaptation to childhood hearing impairment between two groups of families: Chinese families and Czech families;
- (4) To explain the difference in level of adaptation between two family groups from the factor of social stigma, impact of hearing impairment on family life, family characteristics, the change in family beliefs, family perception of childhood education and development, social support;
- (5) To examine the family experience from the point of view of family difficulties, the communication mode used to communicate with their children, family

information needs desired, the most effective help perceived by families while parenting their hearing impaired children, and how families describe their children to validate their outcome of adaptation in two countries;

- (6) To describe the process of family experience with childhood and how to adapt to it from the family perspective in a Chinese context;
- (7) To propose some family resilience-oriented intervention strategies which have been shown effective in resilient families with hearing impaired children that may inform all families, practitioners and policy-makers.

#### 2. Literature review

The research of family resilience in the families of children with hearing impairment is based on an accumulating body of knowledge from multiple fields, mainly including hearing impairment, resilience, and family resilience researches. To provide a sound theoretical framework for further discussions and set a benchmark for comparing the results of this study with relevant findings, the review of this dissertation formulates the previous literature related to the topic into the following three parts: hearing impairment, resilience, convergence of family resilience and hearing impairment research.

#### 2.1 Hearing impairment

#### 2.1.1 Relevant and easily confused terms

In the special education field, because of the characteristics of heterogenity of children with special needs, there exists little uniformity in terms. As an example, in the area of deaf education, hearing impairment, hearing-impaired, hearing loss, deafness, hard of hearing deaf and Deaf etc., are some terms which are easily and usually confused. In order to express precise information in this research, these terms are formulated and explained as follows:

Based on the World Health Organization (WHO) regulations, hearing impairment is a broad term used to describe the loss of hearing in one or both ears. There are different levels of hearing impairment. The level of impairment can be mild, moderate, severe or profound. Hard of hearing is a broad category that includes people with mild to moderate hearing losses. Deafness refers to the complete loss of ability to hear from one or both ears (WHO, 2006a).

According to Bishop (1979), the term of hearing-impaired is used to describe

individuals who have defects ranging from a very slight loss to a total loss of hearing. In the researches and documents relevant to the hearing loss, hearing-impaired is usually used synonymously with the deaf and hard of hearing or simply deaf in some circumstances. But in fact these terms have some difference in implications. Some individual who are deaf may prefer the terms Deaf or Hard of Hearing rather than hearing-impaired, since from their point of view impairment implies disability, one kind of social stigma.

Deaf with upper case "D" is used to refer to Deaf adult and children who use sign language as their primary mode of communication and share common values, rules for behavior, traditions, and views of themselves and others. These people belong to a proud and distinctive subcultural group known as the Deaf community. Many members of the Deaf community don't think hearing loss as a disability and feel they are simply a linguistic minority, and are no more in need of a cure for their condition. The Deaf community has social norms and values particular to their society, which are passed from generation to generation. Since the Deaf member gain the vast majority of information through their eyes, and by observing closely what is happening around them, they form a specific set of social norms. The accepted forms of etiquette within the deaf community are somewhat different from those in the general society (quoted in Potměšil, 2004, p. 104-105). For example:

·Members don't generally use their voices with deaf friends, but will with hearing persons. In fact, many members of the deaf community disassociate themselves from speech.

·Members will wave, tap or throw a small piece of paper to attract a person's attention.

·In deaf culture, it is polite to "talk", that is sign, with one's mouth full, but speaking with one's hand full is not done.

·Members use a variety of devices to replace ordinary alarm clocks, doorbell, telephones, fire alarms, etc.

Deaf culture had no prohibition against staring, because it is necessary for effective communication. In hearing culture, however, it is often considered rude.

For most of hearing people, it is really not easy to understand what it means to be hearing-impaired, but the efforts have been made continuously to get more insights on hearing –impaired life from generation to generation.

#### 2.1.2 The heterogeneity of hearing-impaired children

Many people think that hearing-impaired children are not different from hearing peers except for their hearing losses due to the invisibility of their handicaps and the hearing-impaired children are a group of high homogeniety with more commonality than difference. But thing is not simple like that. In contrast, the hearing impaired children are a group of high heterogeneity. Like any other population, hearing-impaired children vary widely, and in some ways perhaps more widely than the children of normal hearing. They can be classified as various kinds of types via different dimensions.

First, hearing-impaired children can be categorized into different groups according to the degree of hearing loss. The degree of hearing loss refers to the severity of the loss. It is measured in decibel (dB) units in the better ear. The following Table is the definitions of grades of hearing impairment (WHO, 2006).

**Table 1.** Grades of Hearing Impairment (child)

	Grades of hearing	impairment
Grade 0	25dB or less	No/slight problems
None	Hears with whispers	
Grade 1	26-40 dB	Hears/repeats words
Slight		In normal voice in lm
Grade 2	31-60 dB	Hears/repeats words
Moderate		in raised voice in 1m
Grade 3	61-80 dB	Hears words shouted into
Severe		better ear
Grade 4	81dB or more	Can not hear/understand

Profound shouted voice

Note: Average 0.5, 1, 2, 4 kHz in better ear

Source: From Primary ear and hearing care training resources by World Health

Organization, 2006, Geneva: WHO Press.

Second, hearing-impaired children can be classified as three basic types, with sensorineural, conductive, or mixed hearing loss by where or what part of the auditory system is damaged. A sensorineual hearing loss is caused by a problem in the inner ear, specifically the cochlea. Damage to the cochlea or the auditory nerve generally can not be corrected medically or surgically, and it often results in a permanent and significant loss of hearing. A sensorineural hearing loss is characterized by a decreased sensitivity to sounds as well as decreased clarity of sound. Sensorineural hearing loss can be caused by diseases, birth injury, drugs that are toxic to the auditory system, and genetic syndromes. Sensorineural hearing loss may also occur as a result of noise exposure, viruses, head trauma, aging, and tumors. According to some researches, (e.g. Schildroth and Hotto, 1993), 80% of the children with a hearing loss in early intervention programs have a sensorineural hearing loss. A conductive hearing loss is characterized by a decreased sensitivity to sound, but it does not generally affect sound clarity. A conductive hearing loss results from problems in the outer or middle ear such as wax build-up or middle ear fluid. This kind of hearing loss can be corrected medically or surgically. If correction is not possible or is delayed, appropriate amplification and instruction in language and communication may be needed. Mixed hearing loss have both a sensorineural and conductive component. An individual with a mixed hearing loss may experience difficulties with both loudness and clarity. Many young children with sensorineural hearing loss also experience a temporary conductive hearing loss due to ear infections, or otitis media.

Third, the age of onset of hearing loss is important. Hearing loss may occur at any time in life. If hearing loss presents at birth, it belongs to congenital hearing loss. If the loss is severe or profound and occurs before age 2 or 3, it is called prelingual

hearing loss. Prelingual hearing-impairment is typically more problematic for the acquisition of spoken language. Without special help, this kind of children will not develop language. If hearing loss occurs at 4 and 5 years old or older, when language and speech have been acquired, the main task of education for this group is maintaining language and speech, not developing language and speech. The implications of prelingual and postlingual hearing loss are extremely different.

In addition to classification above discussed, hearing-impaired children can be described as children with bilateral versus unilateral hearing loss, symmetrical versus asymmetrical hearing loss, progressive versus sudden hearing loss, fluctuating verses stable hearing loss, to name a few, in term of other descriptors of hearing loss.

Further, hearing impaired children are often divided into others groups to meet the need of education and research in specific condition in term of the environmental factors around them. Some of the divisions are with significant implications for the parents making decisions and school education.

For example, according to the hearing condition of parents of hearing-impaired children, they are often called hearing-impaired children of deaf parents or those of hearing parents. Statistically, 90% hearing-impaired children are born to non-signing hearing parents (Gregory and Knight, 1998). A variety of studies have indicated that the early interactions between hearing mother and their hearing-impaired infants are also similar in many ways to those seen in hearing mothers and hearing children. To some extent a lack of effective interaction between parents and children might contribute to delayed language acquisition and educational underachievement in the years to come. But hearing-impaired children of hearing-impaired parents typically do not exhibit those difficulties. Hearing-impaired parents often have a variety of visual and tactile strategies for communicating effectively with their young children. It would be helpful for hearing parents of deaf children to learn some strategies from them including using facial expression and body language, using hand and body movements, touch to gain attention, using pointing to direct attention and permit language input, reducing communication so the child recognizes it as important, using short utterances positioning self and objects in child's visual field and so on

(Marschark et al, 2002).

Another example, according to the technological devices used to help hearing, hearing-impaired children are divided into children with hearing aids and with cochlear implant. Although hearing aids and other amplification devices have improved significantly over the past years, hearing technologies can never be a substitute for normal hearing. Since hearing aids amplify all sounds, it is often difficult to distinguish important information, such as speech from noise. Newer hearing aids, both analog and digital, can be programmed to particular frequency patterns, matching the hearing losses of their users and blocking out other noise. But they are still expensive. Most audiologists recommend starting children with hearing aids immediately after diagnosis of hearing loss, or as early as possible, so that they become used to them and are exposed to auditory information as early as possible (Sass-Lehrer, 1999). The cochlear implant is an electronic device that, under the appropriate conditions, provides a sense of sound to persons who are profoundly hearing impaired or deaf. It does not restore normal hearing, but it can help the user understand speech and perceive sounds from the environment. A cochlear implant involves the surgical implantation of multiple electrodes into or near the cochlea, in the inner ear. These electrodes stimulate the nerve fibers in the cochlea, creating electrical signals that stimulate the nerve fibers in the auditory nerve and send messages to the brain, where they are perceived as sound. The decision to proceed with cochlear implants should be a very serious one that will be made after parents have a clear understanding of the child and have acquired comprehensive information about the potential risks and realistic outcomes of the surgery. Parents should be informed there is nothing that will turn a deaf child into a hearing child. Even with a cochlear implant, there is no guarantee that a particular child will be able to understand spoken language.

Based on the educational placement, hearing-impaired children also can be primarily classified as children in the special school for deaf and hearing-impaired children in regular school. In detail, Bishop (1979) listed 11 kinds of educational placement for hearing-impaired children including: regular class placement only, the

consultant process, the itinerant teacher process, the resource room, both regular class placement and special class placement, both regular class placement and special school placement, special class placement only, residential school placement only, homebound instruction, exclusion. Up till to now, there is much disagreement about which placement is best for hearing-impaired children. It appears that to a greater degree whether or not a child can profit from the education depends on the children's characteristics. For example, as the suggestions from Bishop (1979), regular class placement appears to best serve students who: (a) are above average in intelligence, (b) are on grade level relative to language development, reading, writing, and math, (c) can communicate with teacher and peers, and (d) have the general ability to fully access the school programs. Resource rooms appear best for students: (a) of average ability, (b) with communications skills which are, in general, adequate for the regular classroom, (c) with a grade level relative to the regular classroom, and (d) who need additional help with one or more subjects or skills (math, reading, speech, etc.). Special or residential schools have the most flexibility in meeting student needs which can not be met in other settings. These needs often include extensive language and academic development as well as vocational training (Bishop, 1979, p.54-71).

The last kind of diversification of hearing-impaired children to be considered in this dissertation is their communication mode. Although a variety of nonverbal, social interaction approaches are available and useful for hearing-impaired children, it is through language that the education really occurs. Many hearing-impaired children grow up within multiple-language background primarily consisting of spoken language, sign language and sign-spoken bilingual context. Historically, there exists long-standing controversy between sign and spoken language. Hearing impaired children and their family often need make communication modality decision from the dichotomy of sign or spoken language. In fact it is rare that hearing-impaired children are exposed only to spoken language or sign language, even if that is the intention of their parents or teachers. Review of past researches on communication mode and development of hearing-impaired children show us that the myth that early use of sign language will impede the development of speech and language ability can be dispelled,

on the other way round, the preponderance of recent evidence with regard to language development favors exposing severe or profound children to sign language as early as possible. However, since sign language is lack of the written form, it is not the ideal end for most of parents and their hearing-impaired children all the time although it can provide early access to communication. Bilingualism is the great compromise between the two opposites. The term of sign bilingualism was coined in the 1990s (Knight and Swanwick, 2002) and is now an accepted term for an approach to the education of deaf children which includes the use of both sign language as a first language and the auditory spoken language, for example English or other language as a second language. Theoretically, being bilingual may have some potential advantage, such as experiencing two or more cultures, and communicating with a greater number and variety of people. However the route to being bilingual for hearing-impaired is complicated, and depends on many factors, largely on the individual's family circumstances, their educational experience and their wider social context.

With the great heterogeniety detailed above, it is clear that it is impossible to look for a single, correct approach to educating all hearing-impaired children, and since the method which is the best for one child is unnecessarily suitable for another, there is no one-size-fit-all method that can be used in parenting all children. This situation challenges both families of children with hearing impairment and practitioners who serve the children and their families.

#### 2.1.3 The development of children with hearing impairment

Almost all the researches in the area of hearing impairment are oriented toward facilitating the development of hearing-impaired individuals explicitly or implicitly. Also, the development of hearing-impaired children has been a well-studied and well-documented branch in science of hearing-impaired education. The review here has no sufficient space to go into extensive detail concerning every aspects of development of hearing-impaired children, but attempts to depict several salient points of development in the areas relative to my research directly, for example, the general map of development in cognition, educational attainment, and social emotion of these children comparing with hearing children. The general map will be used as a

foundation for further analysis.

In the interest of equality, or political correctness, we can claim that the hearing-impaired children are the same as hearing peers except for their hearing losses. In fact, many quantitative and qualitative differences between hearing-impaired children and hearing peers have been observed in cognitive and educational attainment, social and emotional development.

# 2.1.3.1 The general characteristics of cognitive development of hearing-impaired children

There is a long history of research on the development of hearing-impaired children's cognition, such as intelligence, information processing and related educational performance in school. The Early studies conducted by Pintner (1928) and his colleagues consistently indicated that the mental alertness of the deaf as measured on the Pintner Non-Language Tests was on the average about three years behind hearing children of the same age. The comparison was made between deaf children and unselected hearing children at the ages of 12, 13, 14, 15. In educational attainment the deaf made a much worse showing, for in this instance the average deaf child from 12 to 15 achieves on this educational test about what the 8 or 9 year old hearing child achieves (Pintner, 1928). Those early studies set the tone for describing the hearing-impaired children's development, that is, hearing-impaired children were often described as "deficient" or "concrete, literal thinker" who were unlikely to be able to grasp abstract concepts necessary for academic success. Contrary to the Pintner's early findings, another most frequently cited conclusion on the relative intelligence levels of hearing-impaired and hearing children is a more positive one based on a literature review by Vernon (1969) (in Marschark, 1993). Vernon argued that on the basis of his review of "approximately 50 independently conducted investigation, it is clearly evident that the deaf and hard of hearing population has essentially the same distribution of intelligence as the general population." Faced with the confusing and controversial findings about hearing-impaired children, some of the later researchers began to question the cultural fairness and validity of previous intelligence test while other researcher conducted more detailed researches on

information processing of hearing-impaired children, including short-term memory, long-term memory, problem-solving and creativity, and metacognition etc. As a result, most of researchers tend to reach a universal agreement that the difference between hearing-impaired and hearing children in cognitive and educational attainment is clearly observed. The hearing-impaired children experience the slower and lower developmental pace and usually lag behind their normally hearing peers as much as two to four years in reading and writing ability by the time they reach junior high school age. Concurrently, some unbalanced development of different mental aspects objectively exists. For example, the remarkable flexibility and creativity of deaf children in their sign language production as well as the remarkable consistency of deficits observed in their short-term memory spans are two such findings (Marschark, 1993). So it is likely prejudiced that the hearing-impaired children are inborn falling behind the hearing children.

With the progress of audiology and the advent of cochlear implants, numerous researches are concerned with the issue of the cognitive development and educational attainment of the children with cochlear implants. It is understandable that many parents welcome it warmly as panacea to deal with hearing impairment, with expectation that it will improve the hearing and enable the hearing-impaired children to develop with the same pace as normal hearing counterparts. However, in fact, based on a thorough review of the literature, the results are not simple and unified like that. It is evident that there are many more positive outcomes of cochlear implantation than negative outcomes. The average outcome is one in which sounds are detected 90 percent of the time, but spoken language is correctly identified less than 50 percent of the time. The outcome variability of cochlear implants is so great that it is difficult to make any good generalizations (Marschark, 2002). Some researches (for example, Niparko & Blankenhorn, 2003) on the effect of cochlear implants on young children show that the benefit provided by implants may vary with a number of conditions including hearing history, age of deafness onset, age at implantation, etiology of deafness, linguistic abilities, and the presence of a motivated system of support of oral language development. Many children-related variables should be given individual

consideration in judging candidacy for a cochlear implant and in planning rehabilitative and education services after surgery and activation of the device.

Naturally, the difference between hearing-impaired children and hearing counterparts is clear and objective, however, the difference between them is rather from the difference of language and social interaction between these children and their environment around them than from hearing loss itself. No matter how developed the technology is, nothing can turn a hearing-impaired child into a child with normal hearing. More efforts to be made should be how to create an appropriate and less restrictive environment to fit them rather than let them fit the hearing surroundings. At last this research review further uses the Marschark's finding (2002) to stress the general differences in cognition between hearing-impaired and hearing children. The implication of these difference for the parents or school teachers is that in many respects, the two population are not comparable, which means that expectation, interactions, and educational methods appropriate for hearing children may not generalize to hearing-impaired children.

- Deaf students have different experiences that may influence how they view and interact with the world.
- The diversity of both object-oriented and person-oriented experiences is crucial to normal development.
- Deaf students depend more on visual information, but they also may be more prone to distraction than hearing peers in the visual domain.
- Deaf students are often unfamiliar with the multiple meanings of words, even if they know their primary meanings.
- During memory retrieval, problem solving, or reading, the activation of information in long-term memory may not be as directed or focused for deaf students as for their hearing peers.
- In retaining a list of items in working (or short-term) memory, speech-based memory appears more efficient than sign-based memory for deaf students.
  - There may be differences between deaf and hearing learners in terms of the

way they organize knowledge and the strategies they use to access stored information. Some expectations, interactions, and educational methods appropriate for hearing children thus may not always generalize to deaf children.

- Attending to two or more sources of information simultaneously (e.g., a teacher, a computer screen, and an overhead projector) requires constant attention switching and makes communication and learning more challenging for deaf students.
- Learning/problem-solving situations that involve two or more dimensions that have to be considered simultaneously present greater difficulty for deaf than for hearing students (Marschark, 2002, p.188).

#### 2.1.3.2 The general feature of hearing-impaired children's social development

In the same way the issue of social and emotional development of hearing impaired children has also been paid attentions by a vast number of researchers. For example, Pintner (1933) concluded from his test that the deaf are more neurotic, more introverted, and more submissive than those who hear normally. Gregory (1938) compared the social response between deaf and hearing children in institution with the similar level of intelligence and made a conclusion that the most characteristic difference between two groups institutionalized was the tendency of on the part of the deaf to withdraw from social participation and responsibilities. In the later years a number of research studies have been conducted to look at mental health problem and disorder in deaf population and got almost the same findings that higher proportion, about 40-50 percent of deaf children, have emotional or behavioral problems, or sometimes both, compared with 25 percent for the general child population (Ridgeway, 1998). All in all, despite some researchers proposed that the normal personality tests for hearing people were inappropriate for use on a deaf population, a general agreement that has been nearly formed in the long history of deaf research is that the hearing-impaired children, especially children with profound hearing impairment bear some abnormal or negative personality characteristic as compared with normally hearing subjects. These characteristics include emotional instability,

egocentricity, impulsiveness, poor self-concept, and tactlessness (Bishop, 1979). Indeed as Bishop (1979) said deafness separates people from people, consequently separating individuals from the means of learning the social rules of the culture in which they live. In contrast, it is now well established that deaf children of deaf parents generally exhibit normal patterns of development in social and cognitive domain relative to hearing peers. This normality appears to be largely a function of the quality of early interaction with their parents. Looking at the creativity, desirable personality exists in some successful deaf cases, one of the basic principles that guide us to view the difference between hearing impaired and hearing children should be that the apparent difference is not caused by the hearing impairment itself, but reflection of differences in early interaction, communication, and experience from their environment, especially from the family, the immediate environment where the children development occurs. Only this principle can help us to push the hearing-impaired education toward greater facilitation of hearing-impaired children's higher educational achievement and higher level of mental well-being.

#### 2.2 Resilience

Resilience is mainly a research topic in developmental pathopsychology, mental health, and family stress research fields which focus on strengths and empowerment in past decades. Life is filled with various risks or challenges or adversities which create a heightened need for people to be able to adjust to adverse circumstances. As a society, we have a long history of focusing on the cause of disease, deficits, and behavioral problems as adverse result of crises (Patterson, 2002). In past few years, the emerging and flourishing of resilience researches mean the research shift of focusing on negative or pathological sides to exploring the positive factors in the human development concerning people how to deal with their adversities, challenges, or stresses. Resilience research started as an enquiry into the individual resilience, has grown into a broad, dynamic and existing field of study including family, community and across cultural studies. A large number of researchers examined the successful adaptation despite of significant risk context which is more likely connected to

maladaptation. The core question which resilience researchers attempt to answer is "What accounts for why some people stay healthy and do well in the face of risk and adversity while others do not?" (Patterson, 2002). Over decades, the researches from multiple disciplines contributed to a large body of literature on resilience theory, however the term resilience is still a loosely constructed concept and the research literature reflects little consensus about definition with substantial variations in operationalization and measurement of key constructs (Luthar et al., 2000). Accordingly the purpose of this review is not to present a comprehensive synthesis of all previous researches, but to provide a conceptual framework to understand the resilience and family resilience by choosing and analyzing the literatures and research findings most relevant to the topic, namely, family resilience in families of children with hearing impairment.

#### 2.2.1 Individual resilience

Resilience research started with exploration of individual resilience in risk condition or adversity, especially children in socioeconomic disadvantaged conditions. Over the past decades, the research on resilience has gained prominence as a branch to study the processes and mechanisms through which exposure to risk factors may be associated with children's both positive and negative outcomes. Up till to 1960s the researches on child development had been focused primarily on demonstrating that there was a relation between stressful events and illness. Around 1970, a pioneering group of developmental scientists turned their attention to the observable phenomenon of children at risk for problems and psychopathology who nonetheless succeed in life (Masten & Reed, 2002). By the mid of 1980s, researchers had learned more about the complexities of the relationship between experienced stress and psychological or physical outcomes, the label stress and coping had become a less useful guide to research (Haggerty et al., 1996). Some of them began to realize that whilst human being are terribly vulnerable to psychological and physical damage, it is common knowledge that some emerge unscathed, or relatively unscathed, from situations that severely cripple others (Tizard & Varma, 1992). These individual are resilient, or called persons who are with resilience.

# 2.2.1.1 Researches on individual resilience within various risky contexts

Life is filled with risks in the society of increasing uncertainty. In the American traditional dictionary, risk refers to a factor, thing, element, or course involving uncertain danger or a hazard. In the developmental science, risk factor is measurable characteristic in a group of individuals or their situation that predict negative outcome in the future on a specific outcome criterion (Masten & Reed, 2002). Among the previous researches on resilience, the term risk factor is often synonymously used as stressor, adversity, crisis, threat, stressful event or adverse event etc. Risk factors which threat to the survival and development of individuals, especially young children, or are more likely linked with suffering harm or loss are commonplace throughout the world. Risk factors, especially some significant risk conditions, for example, the parental substance abuse or parental maltreatment etc. which greatly challenge individuals and create an ideal context to examine the function of resilience. Resilience only can be demonstrated and examined in the risk context. Without risk factor, resilience does not exist.

The historical roots of resilience research can be traced to early programs of research on children with schizophrenic mothers and on individuals exposed to extreme stress and poverty, as well as on the functioning of individuals who experienced traumatic occurrences earlier in their lives. For example, the seminal works of Garmezy (1984) and his colleagues were among the earliest examples of efforts to emphasize the importance of examining protective factors in high-risk populations (children with schizophrenic mothers) (Cicchetti, 2003). Intrigued with their observations that many children at risk for psychopathology were developing surprising well, by the early 1970s, he and his students turned their attention to the study of competence in children at risk due to parental mental illness and other factors, including poverty and stressful life experience. At that time, Garmezy et al. (1984) named their research program Competence Project and in his research and the term competence was equivalent to the later term resilience.

Another one of most widely cited research on individual resilience in early days was a 40-year longitudinal study of a multi-racial cohort of children who had been

exposed to poverty, perinatal stress, parental psychopathology and family discord by Werner and Smith (1995). This study had involved a team of pediatricians, psychologists, and public-health and social workers who had monitored the impact of a variety of biological and psychosocial risk factors, stressful life events, and protective factors on the development of a multiethnic cohort of 698 children born in 1955 on the "Garden Island" in the Hawaiian chain. These individuals were followed, with relatively little attrition, from the prenatal period through birth to ages 1, 2, 10, 18, and 32. Some 30% of the survivors in this study population were considered high-risk children because they were born in chronic poverty, had experienced perinatal stress, and lived in family environments troubled by chronic discord, divorce, or parental psychopathology. This research reached a conclusion that one third of the children who had experienced four or more such risk factors developed into competent, confident, and caring adults. The protective factors helping these children be resilient individuals are firstly within individuals, such as easy temperament and the ability to actively recruit competent adult caregivers in infancy, a coping pattern that combines autonomy with an ability to ask for help when needed in preschool age, communication and problem-solving skills, intelligence and academic competence, belief in their own effectiveness, a positive self-concept in middle childhood and adolescence. The protective factors within their family include having the opportunity to establish a close bond with at least one competent and emotionally stable person, mainly grandparents in extended families who are attuned to his or her needs. There are also support systems in the community that reinforce and reward the competencies of resilient children and provided them with positive roles models: favorite teachers who listened to the children, challenged them, and rooted for them, caring neighbors, elder mentors, youth workers and peers (Werner, 1995, p.81-85).

At present, the existing researches on individual resilience have been stretched to children, adolescents, adults at-risk in variety of risk conditions, ranging from normative stressors to non-normative ones, such as disasters including earthquakes, fires, hurricanes, plane crashes, terrorism or other willful acts of violence and so on (Peek, 2008). As for the individual resilience in normative stressors, numerous

researchers have paid attentions to the risk individuals due to individual-related factors ranging from individuals experiencing the chronic illness, for instance, asthmatic children (Hee, 2007) and individuals with disabilities (King et al., 2003), through the individuals living within various kind of disadvantaged familial surroundings, for example, children coping with their parent's divorce and remarriage (Hetherington and Elmore, 2003), risk and resilience among children with maternal drug (Luthar et al., 2003), risk and protective factors for children of depressed parents (Hammen, 2003), the young children whose mother are living with HIV/AIDS (Murphy, 2008) to children's positive adaptation to the community risk environment, such as children exposed to community violence (Gorman-Smith and Tolan, 2003) and the youths living urban poverty (e.g. Anthony 2008).

In sum, all the researches demonstrate that the same risk or adversity can result in different outcomes. For example, as stated in the Weiner's research, not all children lived in chronic poverty or other troubled family environment experienced being shattered or damaged by adversities, on the contrary about one third of the children who had experienced such risk factors developed into competent, confident, and caring adults. Also other researchers found that children who lived in high-risk conditions such as parental maltreatment are able to live well and love well. For example, most abused children do not become abusive parent (Kayfman & Ziegler, in Walsh 2002).

To account for these differences, or to explain the phenomena characterized by pattern of positive adaptation in the context of significant adversity or risk (Masten & Reed, 2002), many researchers try to find out the protective factors which modify the impact of adversity or protect individuals in risk context from being damaged.

#### 2.2.1.2 Protective factors of resilient individuals

Protective factor is a measurable characteristic in a group of individuals or their situation that predicts positive outcome in the context of risk or adversity (Masten & Reed, 2002). A wide range of researches have made efforts to explore what factors help some individuals escape from the negative influence of some risk or adversity. In addition to the Werner's findings (1995) above mentioned, some other researchers

also had contributed some insight to this question. For example, Jenkins and Smith's (1990, in Rutter 1999) studied the factors which protect children living in disharmonious homes. In keeping with the result of other studies, a poor relationship between the parents was associated with a higher level of children psychopathology than that in children from harmonious, cohesive families. Nevertheless, this negative effect of marital discord could be mitigated to a very considerable extent, when the children had a warm, close relationship with one of the parents. Similarly, Rutter et al. (1999) had studied the protective factor which protected individuals who had showed antisocial behavior in childhood from the vicious circle. The study showed that those who lacked support of harmonious marriage in adult life had strong tendency to continue with their antisocial behavior and had multiple social problems involving relationships with other people, employment, and other aspects of everyday life. By sharp contrast, those who had marital support tend to show a marked and statistically significant tendency to end crime and to show much better social functioning.

Barnard (1994) had ever reviewed the researches in the periodical literature and had identified some representative protective characteristics from children themselves and their protective families. The child-related protective characteristics included the following assets:

- ·Being perceived as more cuddly and affectionate in infancy and beyond;
- ·Having no sibling born within 20-24 months of ones' own birth;
- ·A higher level of intelligence;
- ·Capacity and skills for developing intimate relationship;
- ·Achievement orientation in and outside of school;
- The capacity to construct productive meaning for events in their world that enhances their understanding of these events;
- ·Being able to selectively disengage from the home and engage with those outside, and then to reengage;

- ·Being internally oriented and having an internal locus of control;
- •The absence of serious illness during adolescence.

At the same time, Barnard collected some factors that were observed in the family environment of resilient individuals:

- ·The extent and nature of the fit or "match" between the child and parents;
- ·Possessing and maintaining rituals in the family;
- •The family's assumption of a proactive posture and confrontation of the problem or stressor in contrast to a passive and reactive posture;
  - ·The absence of parent-child role reversals;
  - ·Minimal conflict in the home during infancy;
  - ·The absence of parental divorce during adolescence;
  - ·A substantial and productive relationship with one's mother;
  - ·Selection of a non-troubled person as a mate.

With the resilience researches moving on over time, some researchers have attempted to explore the protective factors from more wider ecological system and have developed more systematic view of point. As an example, Masten and Reed (2002) collected a long list of protective factors for resilience in children and youth from child's internal world, external world of family and community:

Protective factors within child: good cognitive abilities, including problem-solving and attentive skill; easy temperament in infancy; adaptable personality later in development; positive self-perception; self-efficacy; faith and a sense of meaning in life; a positive outlook on life; good self-regulation of emotional arousal and impulse; talents valued by self and society; good sense of humor; general appeal or attractiveness to others.

Protective factors within the family: close relationships with caregiving adults; authoritative parenting (high on warmth, structure/monitoring, and expectations);

positive family climate with low discord between parents; organized home environment; postsecondary education of parents; parents with qualities listed as protective factors within the child; parents involved in child's education; socioeconomic advantages.

Protective factors within community: close relationships to competent, prosocial, and supportive adults; connections to prosocial and rule-abiding peers; effective schools; ties to prosocial organizations, including schools, clubs, scouting, etc; Neighborhoods with high collective efficacy; high level of public safety; good emergency social service; good public health and health care availability.

Summarily, numerous studies have documented the protective factors which protect individuals from being damaged by risk or get good outcome of adaptation despite of adversity or risk. Meanwhile it is evident that the past researches have not got consensus on at earth what protective factors are. However, one of insightful recognition can be drawn from those researches is that a growing body of previous researches which began as a quest to understand the extraordinary have revealed the power of the ordinary (Masten, in Glicken, 2006). Resilience is not inborn quality which is unique for only few people, it is ordinary attributes which can be developed by everyone within certain supportive circumstance.

## 2.2.1.3 Variation in definition of resilience: from personal traits to process

As stated previously, although a large number of researches on resilience notwithstanding have been conducted by scholars from multiple disciplines, there exists no agreement on the understanding of resilience between researchers. The following are some samples of definitions extracted from first or second hand literatures:

- (1) Resilience is qualities which cushion a vulnerable child from the worst effects of adversity in whatever form it takes and which may help a child or young person to cope, survive and even thrive in the face of great hurt and disadvantage (Gilligan 1997, in Daniel 2006);
- (2) Resilience is a process, capacity or outcome of successful adaptation despite challenges or threatening circumstances (Kumpfer, 1999);

- (3) Resilience refers to a dynamic process encompassing positive adaptation within the context of significant adversity (Luthar et al, 2000);
- (4) Resilience refers to the capacity to respond, endure, and/or develop and master in spite of experienced life stressors (Mandleco and Peery, 2000);
- (5) Resilience is the human capacity to deal with, overcome, learn from, or even be transformed by the inevitable adversities of life (Grotberg, 2003 in Cone 2007);
- (6) Resilience embodies the personal qualities that enable one to thrive in the face of adversity. And it is a multidimensional characteristic that varies with context time, age, gender, and cultural origin, as well as within an individual subjected to different life circumstances (Connor, 2003);
- (7) Resilience is the ability to withstand and rebound from adversity, it involves a dynamic processes encompassing positive adaptation within the context of significant adversity (Walsh, 2002);
- ( 8 ) Resilience generally refers to a class of phenomena characterized by pattern of positive adaptation in the context of significant adversity or risk (Masten & Reed, 2002).

It is apparent that the previous researchers had conducted resilience researches not within uniforming understanding of the term resilience. Resilience is sometimes confused with competence (or in similar forms of quality, ability, attribute and so on), or the outcome of positive adaptation. In this study, the comprehensive model of resilience, the transactional model of resilience proposed by Kumpfer (1999) which combined individual attributes, outcome, and process of resilience together was adopted as the fundamental conceptualizational framework to understand resilience. According to Kumpfer's (1999, p.180) transactional model of resilience, resilience is holistic and dynamic process of interaction between resilient person and his/her high risk environment. The model begins with an initiating event, which is a stressor or a challenge that signifies the disruption in homeostasis of the individual or the environment and calls for a resilient integration to maintain the stable equilibrium of the individual or environment. The initiating event marks the beginning of the

resilient process, and the process ends with an outcome, which may constitute either resilient reintegration or maladaptive reintegration, the latter constituting non-resilience. This model argued six components of resilience demonstrated in Figure 1.

•The stressors or challenge: exposure to stressors or stressful event compel an individual to develop strength and grow from such experience.

The environmental context: while individuals facing the challenging condition, the environmental context serves to either cushion or intensify the impact of stressful event on the individual. For example, caring families, schools and peer group serves to external protective factors by providing effective advice, a sense of connectedness, opportunity for meaningful involvement and so on. On the contrary, family maltreatment, peer bullying and exposure to community violence etc. may worsen the individual existing stressful condition.

• The person-environment transactional process: the level of stress that individuals experience is subject to their own interpretation through individual perceptions and cognitive evaluation. Also, it involves individual can take some initiatives to modify the risk environment.

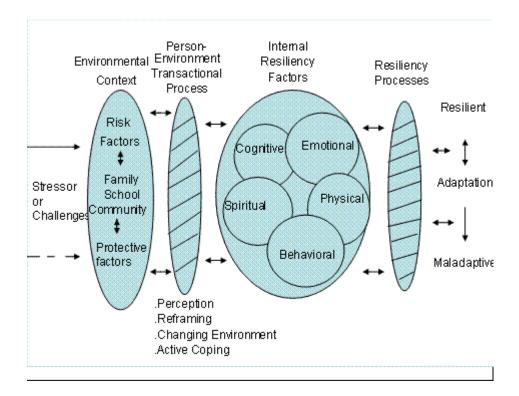


Figure 1: Resilience framework of Kumpfer (1999, p.185)

The internal resilience factors or individual characteristics: the internal protective factors include the spiritual (dreams and goals, belief in uniqueness of oneself and independence etc.), the cognitive (higher intelligence and achievement orientation, the ability to delay gratification to achieve success etc.), the social and behavioral (higher interpersonal skills and problem-solving skills), the emotional (empathy in others and managing their own emotion) and the physical strengths and characteristics (the feeling of physical attractiveness and feeling strong and healthy physically and psychologically) and form the core resilience traits of each individual.

• The resilience process or the area of transaction between the individual and the outcomes. The resilience process is not like something done once-and-for ever and it means the continuous interaction between the internal resilience factors of an individual, the environment and the outcome of transactions.

The outcome of resilience: usually three outcomes follow the resilience process, resilient reintegration (the current resilience surpassing the previous state before risky event occurs), adaptive reintegration (the current resilience returning to the previous state), and maladaptive or non-resilient reintegration that individuals tends to be victims of challenges with loss of hope and enthusiasm (Kumpfer, 1999, p.185).

#### 2.2.1.4 The assessment of individual resilience

As previous empirical researches on resilience have been implemented in loose constructed concept of resilience, the ambiguities in definitions and central terminology, heterogeneity in risks experienced and competence achieved by individuals viewed as resilient, instability of phenomenon of resilience etc. lead to great challenge of objective judgment of resilience (Luthar, 2000). However, despite the meaning of resilience and its operational definition have been the subject of considerable debate and controversy over years, there is little dispute that there are individuals or functional units whom most people would consider "resilient" by almost any definition. Nevertheless, it is not easy to judge who is resilient and who is non-resilient. Encouragingly, some researchers have made valuable efforts to assess the resilience from the different perspectives.

Several researchers have attempted to measure individual difference in resilience by developing standardized scale (Connor & Davidson et al, 2003, Hjemdal et al, 2006). For example, Cornor and Davidson (2003) had developed Connor-Davidson resilience scale (CD-RISC) to be used in empirical research and it had been evidenced as effective scales with acceptable credibility. The CD-RISC contains 25 items, all of which carry a 5-point range of responses, as follows: not true at all (0), rarely true (1), sometimes true (2), often true (3), and true nearly all of the time (4). The scale is rated based on how the subject has felt over the past month. The total score ranges from 0–100, with higher scores reflecting greater resilience. The scale is intended to measure 5 factors theoretically: Factor 1 reflects the notion of personal competence, high standards, and tenacity; Factor 2 corresponds to trust in one's instincts, tolerance of negative affect, and strengthening effects of stress; Factor 3 relates to the positive

acceptance of change, and secure relationships. Factor 4 was related to sense of control and Factor 5 to spiritual influences (Connor et al, 2003, p.76-82). However, from the basic structure and the variables which are really checked in this scale, the CD-RISC primarily aims to explore the personal capacity to deal with life stress.

Other researchers have tried to assess the resilience from the perspective of dynamic process based on the agreement that the term resilience refers to the phenomenon of overcoming stress or adversity (e.g. Rutter, 1999; Luthar 2000). That is, put in more operational terms, it means that there have been relatively good outcome for someone despite their experience of situations that have been shown to carry more a major risk for the development of psychopathology. Furthermore, Luthar et al 2000) proposed that the two fundamental characteristics of the construct of resilience are exposure to significant threat or adversity and individual variations in the response to adversity. Similarly, according to Masten and Powell (in Luthar, 2003) resilience is an inference about a person's life that requires two fundamental judgments: (1) that a person is "doing ok" and (2) that there is now or has been significant risk or adversity to overcome.

It is not difficult to get a conclusion that significant risk and positive adaptation (doing ok or good outcome.) are two elements of resilience. Yet this recognition raises another two issues: (1) which kind of risk can be regarded as significant risk? (For example, parental death or parent drug abuse, which has more likelihood of leading to children's behavioral disorder?); (2) what state of adaptation can be regarded as good outcome while facing the different risk (for example, the negative impact of parental death can be resolved over time while personal disability can not be cured forever)? To some degree, the two questions are too complicated to be answered simply with a definitive answer. However, in an effort to build a precise, clear and uniform conceptual framework for the present study, these two questions are to be discussed further in the following section using the efforts made by previous researchers.

## Significant risk

With respect to which kind of risk can meet the requirement of significant risk,

the answer to this question can be got through three approaches. Firstly, it can be solved through statistical inference (Luthar, 2000). If one kind of risk exposure shows significant population-based statistical association with child maladjustment such as developmental lag in cognition, social and emotional problems or even psychopathology etc., it can be labeled as significant risk. For example, in Werner and Smith (1995) study, only one third of the children who had experienced high risk such as poverty, parent pathopsychology etc. had developed into competent, confident, and caring adults. As stated earlier, many different kinds of risk factors to individual development and functioning have been the target of investigation in studies of resilience. These include poverty, parental divorce, premature, maltreatment, parent illness or psychopathology, homeless, disability, community violence, massive trauma of war and natural disasters and so forth. Although they are of different nature in severity, duration, connection with different developmental area of individuals, all of them have been recognized as significant risk or well-established risk factors for individual development because there is good evidence that such experiences of conditions elevate the probability of one or more developmental problems in individuals (Werner, 1995; Masten & Reed, 2002).

Second, resilience is a context-specific term. Even the most resilient individuals can not be resilient in any risky condition. Also, facing the same risk individuals usually manifest great variation. As Kumpfer (1999) stated, the level of stress that individuals experience is subject to their own interpretation through individual perceptions and cognitive evaluation. Because people differ in how they view bad experience, it seems reasonable to suppose that individual difference in meaning making of risk could be important in determining whether one kind of risk is significant risk or not. As no individual or functional unit is invulnerable to any kind of risk factors it is difficult to develop a universal standard to judge diverse risk factors. Consequently, different researchers usually take specific operationalization in specific research. Some researchers define the term of significant risk according to the respondents' subjective appraisal in specific risk condition. For example, in a study comparing the effects of diabetes, asthma, cystic fibrosis, and deafness, Tavomina et

al. (1981, in Lampropoulou & Konstantareas, 1998) found that parents of the deaf group reported the greatest stress. According to related result in their research deafness were designated as significant risk although the later researches held debate on this issue because of the social construction of deafness.

Third, whether a risk is significant should also be considered from the duration of risk context. Sometimes some stressors of low severity, such as parental unemployment, can develop to be significant risks because of their duration of long time and the accumulation effects. Miller and Smith (2005, in Glicken, 2006) had discussed the effect of three types of risk factor or stress from the dimension of duration: (1) Acute stress. It is the common type of stress we all feel when something goes badly or makes life temporarily more complicated. Acute stress is time limited and goes away when the situation rectifies itself. (2) Episodic stress is experienced by those who place themselves in stressful situations. Being late or continually placing oneself in situations leading to crisis might be examples of episodic often lack the ability to order problems or to deal with them in pragmatic and rational ways, creating situations in which crisis is continual; (3) Chronic stress is the grinding stress that wears people away day after day, year after year. Chronic stress destroys bodies, minds, and lives. It's the stress of poverty, of dysfunctional families, of being trapped in an unhappy marriage or in a despised job or career etc. As a result, some risks of low severity and showing no life-threatening will become significant risk because of long process of exhausting one's energy and wellbeing.

### Positive adaptation

Similarly, some researchers have explored the issue of judgment of positive adaptation within multiple risk exposure. According to Masten (1994), psychological adaptation generally has had two major components: internal mental functioning and external behavior. Internal health has been described in terms of psychological well-being, internal equilibrium, and ego strength. Internal problems have been described in terms of psychological distress, decompensation, and anxiety. Externally, "good" psychological adaptation has been referred to as competence and social adjustment, whereas "poor" adaptation has been called externalizing symptoms,

antisocial behavior, and social maladjustment. Among past decades, diverse criteria have been used for judging good adaptation in studies of resilience. These included positive behaviors, such as the presence of social and academic achievements, the presence of other behaviors desired by society for people of this age, happiness or life satisfaction, or the absence of undesirable behavior, including mental illness, emotional distress, criminal behavior, or risk-taking behaviors (Masten & Reed, 2002). Also, considering one specific risk is more likely to impact on one profile of development domains, for example, the history of maltreatment having more negative impacts on social behavior than academic achievement, some researchers had used circumscribed terms such as "educational resilience", "emotional resilience" and "behavioral resilience" (Luthar, 2000).

Moreover, resilience is of the nature of development across ages. To judge the outcome of adaptation of individuals of different ages under risky condition, Masten and Reed (2002) had proposed the term of developmental task to integrate multiple outcomes. According to their recognition, developmental tasks refer to expectations of a given society or culture in historical context for the behavior of children in different age periods and situations the criteria by which progress in individual development is judged. For example, toddlers are expected to learn to walk and talk and to obey simple instructions of parents. In most societies older children are expected to learn at school, to get along with other children, and to follow the rules of classroom, home, and community. In normal conditions, successful youth are expected to graduate from high school and gain the education and occupational skills needed for economic independence, to abide by the law, to have close friends and romantic relationships, and to begin to contribute to society. Put simply, one individual can be called resilient only if he/she accomplishes his/her age-appropriate developmental task or normal functioning despite exposure to significant risk which is more likely linked with the developmental lag or problems.

Furthermore, with respect to some chronic risk context, like chronic health condition, the adaptation is a long process which could not end at one particular time point. Accordingly it is difficult to judge the outcome of adaptation at a specific time.

Within this situation, some researchers (e.g., Kampfer, 1999; Masten, 1994) had proposed that the outcome of adaptation should be judged by comparing the level of adaptation before, during and after exposure to risky context. As a result, as mentioned prior, Kampfer (1999) had classified the outcome of adaptation as three level, resilient reintegration (the current resilience surpassing the previous state before risky event occurs the level of higher than that before risky exposure), adaptive integration (the current level is returning to the previous level) and non-resilient integration (that individuals tends to be victims of challenges with loss of hope and enthusiasm). This assessment method has been adopted as theoretical framework for this study to assess the outcome of positive adaptation from the perspective of process.

Meanwhile, the outcome of adaptation is assessed relative to the changeability of risky factor. Masten (1994 in Luthar, 2000) had distinguished among three groups of resilient phenomena despite exposure to specific risk: (1) those where at-risk individuals show better-than-expected outcomes; (2) positive adaptation is maintained despite the occurrence of stressful experience; and (3) there is a good recovery from trauma. Some risks, such as poverty or academic failure, may be overcome through personal endeavor and external help. However, some chronic health condition, such as disabilities, childhood cancer, can not be overcome or resolved. The only thing at-risk individuals can do is to come to terms with them.

In sum, the assessment of positive adaptation is an inference relative to the specific context. Till to now, no universal standard can be used to judge the outcome of adaptation to specific risk. Different researchers have used different indicators, such as good academic achievement, mental well-being, good employment, normal social communication, or the combination of variables above listed. Also some researchers have assessed the level of adaptation based on performance higher than average, while others based on a performance than expected. However, no matter what resilient phenomena it is, normal functioning within risky condition is a basic requirement of resilience.

At last, this study has developed its own understanding about individual

resilience. It is operationalized as a systematic structure including three elements: significant risk, the protective process of interaction between risk factor and protective factors, the outcome of normal functioning despite risky exposure. In the following sections, this conceptual framework will be used specifically to explain the family resilience.

## 2.2.2 Family resilience

With the proliferation of researches on resilience and application of their findings in practice, some family scholars (e.g. Walsh, Patterson) began to extend the resilience research to family field and formed an idea that families like individuals can be considered resilient or not as they deal with the challenges in their lifecycle or some unexpected risk in the past two decades. While family as the central context within which individual's development occurs, as a unique social system family itself experiences the process of its development and as it will meet risky event or adversity as individuals do. In the resilience research, family first appeared as context for the resilience of the individual as a risk factor raising the vulnerability of family members or as protective factor to boost the resilience of the family members. However, there is another body of research that conceives of the family as an entity in itself or functional unit rather than as merely a context for individuals. For example, as the perspective expressed by Patterson (2002a), families, like individuals, can be considered resilient as they deal with the challenges in their lives has received increased attention from family scholars in the past decade. Family resilience research mainly seek answers for such questions: What gives a family the resilience to work through a crisis? Why is it that some families fall apart when faced with adversities, while others thrive and become stronger? What are the qualities of these resilient families? And how do these families establish and maintain these strengths? (Australian Institute of family studies, 2001).

# 2.2.2.1 Family as a system

Families are a special subset of social systems and are structured by a unique set of intergender and intergenerational relationships. Family is an open, ongoing, goal-seeking, self-regulating, social system (Broderick, 1993). From the point of view

of sociology, a system is a causal network of elements that are interrelated in a more or less stable fashion within any particular time period. The family fits this definition of system nicely considering these family characteristics:

- (1) The positions occupied by family members, the elements of the family system, are to varying degrees interrelated and interdependent;
  - (2) The family also, through selective boundary maintenance, constitutes a unit;
  - (3) The family modifies its structure of interaction networks;
- (4) The family is a task performance group that meets the demands of other societal groups and those of its members. And because family members are in association with each other, we can take the word social onto the term system, thereby categorizing families as social systems (Aldous, 1996, p.46).

## 2.2.2.2 Family function as a functional unit

Family as unit, it has its own function at the system level. As a system, where a minimum of two family members are involved, its function is not equal to the sum of the individuals. Essentially it represents the product of family relationships, normally including marital relationship between husband and wife, parental relationship between parent and child, sibling relationship between child and child, and extrafamilial relationship between family members and extended family, friends, neighbors, larger community. According to Patterson (2002a, 2002b) family functions involves the needs that families are responsible for, including affection needs, economic needs, health care and protection needs, socialization needs etc. In order to satisfy these needs, family must perform relevant tasks. This process is called family functioning. The principal tasks involved in family functions are presented in Table 2.

### 2.2.2.3 Family resilience research in multiple risky contexts

Every family encounters risks and deals with them. For many families, the risk is just an inevitable accomplishment to everyday life as the special event and transition in family life cycle. But for many other couples and families, some significant risks, such as parental death or loss of child and so on enter their lives. These risks are unanticipated events that disrupt family life and can potentially damage individuals and their relationships. A basic premise from the systematic view is that serious and

Table 2. Family function and relevant tasks for individuals

Family function	Ways each function provides benefits to family members	Examples of positive (+) and
		negative (-) family level outcomes
Membership and family formation	·Provides a sense of belonging	+ Commitment to and maintenance of family unit
	· Provides personal and social	+ Addition of children is planed and desired
	identity	-Divorce
	·Provides meaning and direction	
	for life	
Economic support	·Provides for basic needs of food,	+ Adequate food and clothing + Safe housing
	shelter, and clothing and other resources to enhance human	-Child neglect
	development	-Homeless
Nurturance, education, and socialization	· Provides for the physical,	+ Family love and mutual support
	psychological, social and	+Marital commitment and
	spiritual development of children and adults	satisfaction + Securely attached children
	·Instills social values and norms	-Domestic violence
		-Child abuse
Protection of vulnerable members	· Provides protective care and	+ Family care for child with special needs
	support for young , ill, disabled or otherwise vulnerable members	-Elder abuse
		-Institutional placement of member
		with disability

Source: From *Understanding family resilience* by J. Patterson (2002), Journal of Clinical Psychology, Vol. 58(3), 233-246.

persistent risk factors have an impact on the whole family as a functional unit.

There has been a long history of research on families coping with risk and hardships. Now these researches have been integrated into the umbrella of family resilience. In line with the aim of the individual resilience research, researches on

family resilience are mainly concerned with the questions why some families emerge strengthened and resourceful while others are shattered by crises or chronic stresses. Because of the diversity of the family structure and the family elements, family resilience research has became an umbrella for all the researches concerning the couples, children, siblings, parents, and the whole family as a unit coping with the illness of other family member or other adversity within family context. For example, the book The Dynamics of Resilient Families edited by McCubbin et al. (1999) brought together a variety of studies on the growth-producing process and outcomes of families facing conflicts and adversity. In this book, Daley (in McCubbin et al., 1999) explored the reorganization of self, goals, and relationships for couples experiencing infertility; Thompson's study of mothers of adult children with AIDS pointed to the use of day-to-day coping strategies to face the uncertainty of the illness program (in McCubbin et al., 1999); Mederer's study (1999) examined the impact that changes in the commercials fishing industry have had on traditional fishing families (in McCubbin et al., 1999) and the study pointed to family role flexibility, family coherence, and social support as sources of resilience in the face of major family life changes. Similarly, in another book, Family Stressors: intervention for stress and trauma edited by Catherell (2005), Gilbert (2005) focused on what is commonly regarded as the most difficult kind of loss, the loss of child and she noted how spouses had different relationships with the child and different grief experiences; Armour (2005) examined the immense impact on the family when a family members was murdered and analyzed families' lasting grief and no recovery response to the violent death in contrast to the "natural" dying. Not particularizing one by one, the specific stressors covered in this book included death of child, homicide of a family member, traumatization of a parent, traumatization of a child, dysfuntion of an aging parent, and the threat of terrorism and so on.

Additionally some recent researchers examine the family resilience within broader context, the ethnic group or across-cultural context. For example, Glicken (2006) explored how Latino culture copes with social and emotional problems, resilience in African Americans and traditional Asian Americans. Cone (2007)

analyzed the challenges of Russian immigrants to the Unites States, homesick for Russian culture, ways of living, social context, family and friends, Americans not understanding their cultural background, limited recognition for artist, the intensity of American work force, language barriers, and the difference in skills for a field in a different culture by multiple faces of resilience, the act of making do with very limited resources, risk-taking, coming together as community, attitudes of hope and determination. Younes (2007) analyzed the resilience of families in Israel facing challenges of violence, terrorism and war, poverty, family instability, by diversity of strengths, commitment, religion and the related spiritual practice, and open communication etc. Xu et al. (2007) explored the Chinese family strengths and resiliency in aspects of family and marriage, including equity in marriage, affection, the ability to adapt to changes, mutual trust, compatibility, harmony and family cohesive support while facing social challenge and family stressful events.

# 2.2.2.4 The protective factors for family resilience

As protective factor in individual resilience, protective factors in family resilience are defined as attributes of family members, the family unit and wider environment that help to reduce the negative effects of adversity on families' development. According to Patterson (2002), protective factors that contribute to competent family outcomes can emerge from a family unit, and from multiple community contexts. Due to protective factors related to the family members have been discussed in the section of individual resilience, here more spaces are given to the family-level protective factors. The exploration of protective factors for family resilience aims to answer what help some families from being damaged and function normally while others fall apart or dysfunction when faced with the same significant risk. A group of researchers have concerned about these questions. One important research among them was a National Family Strength Research Project conducted by the Australian Family Action Centre conducted in 1999 and it had developed a family strengths template consisting of eight qualities which contribute to strong family. Each quality is defined and illustrated below:

**Communication:** It is a kind of strength when the family interacts with each

other frequently and predominately in an open, positive, honest manner. Some families also mentioned humor as a kind of strength in their communication.

**Togetherness:** It is the "invisible glue" that bonds the family and gives the family members a sense of belonging. An important ingredient to this 'glue' is sharing similar values, beliefs and morals.

**Sharing activities:** Strong families like to share and do activities with each other – activities such as sports, camping, playing games, reading stories, socializing together, and sharing hobbies and holidays.

**Affection:** It is a kind of strength when family members show love, care, concern and interest for each other on a regular basis through words, hugs, kisses, and thoughtfulness. Expressions of affection are often ritualized in families – for example, with greetings and farewells, bedtime story reading, and during celebrations such as birthday and Christmas.

**Support:** It is assisting, encouraging, reassuring each other and looking out for each other. It is strength when family members feel equally comfortable to offer or ask for support.

Acceptance: It means showing respect, appreciation, and understanding for each other's individuality and uniqueness. Acceptance is a kind of strength when family members acknowledge, value and tolerate each other's differences, and when the members allow each other space.

**Commitment:** It is showing dedication and loyalty toward the family as a whole. Strong families often view the wellbeing of the family as a first priority. Commitment is expressed in many ways, to the family, the partner relationship, children, the extended family, and/or the community.

**Resilience:** All the above attributes are encompassed within the concept of family resilience. (Australian institute of family studies, 2001)

In addition to protective characteristics within family, some protective factors from community or other places outside family can be found to moderate the relationship between the family's exposure to significant risk and their ability to show competence in accomplishing family functions. For example, some researchers had

examined the protective functions of self-help group. According to Riessman (1997, in Glicken, 2006), self-help groups have the following functions and purposes:

·Self-help groups have members who share a similar conditions and understand each other;

- ·Members determine activities and policies, which makes self-help group very democratic and self-determining;
  - ·Helping others is therapeutic for members;
- · Self-help groups charge no fees, are not commercialized, and build on the strengths of the individual members, the group, and the community;
- ·Self-help groups functions as social support systems that help participants cope with traumas through the supportive relationships between members;
- ·Values are projected in self-help groups that define the intrinsic meaning of the group to its members;
  - ·Self-help groups use the expertise of members to help one each other;
- ·Self-help groups members may find that seeking assistance from the group is not stigmatizing, as seeking help from a health or mental health provider may be;
- · Self-help groups focus on the use of self-determination, inner strength, self-healing, and resilience.

In sum it seems that giving help is the best way of being helped. Accordingly, self help group can play an important role to help participants to cope with life adversities.

# 2.2.2.5 Variation in definition of family resilience: from competence to process

Similar to the term resilience, the construct of family resilience, has been defined and applied very differently by those who are primarily clinical practitioners and those who are primarily researchers in the family field. This inconsistence can be revealed from the following definition of family resilience:

(1) Family resilience implies the capacity of a family to successfully manage

challenging life circumstances-now or in the future (Walsh, 2002);

- (2) Family resilience describes the path a family follows as it adapts and prospers in the face of stress, both in the present and over time. Resilient families positively respond to these conditions in unique ways, depending on the context, developmental level, the interactive combination of risk and protective factors, and the family's shared outlook (Haan et al., 2002);
- (3) Family resilience is the interplay of multiple risk and protective factors that occurs over time and involves individual, family and other sociocultural influences, it describes dynamic process that foster positive adaptation to adversity (Heru, 2006);
- (4) Family resilience is the ability of the family to develop and/or maintain healthy family functioning and successfully adapt to life's challenges and risks (Vandsburger et al., 2008);

Similar to researches on individual resilience, family resilience researches are not narrowly limited to describe the characteristics of a strong or resilient family. In effort to support good outcome of adaptation despite exposure to risky condition, some researchers had attempted to understand the protective mechanism which lead to the unexpected competent functioning in some families while other families had been overwhelmed.

Patterson (2002a) had attempted to elucidate the process of family resilience by integrating family resilience and family stress theory. He used the Family Adjustment and Adaptation Response (FAAR) to explain family resilience process. The FAAR model consists of four central constructs: family demands, family capabilities, family meanings and family adjustment or adaptation. Family demands, similar to risk factors, are mainly comprised normative and non-normative stressors. Family's capabilities, similar to protective factors, include tangible and psychosocial resources (what the family has) and coping behavior (what the family does). Family meaning, an important construct in FAAR, can really help us understand how the resilience process unfolds mainly concerning the family perception of risk and their world views and so on. These meanings shape the nature and extent of risk, as well as the

protective capacity of a family. Family adaptation has been defined as a process of restoring balance between capabilities and demands. When the family is successful in this process, good outcome is observed in the family's (a) continued ability to promote the development of individual family members and (b) willingness to maintain their family unit so it can accomplish its life cycle tasks. It is apparent that the FAAP model emphasizes the meaning a family gives to their situation and includes appraisal of the difficulties of the sources of stress and appraisal of the family's capabilities to manage the stress from a perspective of process (Patterson, 2002a).

Another important family resilience model related to the process of family resilience was developed by Walsh (1996, 2002). Walsh and others over the years have attempted to expand the individual resilience construct to families. Her family resilience framework focused on strengthening families in the risk context. Her premise is that rather than studying so-called invulnerable individuals, we need to collaborate to promote resilience-based efforts to support families and other efforts to foster family empowerment. Simply speaking, family resilience can be strengthened by the following family processes: family belief systems, organization patterns, and communication processes.

Family belief systems: family resilience is fostered by shared beliefs that help members making meaning of crisis situations; facilitate a positive, hopeful outlook; and provide transcendent or spiritual values and purpose. Families can be helped to gain a sense of coherence by recasting a crisis as a shared challenge that is comprehensible, manageable, and meaningful to tackle. Normalizing and contextualizing members' distress as natural or understandable in their crisis situation can soften their reactions and reduce blame, shame, and guilt. Drawing out and affirming family strengths in the midst of difficulties helps to counter a sense of helplessness, failure, and despair as it reinforces pride, confidence, and a "can do" spirit.

In family organization, resilience can be fostered through flexible structure, shared leadership, mutual support, and teaming working in facing life challenges.

Communication processes that clarify ambiguous situations, encourage open emotional expression and empathetic response, and foster collaboration problem solving are especially important in facilitating resilience.

Based on the discussions above conducted concerning on the process of family resilience from different researchers, it is evident that family cohesiveness, family communication and family meaning—making are three critical process of family functioning to protect family despite the risk exposure. This exploration in protective factors and mechanism will be used in following sections as a conceptual reference to design the items of questionnaire for family with childhood hearing impairment.

Similarly, due to lack of universally accepted definition of the term resilience, there also exists no uniforming definition of family resilience. In an effort to clarify all terms relevant to this dissertation, paralleling the individual resilience, in this study the term of family resilience is operationalized as a systematic structure including three elements: significant risk facing family, the protective process of interaction between risk factor and protective factors, the outcome of positive adaptation.

## 2.2.2.6 Assessment of family resilience

Although researchers have different understanding of family resilience in the specific research, most researchers view family resilience as a process where there are interactions between risks and protective factors relative to a specified outcome. In other words, similarly to the construct of individual resilience, family as a functional unit, the term of family resilience can be understood systematically from three dimensions, significant risk, the outcome of positive adaptation, and the process of family struggling with the risk condition. Family as a system with a minimum of two individuals, it is clear that the sum of the resilience of family members is not the resilience of a whole family. So it is reasonable that family resilience should be judged based on the family system level rather than individual level. However, how to judge whether a family is resilient from the systematic perspective is more challenging than assessment of individual resilience. Encouragingly, previous researchers have developed some insights into this issue from different perspectives.

Similar to individual resilience, family resilience is contextual, especially in

some chronic risk conditions, the outcome of adaptation can not end at one time point. As a result different researcher used different operationalization to assess the outcome of adaptation in specific research. For example, Gilgun (1999) conducted the resilience research on adults with childhood adversities and used the guideline of loving well, working well and expecting well as the indicator of family resilience to reflect the characteristics of process of family resilience.

Patterson (2002b) detailed the assessment of family resilience from the perspective of family functions. As discussed previously, four normal family functions for individuals or children are collected: family formation and membership, nurturance and socialization, economic support and protection of vulnerable members. Further, according to his opinion, to consider whether a family is resilient, three things are necessary: first, a family-level outcome must be conceptualized in a way that it is possible to assess the degree to which a family is competent in accomplishing the outcome. Second, there must be some risk that is associated with the expectation that the family will not successful relative to the outcome of interest. Third, there is a need to understand what protective mechanism interrupt or prevent the poor expected outcome. Specifically, when adversity or significant risk strikes the family or when the family is living in a high-risk situation, such as family infertility or giving birth to an unwanted child, one way of assessing whether a family is resilient is the degree to which they are able to successfully fulfill their normal functions so that individual family members and other social systems benefit. Namely, whether family can function well or not is the basic standard of family resilience despite the exposure to risk condition.

Haan et al. (2002) proposed a quantitative, longitudinal process-oriented strategy, sensitive to both the context of a family and the unique stressor being examined. According to their understanding of resilience, family resilience are described as the path a family follows as it adapts and prospers in the face of stress, both in the present and over time. Resilient families positively respond to stress conditions in unique ways, depending on the context, developmental level, the interactive combination of risk and protective factors, and the family's shared outlook. They criticized that most

researchers tended to construct the family resilience as a dynamic process, however, in specific research they only reported data collected at a single point in time. In contrast, they advocated that now that family resilience is a concept concerning process, it is visible only over time. To achieve this aim, it is essential to identify a family trajectory on a specified variable over at least three time points: prior to the crisis point, at the time of the crisis, and some time after the crisis. According to this recognition, this strategy gets a positive slope to represent the best indicator of change for family over time base on measurement at four time points (i.e., precrisis, crisis, postcrisis1, postcrisis 2). In each one of the following four conditions, family can be called resilient:

- (1) Scores at all subsequent time points are higher than those at the first time point;
- (2) The time 2 score is lower than the time 1 score, with the time 3 and time 4 scores higher than time 1;
- (3) The time 2 score is lower than the time 1 score, with the time 3 and time 4 scores higher than time 2;
- (4) The time 2 score is lower than the time 1 score, the time 3 score is higher than the time 1 score, but the time 4 score is equal to the time 1 score.

Theoretically, this strategy is ideal way to assess the family resilience from the perspective of process. However, in the practice there are limits to use it, for example, difficulty to determine the time to collect data and bothersome data analysis etc. Nevertheless, it still brings some insightful enlightenment to this study.

Putting together the exploration in theoretical framework conducted by previous researchers, in this study, from the perspective of process, the family resilience will be comprehensively examined from three time point of past, present, and future. To be more specific, the judgment of whether a family is resilient or not in the face of childhood hearing impairment is made from the perspective of dynamic process and the outcome of adaptation is inferred from three measurements: accepting the past well, functioning well at present, expecting well for the future.

### 2.3 Convergence of family resilience and hearing impairment research

## 2.3.1 Family resilience research in the area of disability

# 2.3.1.1 Impacts of child's disability on family life

Disability serves as umbrella term for impairments, activity limitations or participation restrictions (WHO, 2001). The general outcome of disability is restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being. Due to the efforts made by disability movement, at present in the field of special education children with disability is often called children with special needs. They are usually grouped as the physical disabled, learning disabled, hearing impaired, visual impaired, children with social emotional disorder, and multiple handicapped etc. However, no matter what the nature is, any kind of disability, especially childhood disability is a significant risk for individuals and their families because it is significantly linked with developmental lag apparently.

As stated in the section of introduction of this paper, the birth of a child with disability often creates a great challenge to most of families. A large number of researchers have paid attentions to the impact of child's disability on family life. Some researchers proposed that the response of parents to the diagnosis of a serious disability in their child had many parallels with the reaction to the bereavement. The main difference was that the child's disability was a permanent source of sorrow, whereas death marked a crisis point beyond which readjustment could begin (Hall & Hill, 1996). According to Barnett et al. (2003), some common parental reactions to news of child disability are as follows:

- ·Feeling devastated, overwhelmed, and traumatized by the news
- ·Shock, denial, numbness, and disbelief
- ·Feelings of crisis and confusion when attempting to cope with news of their child's diagnosis
  - ·Sense of loss for the "hoped for child"
- ·Experience grief reactions similar to those experienced by individuals who lost someone through death

- ·Expectations and hopes for the future are challenged or destroyed
- ·Feelings of guilt, responsibility, and shame
- ·Strong anger directed toward the medical staff and professional involved with child
  - ·Wondering whether things would be better off if the child dies
- ·Decreased self-esteem efficacy as parent's sense of themselves as severely challenged
  - ·Marital and other family relationships become severely strained
  - ·Family routines are disrupted

Different from other acute and episodic risk, childhood disability is not a life-threatening but a chronic risk that wears people away day after day, year after year. Tell the truth, in the world that has become more competitive with more uncertain future, raising relatively normal children is not easy. For the parent of children with special needs, in addition to normal workload of parenting a normal child, they have to cope with many additional difficulties such as uncertainties about their child's health and prognosis, frequent medical appointments and procedures etc. due to childhood disability. Numerous studies have documented the impact of childhood disability on family life (Singer & Farkas, 1989; Hall & Hill, 1996; Calderon & Greenberg, 1999; Barnett et al 2003).

For example, Singer & Farkas (1989) had used the Impact-on-Family Scales to examine the maternal perceptions of the impact of infant disability on various components of family life. The results showed that a high degree of maternal stress related to caring for their young children with developmental disabilities. 32 respondents reported that the child's disability affected all aspects of family life. Problems with family and social interaction and with finances were those cited by the majority of the mother in this sample. The most salient negative impact involved financial status. More specifically, 67% of respondents felt that their child's disability

caused financial problems for the family, 44% said they were unable to travel out of the city because of the child's disability; 59% mothers felt they lived on a motional roller coaster; 55% agreed or strongly agreed that they worry about what will happen to the child in the future. Fatigue was reported by 41% to be a problem. At the same time, this study also found that greater feelings of master were associated with the absence of neurological problems.

Similarly, Woolfson (in Barnett et al., 2003) examined the family well-being and disabled children. After review of previous related researches, the additional stressors related to the child's disability were collected: the economics of providing care for a disabled child, the time demands any medical or therapeutic interventions may make on the family, strained family relationships, social isolation due to the child's limited mobility or behavior problems, and the parental grieving process through which parents grieve for the loss of the healthy child they had expected etc.. Despite these strain, the research literature indicates that having a child with special needs is not a story of "gloom and doom".

### 2.3.1.2 Resilience research on individuals with disability and their family

As resilience research evolved, some researchers began to extend the resilience research to the specific risky condition, such as disability area. Although resilience research on individuals with disability is at early stage, to lesser or larger extent it provided us with a positive perspective to look at disability by focusing on strength and empowerment. The following studies are some representative examples.

In the book *Resilience: learning from people with disabilities and the turning points*, King et al. (2003) edited stories about 15 persons with the disabilities, more appropriately, the chronic health conditions of cerebral palsy, spina bifida, and attention deficits disorders. While some research studies indicated that having a disability put people at greater risk for poor outcomes in life, such as unemployment, poverty, or social isolation, the authors argued that having a disability was not necessarily a tragedy. Rather, in a revolutionary reframing, the author had come to consider this very personal experience as not only life-changing, but also life-enhancing according to the past experience of many people with disabilities did

well in life—they reached their goals and dreams and were viewed by themselves and others as successful. However, what makes these people resilient and what support them? The book proposed that making of meaning was a basic building block of resilience and a central aspect of many theories of personal growth and change following challenges or crisis in life. By establishing meaning in everyday life, resilient people built bridges from present-day trials and hardships to the vision of a better future. This sense of meaning helped the troubled of the present feel more manageable and provided hope for future.

Additionally more studies explored the family adaptation to the reality of having a child with disability. For example, Hauser-Cram et al. (2001) conducted a longitudinal study of child development and parent well-being. The sample for the investigation consisted of 183 children with Down syndrome, motor impairment, developmental delay and their families who were recruited at the time of their enrollment in an early intervention program in Massachusetts or New Hampshire. The result showed that children's type of disability predicted trajectories of development in cognition, social skills, and daily living skills. Children's type of disability also predicted changes in maternal (but not paternal) child-related and parent-related stress. Beyond type of disability, child self-regulatory processes (notably behavior problems and mastery motivation) and one aspect of the family climate (notably mother-child interaction) were key predictors of change in both child outcomes and parent well-being.

Margalit and Kleitman (2006) conducted a research titled as mother's stress, resilience and early intervention with two aims. One of the aims of the study was to examine factors that predict maternal stress reported by mothers whose infants were diagnosed as having developmental disabilities, the other aim was to identify and to portray a subgroup of resilient mothers. The result showed that during the year of prolonged stress and challenge, mother gradually learnt to experiment and activate their coping strategies. Participation in the early intervention program enabled mothers to try out coping approaches, relieving their tension by experiencing being constructive and effective, and through accepting the limitation of the situations.

Based on the family belief systems are considered to be among the most important factors affecting the adaptation and resilience of families, King et al. (2003) used qualitative method of focus group to analyze the changes in the belief systems of families of children with autism or syndrome. Results indicated that raising a child with a disability can be a life-changing experience that spurs families to examine their belief systems. Parents can come to gain a sense of coherence and control through changes in their world views, values and priorities that involve different ways of thinking about their child, their parenting role, and the role of the family. Although parents may grapple with lost dreams, over time positive adaptations can occur in the form of changed world views concerning life and disability, and an appreciation of the positive contributions made by children to family members and society as a whole. Parent's experiences indicated the importance of hope and seeing possibilities that lie ahead.

Bayat (2007) used quantitative and qualitative methodologies to survey respondents consisted of 175 parents and other primary caregivers of a child with autism within ages between 2 and 18 years and examine factors of resilience in the families with autism children. Results identified some specific resilience processes, such as making positive meaning of disability, mobilization of resources, and becoming united and closer as a family, finding greater appreciation of life in general and other people in specific, and gaining spiritual strength.

In sum, the child's disabilities are undoubtedly significant risk for almost all families, however, they are not barriers which are insurmountable. With the certain support and protective process, especially the knowledge and strategies to perceive and interpret parenting a disabled child positively, some families can reach the positive adaptation to the reality of having a child with disability. It is the processes and mechanisms by which families successfully negotiate risk situations that are of central importance in understanding family resilience in the face of disability.

# 2.3.1.3 Intervention service: most important protective factor leading to resilience

In the medicine the intervention is defined as the act of intervening, interfering

or interceding with the intent of modifying the outcome. Also an intervention is usually undertaken to help treat or cure a condition. Within the special education field, it generally means any service, or cluster of services, made available to children who are at risk for disabilities or who have disabilities, aimed to prevent, reduce, or avoid deficits in children at risk for developmental problem and reduce stress in family. (Raver, 1999; Malone et al., 2000) According to the time of intervention programs enacted, the place where it occurs, or the form of it is organized, intervention services take different forms, such as early intervention or home-based intervention or family-centered intervention, group intervention etc.

Early intervention nowadays has been universally accepted as well-established and cost effective practice to benefit children with special needs and their families. According to Talay-Ongan (2001), there is consensus that early intervention has the following outcomes:

- · It has a facilitating effect on all developmental domains, including improvements in cognitive, communication, adaptive and psychosocial, physical, and self-help areas;
- ·It contributes to the quality of life experiences of children and families, preventing secondary problems and often alleviating present conditions;
- · It benefits families by reducing their stress levels and improving their interactions with their children;
- ·It provides a significant benefit to society, not only by reducing the need for, and the cost of special education services later on, but also by promoting acceptance and community support for children and families with special needs.

In recent years, the importance of being family centered when providing intervention services to children with a disability and their families has gained currency in the research and practice literature (Raver,1999;Dempsey & Keen, 2008). During past decade many researches had explored the basic belief and some principles to guide its practice. For example, Baird and Peterson (1997) had detailed

the special tenets of family-centered philosophy. Those tenets included recognition of respect for (a) the family as the expert on the child; (b) the family as the ultimate decision maker for the child and family; (c) the family as the constant in the child's life and professional service providers as temporary; (d) the families' priorities for goals and services; (e) the families' choices regarding their level of participation; (f) the need for a collaborative, trusting relationship between parents and professionals; and (g) the need to respect differences in cultural identity, beliefs, values, and coping styles.

In addition, some researchers also had explored some other form of intervention services which were specific to help parent adapt to child's disability from psychosocial perspective. As an example, Barnett et al. (2003) had developed a parent group intervention to help parent of child with disability to build new dream. More specifically, the parent group intervention aimed to facilitate parental adaptation identifying and validating the range of feeling, to encourage mutual support and sharing of information among group members, increase perceptions of support available and quality of important relationships including the spousal relationship, improve skills at seeking information, support, and resources regarding child medical diagnoses and services for children and families, promote parenting sensitivity and effective parenting skills.

Summarily, numerous literatures have documented the protective function of intervention service which can cushion the adverse influence of child's disability on family life. However the issues like what the protective mechanism is, how they function etc. still remain to be further explored.

### 2.3.2 Hearing impairment and family coping

Childhood hearing impairment, especially the severe and profound hearing loss, constitutes a disability with serious ramifications for the rest of the families with hearing parents because of the significant developmental gap between hearing impaired children and hearing children. A lot of studies have investigated the impacts of hearing loss on family life.

As an example, Meadow-Orlans (1995) investigated the stress of hearing mothers and fathers of 20 deaf or hard of hearing (D/HH) and 20 nine-month-old babies via Parenting Stress Inventory and a questionnaire tapping the Stress of life Events and found that mother whose infants were D/HH reported greater life stress compared to mothers of hearing babies.

According to Calderon et al. (1999), the diagnosis of hearing loss in a child presented the family of that child with a variety of intrapsychic and environmental stresses or challenges. The stresses and challenges of raising a child with hearing loss most often were associated with the diagnosis of the hearing loss, learning new communication methods, being more involved in educational decision making, increasing contact with professionals in a number of disciplines, and purchasing and using technological supports, as well as the everyday experience of having a child who is different and communicates in a different manner. As the child grows up over time, families not only continue their efforts to meet familiar needs of their child; they also face new situations and challenges to address and resolve. Parents of very young children who are deaf or hard of hearing may rely more on support groups, professional help, and early intervention programs. Parents of older children with hearing loss may need to use more creative problem solving or seek out less familiar resources or experts to address the very different situations and challenges.

Similarly, Jackson and Turnbull (2004) had examined the impact of deafness on family life comprehensively including family interaction, family resources, parenting and support for the child who is deaf. According to their review of the literature on deafness, the presence of deafness in a family had the potential to affect all areas of family life. Especially hearing parents of children who are deaf or hard of hearing may experience many challenges and potential obstacles in parenting. Further, Jackson et al. (2008) had used qualitative method to collect nine parents of eight children who was deaf to get thick description of parent's experience. The results showed that the hearing mothers all expressed feelings of intense emotion such as shock, fear and uncertainty of the future etc. when the child was diagnosed with deafness. Also in the study most hearing parents emphasized their relationship with

their children was often influenced by the influence of deafness and communication difficulties etc.

It is needless to collect more research studies to evidence that childhood hearing impairment, especially deafness creates a significant risk for the family. However, the impacts of hearing impairment of individual and family vary greatly. The differences in impacts may be contributed to multiple factor: the hearing condition of parent, the severity of child's hearing loss and the subjective appraisal of meaning of hearing impairment. Sometimes the three factors are not mutually exclusive and overlapped and their interrelatedness may be an important indicator of the outcome of family adaptation to the childhood hearing impairment.

It is also evident that families and individuals not only differ widely in their level of adjustment but in the styles used to cope with the hearing loss. Multiple studies have investigated the family coping strategies. Calderon et al (1999) had recruited 36 families with different degree of hearing loss (24 to 110 dB) to examine the factors affecting mother and child adjustment. Results indicated that (a) social support emerged as an important predicator of maternal adjustment as well as a buffer between current life stress and maternal adjustment, and (b) maternal problem-solving skill for example, finding someone to talk, finding appropriate resources for child and arranging child's educational programme etc. emerged as a significant predicator of a child adjustment. More importantly, research also had examined the varying relationship between severity of hearing loss and maternal outcomes and found that many hard of hearing individuals did not demonstrate the same extent of limitations in communication, educational, social, or vocational competencies that many profoundly deaf individuals often exhibit. As a conclusion, the effect of a hearing loss on the family and the individual can vary greatly.

Moreover, many measures have been taken to reduce the negative influence of hearing impairment on children and their families. The widely accepted practices across the countries are early diagnosis of hearing loss and early intervention services. A large number of researches have provided the strong evidence for the early intervention service. For example, Yoshinaga-Itano and colleagues (2000) reported

that children with hearing impairments, who were identified by 6 months of age and who received appropriate early intervention services, were 2.6 times more likely to have language skills at, or near typical levels than children who received services later. At present, the importance of early identification and early intervention for children with hearing impairment has been widely endorsed. As the American Joint Committee on Infant Hearing (2007) stated in their position statement: "Without appropriate opportunities to learn language, these children will fall behind their hearing peers in communication, cognition, reading, and social-emotional development, and such delays may result in lower educational and employment levels in adulthood. To maximize the outcome for infants who are deaf or hard of hearing, the hearing of all infants should be screened at no later than one month of age. Those who do not pass screening should have a comprehensive audiological evaluation at no later than three months of age. Infants with confirmed hearing loss should receive appropriate intervention at no later than six months of age from health care and education professionals with expertise in hearing loss and deafness in infants and young children." (p. 898)

Some other intervention programmes also have been evidenced to be effective practices. For example, SKI\*HI was a program started in 1972 in U.S.A and designed to identify children with hearing impairment as early as possible and to provide them and their families with complete home programming that will facilitate development. In this program, a parent advisor made weekly home visits to families and worked closely with parents and other members of a multidisciplinary team to assess, plan, and provide appropriate home-based service for all family members. Some data had been collected to analyze the relationship of child achievement and home-based intervention. The study concluded that SKI\*HI children showed higher rates of development during intervention than prior to intervention and greater gains in receptive and expressive language development than would be expected. Also SKI\*HI parents showed increased ability to manage their child's bearing handicap, communicate meaningfully with their child, and promote their child's cognitive development (Strong, 1992).

Additionally, some studies have studied the other protective sources. For example, Hintermair (2000a) had reported the stress experiences of parents with hearing-impaired children in Germany. The results suggested that parents who frequently met with other parents showed evidence of a warm, accepting, trusting relationship with their child. Also the findings of his study demonstrated that parents who had many contacts with hearing-impaired adults showed evidence of a strong sense of competence in regard to their child's upbringing. According to these results some recommendations had been proposed that social support is to be regarded as a cornerstone of psychosocial intervention and has to play as great a role as possible in institutional programs.

More specifically, Štěrbová (2007) had studied the coping behavior of 32 families with hearing impaired children in Czech. As a result the study had listed 26 forms of coping behavior which have been indicated as very beneficial and useful by mothers. The following are 10 top responses (Štěrbová, 2007, p. 129):

- ·Active contact with children
- ·Endeavor to maintain family stability
- ·Guidance of children with health disability to greater independence
- ·Maintenance of calm and balance
- Possibility of speaking with doctor and specialist about matters relating to children with health disability
  - ·Building of closer relationship with partner
  - ·Feeling that I and my children are important to my partner
  - ·Co-operation in family
  - ·Possibility of visiting child regularly in facility
  - ·Sleep

In general, numerous studies have been conducted about the impacts of hearing

impairment on family life and the support factors which attempted to help children and empower families also have been well-explored, however, few researches are undertaken in the framework of resilience and family resilience.

## 2.3.3 The importance of research on family resilience in families of children with hearing impairment in China and Czech

As discussed above, although a great deal of efforts have been made to support hearing impaired children and their families, there is little known about what processes and mechanisms by which some families successfully negotiate risk situation of childhood hearing impairment while others not. Indeed, as Green and Katherine (2008) argued, the theoretical frameworks encompassed by resilience has scarcely been applied to an understanding of the experience of deaf children and their families nor to specific interventions in relation to this group. This is more likely to relate to social construction of hearing impairment, or deafness in simpler form, given the medical, social and cultural definitions of what it is to be deaf and there exist difficulties associated with the perception of deafness as a risk factor. In fact, this is really an issue within controversy and dispute.

According to World Health Organization (2001), a person's functioning and disability is conceived as a dynamic interaction between health conditions (disease, disorders, injuries, traumas, etc) and contextual factors. Contextual factors represent the complete background of an individual's life and living. They include two components, environmental factors and personal factors, which may have an impact on the individual with a health condition and that individual's health and health-related states. Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. These factors are external to individuals and can have a positive and negative influence on the individual's performance as a member of society, on the individual's capacity to execute actions or tasks, or on the individual's body function or structure (WHO, 2001, p.16). With the influence of disability movement spreading over time, in some western developed countries, deafness or hearing impairment may not be treated as disability but considered as a linguistic and cultural minority (Gregory et al., 1998).

Supported by this notion and well-developed social security system, childhood hearing impairment, regardless of the severity of hearing loss, might not be treated as significant family risk in these countries. However, in some developing countries, such as China, where the idea of social construction of disability is not widely spread and social security system is absent, the questions of how the families view the childhood hearing impairment, how the families adapt to the reality of having a child with hearing impairment etc. are worthwhile being further studied. Naturally this is one impetus for and one purpose of this comparative study of the family adaptation to childhood hearing impairment in China and Czech.

Theoretically, based on the review of previous researches on resilience and family resilience, it is apparent that till to now most resilience and family resilience theories are developed primarily using white, middle class families as samples, less attention has been given to the families with diversified culture and social context, for example, from the developing world. Given that family resilience is a strongly context-specific term and the social construction of hearing impairment have important implication for understanding diverse experience of family adaptation to the reality of having a child with hearing impairment, this study of examining the family adaptation to the childhood hearing impairment across social contexts will add new content to the body of knowledge of special education and extend understanding of family resilience.

In addition, this research has important implications for both China and Czech hearing impaired education. According to Štěrbová (2007), examination of families with disabled children in Czech had been developed in more depth only in the last twenty years, in which the primary concentration had been on families with a mentally handicapped child, a child with a physical disorder or chronically ill child. Less attention had been devoted to families with children with a sensory disability. Also family stress, and particularly coping mechanism in families with hearing disabilities had not been examined in the Czech Republic, and there were only references to partial foreign studies ((Štěrbová, 2007, p.100). Similarly to the research in China, several researchers had examined the family pressure and issues of family

education in the face of childhood disability. For example, some researchers classified the pressures of families with childhood disability as follows: pressure from family members' problems, financial pressure, over protection, lifetime dependence, lack of feeling of achievement (Wang, 2004). Wang and Yang (2004) had argued that parent ability to deal with these pressures depended on the degree of child's disability, child's age, parental educational level, family income, whether there is another normal child in family, social support etc. As for the resilience research on families with children with disability, several researches had concerned the family adaptation to childhood autism (Xue, 2004; Cheng, 2007). Up to now, few studies on family of children with hearing impairment have been undertaken in the framework of resilience and the related area, such as family stress and family coping. As a result it is imperative that further endeavours should be devoted to explore the protective process and mechanism which helps some families negotiate the pressures imposed on families by childhood hearing impairments.

Practically, this research has particular implications for furthering special education in China. As a largest developing country with a population of more than 1.3 billion, China is also a country with a largest handicapped children group. According to the statistics of the second national Disabled Persons Sample Survey (SNDPSS) in 2006 in China, up till to the April 1<sup>st</sup>, 2006, there are 82,960,000 disabled people in China, with the prevalence rate of disabilities of 6.34 % in general. Among them, there are 3,890,000 children from birth to 14 years old (National Bureau of Statistics of China, 2007). In recent years much effort has been made and measures have been taken by government to boost the development of education for children with special needs and to provide individuals with disability with support in best power while China keeping sustaining and rapid economic growth. In addition to including the education for children with special needs into national compulsory education system, more recently China government is taking actions to develop social security system and intervention service system for individuals with disability with an aim of reducing the life gap between them and the societal average level. In some bigger cities and relatively developed area, various levels of organizations serving persons with disability, including hearing impairment are devoting their attentions to improve the quality of services for children with special needs and their families. It is urgent task for theoretical researchers to investigate the questions of what specific difficulties families are meeting, what supports are perceived as the most effective help by families themselves, and what supports they desire and so on. Based on the notion of children are best helped by empowering their families, it is desirable that this study will inform some policy-makers and practitioners the family experiences and associated information from the position of families of children with hearing impairment and make the intervention service programs be more evidence-based and suited to family needs.

#### 3. Research design

#### 3.1 The operationalization of relevant terms

All scientific researches must include precise statements of the concepts used to clearly express understanding and the criteria used to specify the relevant terms unique to particular research design. In the present study, it is of particular importance to specify terms associated with family resilience due to great variations in understanding of hearing impairment, resilience and family resilience. According to the conceptual discussions already noted, several critical concepts related to the research topic are operationalized as follows:

(1) Children with hearing impairment: also called hearing-impaired children. In

this study it specifically refers to the children who can not attend regular school due to severe to profound hearing loss or mild hearing loss together with additional handicaps simultaneously.

- (2) Family: A functional unit which includes the minimum of two individual members, a parent and a child with hearing impairment.
- (3) Family resilience: the construct of the process through which family adapt to the reality of having a child with hearing impairment. It mainly includes three parts: the impacts of hearing impairment as a significant risk on family life, the transactional process of hearing impairment and protective factors or supportive factors, and outcome of positive adaptation to the childhood hearing impairment.
- (4) Outcome of family adaptation to childhood hearing impairment: the level of family accepting child's hearing impairment, functioning, expecting for children.
- (5) Family positive adaptation: the overall score of the outcome of family adaptation to childhood hearing impairment is higher than boundary score of 3.00 point which stands between positive and negative adaptation.
- (6) Resilient family: family who can adapt to childhood hearing impairment positively with score of higher than average score in outcome of resilience.

## 3.2 Research purpose

The purpose of the present study is to examine how families from two different social contexts, China and Czech, adapt to the risk of childhood hearing impairment and explore the process of Chinese resilient families adapting to such risk condition positively based on the conceptual framework of family resilience the impacts of hearing impairment as a significant risk on family life, the transactional process of hearing impairment and protective factors or supportive factors, and outcome of positive adaptation to the childhood hearing impairment. To be more concrete, the purpose of the study can be described as follows:

- (1) To assess the overall level of adaptation among families experiencing with childhood hearing impairment from China and Czech;
- (2) To seek for influential factors contributing to the overall level of adaptation and to describe them;

- (3) To compare the difference in level of adaptation between Chinese families and Czech families;
- (4) To explain the difference in level of adaptation between two groups of families from the factor of social stigma, impact of hearing impairment on family life, family characteristics, the change in family beliefs, family perception of childhood education and development, social support;
- (5) To examine the family experience from family difficulties, the communication mode used to communicate with their children, family information needs, the most effective help perceived by families while parenting their hearing impaired children and how families describe their children to validate their outcome of adaptation in two countries;
- (6) To explore the process of Chinese resilient families adapting to childhood hearing impairment from the perspective of families themselves including their reactions to the diagnosis of hearing loss, the impact of hearing impact of family life, the rationale for decision-making in sensory devices, communication mode, and educational placement, the support services got and desired, and the coping strategies used to adapt to the reality of having a child with hearing impairment in family;
- (7) To propose some family resilience-oriented intervention strategies which have been shown effective in resilient families with hearing impaired children to inform the families, practitioners and policy-makers in China.

#### 3.3 Research questions

The research topic of Research on Family Resilience in Families of Children with Hearing Impairment, the research question is unpacked to contain the following subquestions:

- (1) Whether the families from two countries, China and Czech are resilient or not in general while risky exposure to childhood hearing impairment over several years of experiencing with it?
- (2) What factors contribute to the family's adaptation to the childhood hearing impairment generally?
  - (3) Is there significant difference in the outcome of adaptation to the childhood

hearing impairment between two family groups?

- (4) Are there significant differences in factors of social stigma of hearing impairment, family characteristics, impacts of childhood hearing impairment on family life, social support, change in family belief and family perception of childhood education which can contribute to the difference in outcome of adaptation between two family groups?
- (5) Does there exist difference in the biggest difficulty that families have experienced during parenting the children with hearing impairment between two family groups?
- (6) Does there exist difference in the main communication mode which families have used to communicate with their children and in the approach via which family has got it between two family groups?
- (7) Do there exist difference in family information need while parenting their children between two family groups?
- (8) Does there exist difference in the most effective support perceived by families while parenting their children between two family groups?
- (9) Does there exist difference in family describing their children between two family groups?
- (10) How the resilient Chinese families experience the process of adaptation to the childhood hearing impairment?

Generally, the questions listed above tend to be more and more open gradually to fit the different purposes.

## 3.4 Research hypotheses

H<sub>1:</sub> Overall, the two groups of families are resilient with positive adaptation to childhood hearing impairment according to the standard of accepting well, functioning well, and expecting well.

H<sub>2</sub>: The outcome of adaptation can be contributed to the factors of social stigma, family characteristics, impact of hearing impairment, changes in family belief, social support, family perception of childhood education and development.

H<sub>3:</sub> There is significant difference in the outcome of adaptation to the childhood

hearing impairment between China and Czech family group.

H<sub>4</sub>: The significant differences in outcome of adaptation between two family groups can be contributed to the factors of social stigma of hearing impairment, family characteristics, impacts of childhood hearing impairment on family life, social support, change in family belief and family perception of childhood education.

H<sub>5:</sub> There exist differences in the biggest difficulty families have experienced during parenting the children with hearing impairment between two family groups.

H<sub>6</sub>: There exist differences in the main communication mode which families have used to communicate with their children and in the approach via which family has got it between two family groups.

H<sub>7:</sub> There exists difference in the information families need most while parenting their children between two family groups.

H<sub>8:</sub> There exists difference in the most effective support perceived by families while parenting their children between two family groups.

H<sub>9:</sub> There exists difference in family describing their hearing-impaired children between two family groups.

### 3.5 Research methodology

The present study adopted the methodology of combination of quantitative and qualitative research. Traditionally, qualitative and quantitative researches appeared quite different and indeed they sometimes seemed to be at war. Indeed there existed fundamental distinctions between two research paradigms in knowledge claims, strategies of inquiry and methods of data collection and analysis (Creswell, 2003). According to Creswell (2003), a quantitative approach is one in which the investigator primarily uses positivist claims for developing knowledge while a qualitative approach is based primarily on constructivist perspectives. Regarding the strategies of inquiry, quantitative approach uses experimental and non-experimental designs, such as survey while qualitative approach uses narratives, grounded theory study studies, or case studies and so on. There also exists fundamental difference in data collection and analysis. Quantitative researchers collect data on predetermined instruments that yield statistical data while qualitative researchers collect open-ended

emerging data with the primary intent of developing themes from the data. More specifically, quantitative research emphasizes on testing hypothesis and developing relationship between variables. In contrast, qualitative research is interpretative. This means that the researcher makes an interpretation of the data including developing a description of an individual or setting, analyzing data for themes or categories, and finally making an interpretation or drawing conclusions about its meaning personally and theoretically, stating the lessons learned, and offering further questions to be asked etc.

However, today most researchers apparently see qualitative and quantitative approaches as complementary rather than antagonistic. More and more researchers tend to use quantitative and qualitative research in supplementary and complementary forms (Murray, 2003). According to Creswell (2003), the mixed approach is one kind of thinking in which the researcher tend to base knowledge on pragmatic grounds (e.g. consequences-oriented, problem-centered ) (Creswell, 2003). It employs strategies of inquiry that involve collecting data either simultaneously or sequentially to best understand research problem. Either quantitative or qualitative researches have their own strengths and limitations, certain types of research problems call for specific approaches. For example, if the problem is identifying factors that influence an outcome, e.g., the utility of an intervention, or understanding the best predictors of outcomes, then a quantitative approach is best. On the other hand, if a concept or phenomenon needs to be understood because little research has been done on it, then it merits qualitative research. Qualitative research is especially useful when the researcher does not know the important variables to examine and seek to understand the continuity and change in development. Consequently, the best choice in research method is the match between question and approach (Creswell 2003).

The rationale for the decision in methodology of this study was also based on the match between question and method. Neither qualitative nor qualitative research is not superior to other. Both of them have special role in research. To some degree qualitative research can direct the quantitative theoretically and the quantitative can provide feedback into the qualitative or offer the question needed to be studied

in-depth. Specifically, this study included three types of subquestions of different nature: the first type of subquestions, namely question 1, 2, 3, 4 are quantitative questions addressing the numerical assessment of the level of family's adaptation to child's hearing impairment (subquestion 1: whether the families from two countries are resilient or not in general while risky exposure to childhood hearing impairment over several years of experiencing with it?), the analysis of influential factors contributing to the family adaptation (subquestion 2: what factors contribute to the family's adaptation to the childhood hearing impairment generally?), the group comparison of family adaptation (subquestion 3: is there significant difference in the outcome of adaptation to the childhood hearing impairment between Chinese and Czech family group?) and analysis of associated factors contributing to the group difference (subquestion 4: Are there differences in factors of social stigma of hearing impairment, family characteristics, impacts of childhood hearing impairment on family life, social support, change in family belief and family perception of childhood education which can contribute to the difference in outcome of adaptation between two family groups?). Obviously, the four questions discussed here only can be examined in numerical form and statistical ways, so they are of nature of quantitative research. In sharp contrast, the other question namely subquestion 10, "how the resilient Chinese families experience the process of adaptation to the childhood hearing impairment?" is of aim to understand the meaning or nature of experience of families with childhood hearing impairment in the Chinese social context. From the previous researches in the field of deaf education in China, this question is within one area about which little is known and it aims to understand the process of development. In addition, this question is required to explore the feelings, thought process, emotions that are difficult to extract or learn about through quantitative methods. Accordingly qualitative research paradigm is selected to explore this subquestion. As for the subquestion 5, 6, 7, 8, 9, they stand between quantitative and qualitative question. However in this study these subquestions are mainly used to examine the group difference, they are more likely to be treated quantitatively. In sum, the nature of the research questions, the mixing of quantitative questions and qualitative questions is

the mainly valid reason for choosing the methodology.

More specifically, this study followed the sequential procedure of combination of qualitative and qualitative research and at last it forms a circle of qualitative quantitative and qualitative research. This study firstly began with informal interviews before and after the questionnaire was constructed. In this study, one questionnaire to investigate the impact of hearing impairment on family life, family perceptions of meaning of hearing impairment, social support and other related themes have been developed. Before the questionnaire was developed, the researcher of this study conducted two preliminary informal interviews to collect the main concerns of families with hearing impaired children and develop the items of questionnaire. After the items were formed, a pilot study was conducted in China to examine the clarity and validity of questionnaire. The preliminary qualitative research in first stage helped the researcher develop the basic understanding of family experience with childhood hearing impairment and find several problems in questionnaire needed to be addressed. For example, the wording and phrasing of some items in the previous questionnaire were too formal to be comfortably accepted by participants; some open-ended questions, like "please write out the biggest positive change during your parenting the child with hearing impairment", were ambiguous and easily misunderstood by the respondents. To be more important, both the preliminary interview and the pilot study were warmly supported by the families and the consistence of their responses with research purpose helped the researcher develop the confidence in the validity of questionnaire. It meant that the questionnaire can collect the data which is supposed to collect. Following the qualitative research in first stage, the formal questionnaire survey was implemented in several locations. Indeed, the questionnaire helped the researcher collect reliable and reasonably valid data about the family background and the process of family's adapting to the risk of having a hearing child in family from a number of respondents who are in China and Czech. However, the questionnaire survey manifested its limitation, such as a danger of people not understanding the question, and not allowing for in-depth analysis and pursuit of details geared to each respondent while it was efficient for routine data

collection with a large number of respondents. For example, in this study, there was an item of No.12, "Because of the child's hearing impairment, the economic state of our family has deteriorated". According to the response of respondents in questionnaire, theoretically the information on certain degree of family economic deterioration can be obtained. However, it was not known about the question that what led to economic status worsening, how and why it happened. It was evident that questionnaire survey could not fully accomplish the purpose of exploring the process of family adapting to the risk condition of having a hearing impaired child in family. Eventually, one qualitative research by semi-structured interview was designed to describe the rich and thick experiences of family adapting to the childhood hearing impairment in China. In sum the combination of qualitative and quantitative research fitted the nature of research question and served the purpose of the study exactly.

#### 3.6 Research methods

To reach the objectives of this study, two kinds of specific research methods, questionnaire survey corresponding to quantitative research paradigm and interview corresponding to qualitative research paradigm were used.

## 3.6.1 Questionnaire survey

## 3.6.1.1 The steps for developing questionnaire

A questionnaire for family resilience of families with hearing impaired children was developed for the study. When it was used in survey, it was renamed after questionnaire of families with hearing impaired children given that the term of resilience is a professional jargon that can not be easily understood by normal participants.

The task of constructing questionnaire was not easy. It was accomplished by following the six steps outlined by Anderson and Arsenault (1998). In the concrete, they are determining questions, drafting the questionnaire items, sequencing the items, design the questionnaire, pilot test, and developing a strategies for data collecting and analysis. To determine items of question, literature review on resilience, family resilience, hearing impairment and family life had been conducted and preliminary research also had been done through the field contact with target families of children

with hearing impairment in Chengdu Special School and Chengdu Deaf Children Rehabilitation Center. After the questionnaire had been drafted, pilot study had been conducted to test its validity and fitness to the target families. The pilot study helped in identifying the errors in the questionnaire (including format), overlapping questions and reading comprehension difficulties, misunderstood items. The 5 respondents in pilot study were asked to comment on the clarity, readability, and if those questions in questionnaire reflected the main concern and their need. Their comments led to revision and reworking of the questionnaire, some ambiguous subquestions were replaced by new ones, and some easily misunderstood items were deleted. At last the original 25 close-ended questions had been changed to 29 close-ended questions. Then the developed questionnaire had been sent to several experts in special education and special educators to further collect the comments about questionnaire. The positive comments from respondents in pilot study and the proposals from experts help the investigator build the confidence in questionnaire's validity and practicality. After the questionnaire included in the research project was passed by all dissertation members in the research project defence, it was translated into Chinese and Czech language to use in the survey.

## 3.6.1.2 The structure of questionnaire

The questionnaire in this study consisted of four parts. The first part concerned the information data about informant including the relationship between the informant and participant child, residence, educational attainment, and the time of taking care of the participant hearing impaired child. The second part collected the background information about the participant child involving age of child, gender, the marriage of child's parent, hearing of child's parent, economic of family, education level of family, religious activity, the number of children in family, hearing loss of child, time of hearing diagnosis, onset of hearing loss, time of wearing hearing aids, payer of hearing aids, time of using cochlear implants, payer of cochlear implants, communication mode, types of therapy, payer of therapy, educational placement, payer of special education.

The third part was main body of questionnaire consisting 29 items. The 29 items

were designed according to the framework of family resilience for families of children with hearing impairment discussed earlier. The 29 items were used to mainly examine 7 factors: the outcome of family adaptation (item1, 14, 24, 25, 27, 28, 29); the social stigma associated with hearing impairment (item 2, 3); changes in family beliefs (item 4, 7, 8, 9); family characteristic (item 5, 6, 15); the impact of hearing impairment on family life as a risk factor (item 10, 11, 12, 22); the family perception of childhood education and development (item 16, 20, 21, 26), the social support (item 13, 17, 18,19, 23). 29 items took the form of Likert five- point scale. Every sentence contained only one complete thought whilst every of which carried a 5-point range of responses as follows: not true at all (1), rarely true (2), sometimes true (3), often true (4), and true nearly all of the time (5).

The fourth part of questionnaire consisted of five open-ended questions as follows:

- (1) Write out the biggest difficulty your family has met during you parenting the child with hearing impairment;
- (2) Write out the main way your family has used to communicate with your child and the place where you got it;
- (3) Write out the information your family need most while you parenting the child;
- (4) Write out the most effective help your family has got while you parenting the child;
  - (5) Please describe your child with three sentences.

These five questions were designed to collect more detailed information on family parenting difficulty, the main communication mode used, the most salient information needs, the most effective help perceived from the position of family itself and the family's perception of hearing impaired child which are correspondent to research subquestion 5, 6, 7, 8, 9. Slight difference can be found in wording and phrasing between research subquestions in this dissertation and items in questionnaire aiming to make questionnaire more understandable to common parents. The information and opinion from the open-ended questions would be used to either detail

or validate the results shown in the form of close-ended items.

The detailed and complete items in questionnaire can be found in appendix A in English and in appendix B in Czech.

#### 3.6.1.3 The respondents

The main caregiver of hearing impaired children in two special schools and one early rehabilitation center in China and in three special schools for hearing impaired children in Czech were invited to participate in research and constituted two family groups. In order to meet the inclusion criteria, children should be within the preschool and primary education stage, a typical age range of childhood and relevant families can have some experience of adapting to childhood hearing impairment. Also, in order to meet the requirement of significant risk, the participant children should be with severe or profound hearing loss, or with mild hearing loss and additional handicaps. Considering the diverse family systems, parent were not always the persons who know child best and not always main caregiver of hearing impaired child in every family, so in this study main caregivers who were together with children more than one year and consequently know child best, either parent or not, were invited to represent the family of hearing impaired child and present their responses on behalf of the whole family.

More specifically, 107 caregivers from Sichuan province in China returned the valid questionnaire to the researcher. As a whole, China is a developing country with a Human Development Index (thereafter HDI) of 0.772 which composites measure of three dimension of human development: living a long and healthy life, being educated and having a decent standard of living. (United Nations Development Programme, 2009) and which gives the country a rank of 92<sup>nd</sup> out of 182 countries. Located in the southwestern area of China, Sichuan is a province with a population of 82.12 million (by the end of 2005) in an area of 488,000 square kilometer. Compared with some developed area, such as Shanghai, Beijing etc., Sichuan is a relatively underdeveloped province of average developmental level in China. However, from the perspective of the degree of being representative, it is better sample to denote the current condition of socially and economically development of China.

There were 55 main caregivers of children from 3 special schools for hearing impaired pupils, respectively in Hradec Králové, Ostrava, Olomouc in Czech who returned questionnaire and became the participants of this study. Subsequently two questionnaires were excluded from the research population because of one family's response missing in most of items and another family's report that the child can hear and can not speak. Compared with China, Czech is a developed country with a population of 10,500, 000 (2009 estimate), an area of 78,864 square kilometers and with a high HDI of 0.903 which gives the country a rank of 36<sup>th</sup> out of 182 countries (United Nations Development Programme, 2009). The relevant characteristics of informants in this study are demonstrated in Table 3.

According to the basic information from Table 3, we can get the first impression of the commonalities and difference between main caregivers from Chinese families and Czech ones. Mothers are main caregiver of hearing impaired children in both countries while grandparents or other persons play different play in two states. The overwhelming majority of participants from both countries have been taking care of their child for more than 3 years, consequently it can be inferred that they know their hearing children well and are qualified to be competent informants to provide accurate and adequate information about parenting their children. It is of interest that some readers will question how the illiterate participants fill the written questionnaire. This problem has been addressed by research assistant via reading the questionnaire to help

**Table 3.** The relevant characteristics of informants from China and Czech

Variable	China(n=107)	Czech(n=53)
Relationship with child		
Father	20	8
Mother	62	45
Grandparent or others	25	0
Residence		
Urban	35	35
Rural	72	17

No response	0	1
Education		
Illiterate	8	0
Primary education	33	5
Secondary education	56	43
Higher education	10	5
Time of taking care of child		
1 year	4	0
1~2 years	7	0
2 ~ 3 years	4	2
>3 years	91	51

the illiterate participants complete if they report they do not know how to fill in the questionnaire in the survey. It is evident that most participants in China live in rural area while most Czech participants live in urban area and there exists apparent difference in educational attainment of them. This condition is consistent basically with the development level of two countries. As a whole, one conclusion can be drawn from the data above mentioned is that these participants constitute two subgroups of proper samples which will represent the population of families in two countries.

## 3.6.2 Semi-structured interview

Interview is a useful method of collecting data in qualitative research. Unlike everyday interviews, the interview used for research purpose is a highly disciplined endeavor and dynamic process of interaction between an interviewer and interviewee. It takes various forms, face to face interview or telephone interview, structured interview, semi-structured or unstructured interview. This study took the form of face-to-face semi-structured interview which has an interview guide with open-ended issues but will gather data to illuminate these issues in a far less pre-determined manner. Interview guide had a double function in present study: firstly, it ensured that

the researcher did not present him or herself as an incompetent interlocutor; secondly, the orientation to an interview guide also ensured that the interview did not get lost in topics that were of no relevance and did not permit the interviewee to extemporize his or her issues and view on matters.

#### 3.6.2.1 Interview guide

In order to keep interview going on smoothly and centering around the core topic of relevance to the research, the interview guide was designed to elicit views and opinions from the participants including the subquestions as follows:

· Family reaction to the diagnosis of hearing loss such as emotional response and change in life focus or others;

·Impact of hearing loss on quality of family life such as family communication, family emotional climate, family economy, family relationship with extended family, marital relationship;

- · The rationale for decision making in sensory device, communication mode and educational placemen;
- The support and source of social support including extended family, special school, other parents and desired support etc.;
- · Acceptance of childhood hearing impairment: the degree and the coping strategies;
- The meaning of childhood hearing impairment to family such as family belief, family future, child future etc.

#### 3.6.2.2 Respondents

Considering the language barrier of researcher in Czech and the requirement of interviewer being competent in the face of interviewee, the interview was only conducted in China in Chinese. The target interviewees were selected from the main caregivers of resilient families who scored higher than 3.97 points in average score in the outcome of adaptation in the Likert-type scale in questionnaire survey (this part will be detailed in the following section of results of qualitative research).

## 3.6.2.3 The administration of interview process

The interviews of this study with eight main caregiver of hearing impaired children were accomplished with the help of Zheng Linying, a graduate student of applying for master degree in special education in Sichuan Normal University in China following a formal procedure. Every interview began with an introduction on interviewer and the aim of the study to establish a rapport with the participant. Then the interviewer clarified any questions about the research and informed the participant about the confidentiality and the use of data. Permission to use recording device and so forth was obtained at this stage. Eventually the main caregiver was encouraged to describe his or her experience freely centering around the issue which the interviewer attempted to investigate. All the interviews were recorded and transcribed shortly after interview. After collecting the data, the raw data spoken in Sichuan accent mandarin was translated into written raw data in general Chinese mandarin words by words.

#### 3.6.2.4 The process of analyzing the qualitative data

This study followed the generic process of data analysis proposed by Creswell (2003, p.190-195):

- Step 1: Organize and prepare the data for analysis. This involves transcribing interviews, optically scanning material, sorting and arranging the data into different types depending on the sources of information.
- Step 2: Read through all the data to obtain a general sense of the information and to reflect on its overall meaning.
- Step 3: Begin detailed analysis with a coding process including organizing the material into "chunk", taking text data into categories, labeling those categories with a term.
- Step 4: Use the coding process of constant comparison to generate categories or themes for analysis. Those themes are ones that appear as major findings in qualitative studies.
- Step 5: Advance how the description and themes will be represented in the qualitative narrative or use a narrative passage to convey the findings of the analysis.
  - Step 6: A final step in data analysis involve making a personal interpretation or

meaning of the data, for example, comparing the findings with the information gleaned from literature or bringing the findings to particular culture or social context etc.

One point to be mentioned here particularly is that the analysis is easily taken for granted subjectively in qualitative research, especially in the tache of coding data while facing mountainous data. To avoid taking for granted subjectively and to reach agreement in coding, the qualitative coding were discussed and completed by interviewer and the author of this dissertation again and again using several coding methods, such as open coding, conceptual ordering and comparative analysis advocated by grounded theory (Strauss & Corbin (1998, 2008). As a result, some concepts, categories and relationship between them were formulated.

#### 4. Results and discussions

For the sake of clarity, the section of results was divided into two parts: results of questionnaire survey and that of qualitative interview. Further, according to the nature of questions in the questionnaire, the results of questionnaire were grouped into three parts: the first part was about background information about participant families and children and hearing loss related characteristics regarding hearing impaired children, the second part was directed to results of close-ended question and the third part was

concerning the results of open-ended questions.

## 4.1 Results of questionnaire survey

The participants in this study were main caregiver of children from special schools or centers for hearing impaired children in two countries, China and Czech. 122 questionnaires were distributed in China and 115 were returned indicating a 94.3% response rate. Because of data missing in most of questions, eight questionnaires were excluded from the study. At last this study got 107 valid questionnaires from China. In Czech, with the help of three special schools for hearing impaired pupils, 55 questionnaires are returned with about 30% response rate. Two questionnaires were excluded from the study while one questionnaire missed responses in most of questions and the participant child in another questionnaire was not hearing impaired despite his attendance to special school (he can hear but not speak according to information written in the questionnaire).

## 4.1.1 The background information about participant families and their children Background information about 160 families from China and Czech

From the information provided by 160 informants in sum, this study firstly got a body of information relevant to the family as a functional unit. From the background information in the Table 4 some demographic characteristics of two family groups can be found out as follows: (1) more than 90 percent families from both of two family groups were of hearing parents (2) most Chinese families (67.29%) resided in rural area while most of Czech families (69.81%) resided in urban area; (3) more Chinese families (57.01%) were with lower income while more Czech families (43.40%) reported their middle family income; (4) Czech group demonstrated higher proportion

**Table 4.** The background information about participant families:

V2-11.	China (n=107)		Czech (n=53)	
Variable	N	%	N	%
Parent hearing				
Both hearing	100	93.46%	48	90.57%
Both hearing-impaired	2	1.87%	4	7.55%

Shenglin LIU Research on Family Resilience in Families of Children with Hearing Impairm				
Combined	5	4.67%	1	1.89%
Residence				
Urban	35	32.71%	37	69.81%
Rural	72	67.29%	16	30.19%
ncome				
Lower	61	57.01%	13	24.53%
Middle	46	42.09%	23	43.40%
Higher	0	0	7	13.21%
he highest educational attainment				
Illiterate	2	1.87%	0	0
Primary education	16	14.95%	4	7.55%
Secondary education	77	71.96%	36	67.92%
Higher education	13	12.15%	13	24.53%
arent marriage				
Married	97	90.65%	36	67.92%
Separated	6	5.61%	5	9.43%
Divorced	4	3.74%	8	15.09%
Cohabited	0	0	4	7.55%
Religion				
Religious	8	7.48%	18	33.96
Non-religious				%

of receiving higher education (24.53%) as compared to Chinese counterparts (12.15%); (5) Chinese families held higher rate (90.65%) of parental marriage in the married status while Czech counterparts revealed higher rate of divorced, separated, and cohabited families (32.08%, the sum of the three kinds of families); (6) Chinese

99

0

92.52%

0

31

4

58.50

7.55%

%

No response

group had much lower rate of believing in religion (7.48%) as compared to Czech counterparts (33.96%). More detailed information about two family groups are presented in Table 4.

### The demographic characteristics of participant children

The demographic information about participant children were collected from informants, including the gender, age, range of age, and whether they were only one child or not in families. They are detailed in Table 5.

**Table 5.** The demographic characteristics of participant children in two family groups

Variable	China(n=107)	Czech (n=53)
Average age (months)	101.6	117.2
Range of age(months)	31-220	35-172
Gender		
Boy	66 (61.68%)	30 (56.60%)
Girl	41 (38.32%)	23 (43.40%)
One-child		
Yes	63 (58.88%)	15 (28.30%)
Not	44 (41.12%)	38 (71.70%)

From the information presented in Table 5 we can see that overall, the participant children in Chinese group were more than 15 months younger than Czech counterparts but with more extensive range of age, 31-220 months as compared to 35-172 months of Czech counterparts. Interestingly, although one-child policies have been conducted since 1980s as a national policy in China, 41.12% participant children were not only-child in families. This phenomenon probably can be attributed to the supplementary regulations of one-child policy in China that if the first child of family is with certificated but not genetic disabilities the family is entitled to give birth to the second child.

## Hearing loss-related characteristics of participant children

In addition to the demographic characteristics, some hearing loss-related

characteristics were collected by questionnaire concerning degree of hearing loss, onset of hearing loss, the average time of diagnosis of hearing loss, percent of using hearing aids, average time of using hearing aids, percent of using cochlear implants, the average time of using cochlear implants, and the payer of hearing aids and cochlear implants. Specifically, the overwhelming majority of participant children were of severe to profound hearing loss. The time of hearing loss identified were varied and the average time of diagnosis of hearing loss were around two years old. The time of Chinese children using hearing aids was around 12 months later than Czech children while Czech children used hearing aids at the age of 31 months. The rate of Chinese children using hearing aids (71.96%) was apparently lower than that of Czech counterparts (92.50%). Similar to the situation of using hearing aids, the rate of using cochlear implants in Chinese children group (14.95%) was also much lower than that of Czech children group (32.08%). Additionally, the main payers of hearing aids and cochlear implants in China were families while they were mainly paid by healthy insurance in Czech. The detailed information was presented in Table 6.

**Table 6** Hearing-loss related information about participant children (n=160)

Variable	China(n=107)	Czech(n=53)
Degree of hearing loss		
41-55dB	0	3(5.66%)
56-70dB	3(2.80%)	0
71-90dB	4(3.74%)	12(22.64%)
90-110dB	11(10.28%)	11(20.75%)
>110dB	51(47.66%)	18(33.96%)
Not clear	38(35.51%)	9(16.98%)
Onset of hearing loss		
Birth	15(14.02%)	16(30.19%)
Less than 1 year old	33(30.84%)	10(18.86%)
1-3 years old	44(41.12%)	14(26.42%)
After 3 years old	4(3.74%)	5(9.43%)

Not clear	11(10.28%)	8(15.09%)
The average time of diagnosis of HL	24.5 months	24.8 months
The average time of using HA	43.8 months	31.0 months
The rate of using HA	71.96% (77)	92.50%( 49)
The payer of HA		
Government	7(9.09%)	0
Family completely	53(68.83%)	0
Health insurance	0	38(77.55%)
Family partially	10(12.99%)	9(18.37%)
<b>Donation (institute)</b>	6(7.79%)	2(4.08%)
The average time of using CI	33.19 months	40.31 months
The rate of using CI	14.95% (n=16)	32.08%(n=17)
The payer of CI		
Government	1(6.25%)	0
Family completely	1(6.25%)	0
Health insurance	0	17(100%)
Family partially	13(81.25%)	0
Donation	1(6.25%)	0

Note: HL represents hearing loss, HA represents hearing aids, and CI represents cochlear implants.

## Communication mode, therapy and educational placement for two groups

Similarly this study got some information about the communication mode used, therapy service received and educational placement relevant to the hearing impaired children (see Table 7). Two of the commonalities between two group children were: (1) mixed approach was used as main communication mode in both group children; (2) both groups of children were educated in special school and were included into

**Table 7.** Communication mode, therapy and educational placement for two groups of children

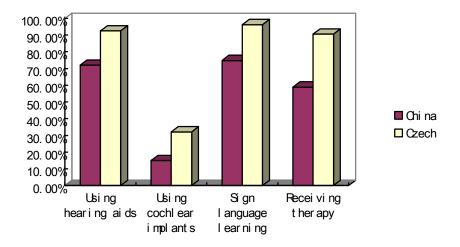
Variable China	(n=107) Czech (n=53)
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Communication mode			
Natural gesture	13(	(12.15%)	1(1.89%)
Sign language	34(	(31.78%)	3(5.66%)
Spoken language	12(	(11.21%)	12(22.64%)
Mixed approach	48(	(44.86%)	37(69.81%)
Sign language training			
Yes	80(	(74.77%)	51(96.23%)
No	27(	(25.23%)	2(3.77%)
Therapy items			
Medication	8(	(7.48%)	1(1.89%)
Speech therapy	53(	(49.53%)	25(47.17%)
Social skill training	1(	(0.93%)	0
Sensory integration	1(	(0.93%)	0
Mixture of two or more the	erapy	0	24(45.28%)
None	44(	(41.12%)	3(5.66%)
Payer of therapy			
Government (school)	15(	(14.02%)	0
Family completely	89(	(83.18%)	2(3.77%)
Insurance		0	26(49.06%)
Family partially		0	7(13.21%)
Not clear	3(	(2.80%)	18(33.96%)
	All children are from specia	l schools or c	enters and the
Educational placement e	xpenses are paid by govern	ment	

category of compulsory education. Three of the significant differences were demonstrated in sign language learning and associated therapy: (1) the rate of receiving sign language learning in China (74.77%) was much lower than that in Czech (96.23%); (2) Much higher rate of Czech children (45.28%) received two or more kinds of therapies while Chinese counterparts only can received single or

limited therapy of hearing speech training or mediation; (3) the main payer of therapies received by hearing impaired children in China were families while insurance accompany became main payer for therapies for Czech counterparts.

In sum, according to the descriptive data above listed about characteristics of children hearing loss and the condition of intervention services in using sensory devices and receiving therapy, the further comparison of difference in intervention services, mainly from three aspects of the rate of using hearing aids, the rate of using cochlear implants, the rate of receiving therapy between two families from two countries was proceeded. It is evident that Chinese participant children demonstrated much lower rate in three aspects than Czech counterparts. This point was reflected clearly in the figure 2.



**Figure 2** Rates of using hearing aids, cochlear implants, sign language learning and receiving therapy in two family groups.

#### 4.1.2 Results of close-ended questions

As discussed earlier, 29 close-ended questions were included in the questionnaire, mainly designed to examine the family's responses in subjective appraisal of stressful level caused by childhood hearing impairment, family characteristics, impacts of hearing impairment on family life, family perception of childhood education and development, change in family belief while parenting child with hearing impairment and the outcome of family adaptation to childhood hearing impairment. To be more clear, the result of this section were classified as the following parts according to the

research questions:

#### **Research question 1:**

Whether the families are resilient with positive adaptation to childhood hearing impairment after several years of experiencing with it according to the standard of accepting well, functioning well and expecting well?

In this study, whether families are generally resilient or not were judged according to the outcome of family adaptation to childhood hearing impairment. Based on the framework of family resilience developed previously, this study inferred the outcome of family adaptation from the perspective of process via three criteria of accepting well, functioning well, and expecting well. The degree of accepting well was reflected in the score in item1 and item 25. The item 1 was designed to measure the subjective appraisal of stressful level due to childhood hearing impairment, and item 25 was used to quantify the level of acceptance at present by comparing with that at the early days just after the diagnosis of hearing loss. The level of family functioning was inferred from the scores in item14, item 24, item 28 which were designed to quantify the change of marital relationship while parenting the participant child, the degree of best efforts have been made and the degree of change in family cohesion respectively. The level of family's expecting for child's future was calculated according to the score in the item 27 and item 29 which were aimed to measure the family expectation for child's future and family belief in ability to deal with the future problems. According to the overall responses in these items, the results of all the 160 families got an average score of 3.97 point. It was significant higher than expected 3.0 point which was operationalized as family's boundary level of adaptation which stood between positive and negative adaptation. As a whole it showed a good outcome of positive adaptation, namely, higher moderate level of adaptation to the childhood hearing impairment over the average time of 107 months. Specifically, it meant that in general the families of children with haring impairment were accepting well, functioning well and expecting well despite the presence of hearing impairment as a chronic and grief health condition. Most significantly the participant families had got extremely high scores in marital relationship and families'

best efforts made and consequently lead to higher functioning relatively. The results in overall adaptation, three factors, and seven items for the 160 participant families were listed in the following Table 8.

**Table 8.** Overall level of family adaptation to childhood hearing impairment

Variable and brief description of items	Mean	Mean
variable and brief description of items	response	score
Accepting		
Item 1: Parenting a child with hearing impairment has been linked with chronic sorrow and grief.	3.13	2.86
Item25: There is more acceptance and peace at present.	4.33	4.33
Functioning		
Item 14: My marital relationship has deteriorated	1.81	4.24
Item 28: My family relationship has become closer.	3.97	3.97
Item 24: Best efforts have been made to promote his/her communication and learning in my family.	4.68	4.68
Expecting		
Item 27: My child will have bright future and be a beneficial member in society in the future.	3.97	3.97
Item 29: My family has ability to deal with the children's difficulties and problems in the future.	3.75	3.75
Average score		3.97

Overall, the two groups of families are resilient with positive adaptation to childhood hearing impairment according to the standard of accepting well, functioning well, and expecting well. As a result, the research hypothesis  $H_1$  was accepted.

#### **Research question 2:**

## What factors contribute to the family positive adaptation to the childhood hearing impairment generally?

As discussed earlier, the 29 items in the questionnaire had been classified as seven factors: outcome of family adaptation (item 1, 14, 24, 25, 27, 28, 29), social stigma of hearing impairment (item 2, 3), change in family belief (item 4, 7, 8, 9), family characteristics (item 5, 6, 15), impact of hearing impairment on family life (10, 11, 12, 22), social support (13, 17, 18, 19, 23) and family perception of childhood

education and development ( item 16,20,21,26). To answer the question of what factors contributing to the good outcome of family adaptation to childhood hearing impairment, the correlation between the outcome of adaptation and other factors were examined using the Pearson Correlation Analysis in SPSS (Statistics Package for Social Science). The overall score of outcome of adaptation was treated as dependant variable while the other six factors being treated as independent variables. The statistics showed that the factors of family characteristic, the social support and the change in family belief were positively and significantly correlated to the outcome of family adaptation while the factor of impacts of childhood hearing impairment on family life and social stigma were negatively and significant correlated to the outcome of family adaptation. At the same time, results of statistics showed that family perception of childhood education and development had no significant correlation to the outcome of family adaptation. In detail, all the value of correlation between factors and the outcome of adaptation were exhibited in the following Table 9:

**Table 9.** Correlation between factors and outcome of adaptation

	Correlation to the
Factors	outcome of family
	adaptation (two-tailed)
Social stigma	-0.350**
Change in family belief	0.293**
Family characteristics	0.516**
Impact of hearing impairment on family life	-0.542**
Social support	0.214**
Family perception of education and development	0.007

Note: \*\*. Correlation is significant at the 0.01 level (2-tailed)

As a result, the research hypothesis  $H_2$  was accepted partially. All the discussed factors of social stigma, family characteristics, impact of hearing impairment, change in family belief, social support but family perception of childhood education and development were significant correlated to the outcome of adaptation.

## Research questions 3

# Whether or not is there significant difference in the outcome of adaptation to the childhood hearing impairment between Chinese and Czech families?

Further analysis was performed to answer the question above mentioned concerning the difference in overall level of adaptation, the scores in factors and relevant items between two family groups by using Independent-Sample T-Test statistics in SPSS The test got a t- test value of 0.24 with degree of freedom of 153 which means no significant difference in the overall outcome of adaptation generally between two family groups. The detailed statistical result was presented in Table 10.

**Table 10.** Difference in outcome of family's adaptation between Chinese and Czech families

		C	China Czech		China Czech		China		T-test for Equality
Variable	Relevant item	M	Std.	M	Std.	of Means			
		Mean	Deviation	Mean	Deviation	( Sig. 2-tailed)			
Accepting	Item 1, 25	6.90	1.66	7.71	1.32	-3.31 (0.001)**			
Functioning	Item 14,24,28	13.19	2.18	12.18	2.00	2.86(0.005)**			
Expecting	Item 27,29	7.73	2.13	7.73	1.34	-0.01(0.995)			
Overall	Item 1, 14, 24,	25.01	4.72	25.65	2.62	0.24(0.01)			
adaptation	25, 27, 28, 29	27.81	4.73	27.65	3.63	0.24(0.81)			

Note: \*\* stands for being significant at 0.01 level.

Interestingly, from the data listed in the above table, although no significant difference existed in the overall level of family adaptation, significant differences had been found in factors of family accepting and functioning at 0.01 significant level. This is a phenomenon needed to be further discussed.

To make clear the nature of difference in family accepting and family functioning between two countries, the further analysis of difference in terms of items were conducted. Indeed there is lack of significant difference in overall outcome of adaptation between families from two countries, however, there exist significant differences in specific item 1 (subjective appraisal of stress level), item 25 (more

acceptance at present than early days after diagnosis), item 28 (family relationship becoming closer). To be more concrete, the result may be obtained from the statistical test (see Table 11) is that Chinese families experienced more sorrow and grief than Czech families, however, they were getting more acceptance and becoming closer over time while Czech families showed more stable acceptance and originally close family relationship facing the challenge of childhood. As an example, the words written in one questionnaire by one parent, "Nothing has changed, family relationship was good enough originally (Ostrava 28)", can support this result to less or larger degree. In general, this can be regarded as difference in pattern of adaptation while both groups manifested the similar outcome of positive adaptation to the given risk of having a child with hearing impairment in families.

**Table 11.** Difference in accepting and functioning between two family groups

		C	China		zech	T-test for Equality
Variable	item	Mean	Std.	Mean	Std.	of Means
		response	Deviation	response	Deviation	( Sig. 2-tailed)
Accepting	Item 1	3.59	1.27	2.19	1.05	7.33(0.000)***
	Item 25	4.52	0.79	3.94	1.10	3.38(0.001)***
Functioning	Item 14	1.80	1.25	1.82	1.05	-0.10(0.91)
	Item 24	4.62	0.77	4.77	0.42	-1.56(0.12)
	Item 28	4.16	1.00	3.15	1.26	6.06(0.000)***

Note: \*\*\* stands for being significant at 0.001 level.

As a result, the research H<sub>3</sub> that there is significant difference in the outcome of adaptation to the childhood hearing impairment between China and Czech family groups was refused. However there existed apparent difference in family stressful experience and changes in acceptance and family relationship relative to the early days after diagnosis of hearing loss between two family groups which may lead to different adaptive pattern.

## Research question 4

Are there differences in factors which can contribute to the difference in

#### outcome of adaptation?

As the above discussed, although there existed no significant difference in the overall outcome of family adaptation to childhood hearing impairment, the two family groups demonstrated the difference in adaptive pattern. To better map the feature of family adaptation to childhood hearing impairment in two groups, the group comparisons in factors of social stigma of hearing impairment, change in family belief, family characteristics, impact of hearing impairment on family life, social support, family perception of childhood education and development hade been made within this question.

## Difference in social stigma associated with hearing impairment between two groups of families

According to the responses in item 2 (My family has always been teased by other people because of my child's hearing impairment) and item 3 (My child's hearing impairment means the child will not have bright future), it can be found that both Czech families and Chinese families basically disagree with the two statements while Chinese families tend to experience more social stigma compared with Czech families. There existed significant difference in social stigma of hearing impairment between two groups generally. The statistical result was exhibited in Table 12.

#### Difference in family characteristic between two groups of families

In this study family characteristics were explored from the dimensions of family self-efficacy, family cohesion, and the status of open communication. The scores of family characteristics were calculated according to the family responses in item 5 (I strongly believe in my family's ability to face the challenge of child's hearing impairment), item 6 (My family is characterized by close relationship and mutual support), item 15 (To educate the child with hearing impairment, we often share emotions and opinions together in my family).

**Table 12.** Difference in social stigma between Chinese families and Czech families

Item	China(n=107)	Czech(n=53)	<b>T-test for Equality</b>
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	Mean	Std.	Mean	Std.	of Means
	response	Deviation	response	Deviation	( Sig. 2-tailed)
Item 2	2.97	1.08	2.19	0.84	4.99 (0.000)***
Item 3	2.97	1.28	2.42	0.94	3.06(0.003)***
Overall of social stigma	5.94	1.92	4.62	1.51	4.75(0.000)***

Note: \*\*\* stands for significant at 0.001 level.

Statistically, according to data in Table 13, Chinese families demonstrated lower self-efficacy in dealing with childhood hearing impairment and higher level of open communication by sharing emotion and opinions in education as compared to Czech counterparts. Also, because both group families got higher scores in family cohesion, there existed no significant difference in this dimension.

**Table 13.** Difference in family characteristics between two family groups

	China(n=107)		Czech(n=53)		T-test for Equality of
Variable	Mean	Std.	Mean	Std.	Means
	response	Deviation	response	Deviation	( Sig. 2-tailed)
Self-efficacy	3.57	1.29	4.32	0.75	-4.63(0.000)***
Cohesion	4.16	1.13	4.47	0.85	-1.96(0.052)
Open communication	3.62	1.14	2.87	1.02	4.25(0.000)***

Note: \*\*\* stands for being significant at 0.001 level.

As a result, we can see that Czech families exhibited higher self-efficacy faced with childhood hearing impairment and lower status of open communication as compared to Chinese counterparts while both groups demonstrated high level of family cohesion.

# Difference in impacts of childhood hearing impairment on family life

In this study the impacts of hearing impairment were estimated from the scores in item 10 (During the time of parenting my child, I often feel difficulty in communicating with my child), item 11 (Parenting my child make me have a feeling of great fatigue), item12 (Because the child's hearing impairment, the economic status of our family has deteriorated), item 22 (The mutual communication of the family members has been affected by the child hearing loss).

**Table 14.** Comparison of impacts of hearing impairment on family life between two family groups

	China	China(n=107)		h(n=53)	T-test for Equality	
Item	Mean	Std.	Mean	Std.	of Means	
	response	Deviation	response	Deviation	( Sig. 2-tailed)	
Item 10	3.48	1.00	3.02	1.12	2.55(0.013)*	
Item 11	3.50	1.16	2.74	1.04	4.23(0.000)***	
Item 12	3.51	1.35	2.57	0.99	5.03(0.000)***	
Item 22	2.29	1.25	2.33	1.03	-0.18(0.856)	
Overall	12.80	3.54	10.69	3.02	3.87(0.000)***	
impact						

Note: \* stands for being significant at 0.05 level;

According to the statistics in Table 14, there existed most markedly significant differences in deteriorated economy and feeling of fatigue at significant level of 0.001, also significant difference in communication difficulty at significant level of 0.05 between two groups. Nevertheless the significant difference is not observed in relationship of family members. To some degree it seems that the family relationship between members was not affected greatly by childhood hearing impairment in both

<sup>\*\*\*</sup> stands for being significant at 0.001 level.

countries. In one word, Chinese families had experienced much higher increased economic burden and feeling of great fatigue than Czech families while families from both countries similarly have experienced difficulty with communicating with their children.

# Difference in social supports for families of child with hearing impairment in two countries

In this study social supports were examined from the item 13 (The support from my extended family and other relatives often help me greatly), item 17 (My family can often get necessary information related to hearing impairment from professionals), item 18 (My child can choose to attend specialized preschool or regular preschool age-appropriately and freely), item 19 (My family has access to self-help group of parents of hearing impaired children), item 23 (The financial support from welfare is high enough to meet the special needs of the child with hearing impairment). From the source of the support perceived, both Chinese family group and Czech counterparts emphasized support from extended families and relatives. However this kind of support seemed to be the main source for Chinese families while Czech families could get support from multiple channels such as parent group and professionals etc. Furthermore, the statistical results demonstrated that there were extremely significant differences in access to parent self-help group, in choice of educational placement for children, in information support from professionals, slightly significant differences in support from extended family and relatives, and no significant difference in financial support. Overall, there existed extremely significant difference in social support for families of children with hearing impairment in two countries. The more specific information about social supports for families from two counties was detailed in the following Table 15.

# Difference in change in family belief while families experiencing with childhood hearing impairment

**Table 15.** Difference in social support between families from two countries

Czech(n=53) T-test for Equality of

	Mean	Std.	Mean	Std.	Means
	response	Deviation	response	Deviation	( Sig. 2-tailed)
Item 13	3.34	1.50	3.81	1.16	-2.20(0.030)*
Item 17	2.69	1.46	3.38	0.92	-3.61(0.000)***
Item 18	1.30	0.74	2.83	1.34	-7.70(0.000)
Item 19	1.91	1.43	3.84	1.01	-9.89(0.000)***
Item 23	2.52	1.30	2.32	1.14	1.01 (0.316)
Overall social support	11.78	3.54	16.19	2.89	-8.418(0.000)***

Note: \* stands for being significant at 0.05 level

Family belief systems are considered to be among the most important factors affecting the adaptation and resilience of families while facing great challenge. The factor of change in family belief in this study was explored via item 4 (Facing the reality of child's hearing impairment, I tend to be a fatalist.), item 7 (During the time of parenting my child, the degree of my altruism increased), item 8 (During the time of parenting my child, the degree of my tolerance toward difference increased), item 9 (During the time of parenting my child, the degree of life optimism increased). According to statistics, both groups of families tended not to be a fatalist, in contrast, they tended to be more altruistic, optimistic, tolerant toward difference. Further more, Chinese families experienced more significant changes in optimism and tolerance toward difference. The more detailed statistics was listed in the Table 16.

**Table 16.** Difference in changes in family beliefs of two family groups

Item China	(n=107) Czech	(n=53) T-test for Equality
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<sup>\*\*\*</sup> stands for being significant at 0.001 level

	Mean	Std.	Mean	Std.	of Means
	response	Deviation	response	Deviation	( Sig. 2-tailed)
Item 4	2.82	1.31	2.72	1.25	0.495(0.621)
Item 7	3.98	0.85	3.40	1.01	3.371(0.001)***
Item 8	3.94	0.98	3.75	1.07	1.08(0.283)
Item 9	3.71	1.13	3.00	1.09	3.83(0.000)***
Overall belief change	14.46	2.45	12.83	3.62	2.94(0.004)***

Note: \*\*\* stands for being significant at 0.001 level.

# Comparison of family perception of hearing impaired education and children development

In this study family perception of hearing-impaired education and children's development was examined from item 16 (In my family parenting the child with hearing loss means providing best care and protection), item 20 (I believe learning sign language is of no benefit to my child's future), item 21 (I believe that mastery of spoken language is most fundamental educational goal for my child), item 26 (Up to now my child does not show developmental lag relative to same age peers). These items were not of same nature, concerning different aspects such as the opinion of family education, the benefit of sign language learning, the general goal of hearing impaired education, and subjective appraisal of children's developmental lag, consequently the overall comparison of this factor was neglected. Also as already discussed, this factor was likely to have no close relation to family adaptation to childhood hearing impairments, however, it was of importance to better understand why families from different countries had different feeling of fatigue, different choice in communication mode etc. The t-test results of four items in table 17 showed that Chinese families almost completely agreed that parenting the child with hearing

impairment meant providing best care and protection while Czech families also tend to moderately agree the same statement. The result also indicated that both Chinese families and Czech family moderately disagreed learning sign language is of no benefit to child's future and at the same time they valued the mastery of spoken language. It is another question of interest for readers that Chinese families manifested significant difference in perception of children developmental lag from Czech families (see Table 17).

**Table 17.** Difference in family perception of childhood education and development between two family groups

	China(ı	China(n=107)		h(n=53)	T-test for Equality of	
Item	Mean	Std.	Mean	Std.	Means	
	response	Deviation	response	Deviation	( Sig. 2-tailed)	
Item 16	4.78	0.67	3.45	1.07	8.245(0.000)***	
Item 20	2.30	1.63	2.63	1.39	-1.315(0.191)	
Item 21	3.81	1.22	3.86	1.23	-0.237(0.813)	
Item 26	3.54	1.24	2.72	1.10	4.283 (0.000)***	

In sum, the research hypothesis 4 that the significant differences in outcome of adaptation between two family groups can be contributed to the factors of social stigma of hearing impairment, family characteristics, impacts of childhood hearing impairment on family life, social support, change in family belief and family perception of childhood education was partially accepted due to all the factors but family perception of childhood education have no significant correlation to the outcome of family adaptation.

## 4.1.3 Results of open-ended questions in questionnaire

**Research question 5** 

Does there exist difference in the biggest difficulty that families have experienced during parenting the children with hearing impairment between two family groups?

104 families among 107 participant family population from China presented their responses to this question. Some families provided more than one responses while some families missed response to this question. In this condition only first response was used to analyze the result. Generally, their responses involved an array of difficulties including the increased financial demands, increased time demands, worry about future, fear of being teased by others, feeling of fatigue, difficulty with

**Table 18.** The five top responses in parenting difficulty from Chinese families

#### The five top responses in parenting difficulty from Chinese families

#### • Financial burden (37)

e.g.: "We can not afford for his cochlear implant and one parent have to stop working in order to accompany his study." (A16)

## • Difficulty in Communication (30)

e.g.: "The biggest problem is we can not understand her when she communicate with us by sign and she can not understand what we say when we speak to her by spoken language." (B23)

#### • Educational puzzle (18)

e.g.: "Sometimes we do not know how to educate him as we are lack of the professional knowledge about hearing impairment." (D16)

#### • Worrying about child' future(5)

e.g.: "He can not speak and understand well, what would happen if both his parent and grandparent die?" (A14)

### • Impact of childhood hearing impairment on normal work(4)

e.g.: "I feel tired and can not work normally because every day I need send him for speech therapy and take him back after work." (C6)

communication with child, not understanding child and difficulty in being understood

by children, difficulty with dealing with children's behavioral problems etc. (see the Table 18). Sorting and categorizing all the responses, the study got the five top difficulties of Chinese families demonstrated in the table 18, namely economic burden, communication difficulty, educational puzzle, worrying about child's future, impact of childhood hearing impairment on normal work. The numbers of families were given in brackets and the specific descriptions of the difficulty from the most representative family were presented as an example.

Also 49 of 53 families in Czech presented their responses about family difficulty while parenting their children. By sorting and ordering the responses, the six top

**Table 19.** The six top responses in parenting difficulty from Czech families

#### The six top responses in parenting difficulty from Czech families

# • Communication problems between parent and child, child and other children (15)

e.g.: "We have difficulty with explaining learning material when he prepares his home work." (Hradec 05)

## • No problem (8)

- e.g.: "Both parent are deaf, we have no problem." (Ostrava 22)
- e.g.: "we have no problem, only feel shock with her diagnosis of hearing loss; after 6 years old, everything is ok." (Olomouc 15)

#### • Doctor's response and attitude (5)

e.g.: "Bad communication with doctor and doctor's indifference to child. Doctor said to us that parent should go to expert for more information." (Olomouc 01)

#### • Accepting the disability (3)

e.g.: "I can not keep calm with child's disability and others' attitude" (Ostrava 16)

#### • Child's attending normal school: aloneness, being teased by others(3)

e.g.: "We have problem with registering child to normal school and worrying about child's communication with normal child." (Oloumouc 08)

### • Problem with sensory cochlear implants (3)

e.g.: "We have no other problem but with cochlear implants because the insurance only pay the first cochlear implantation." (Ostrava 25)

family responses (the fourth, fifth and sixth with the same frequency) in this subquestion were communication problem, no problem, doctor's response and attitude toward to children' hearing loss, accepting the disability, children's attending normal school, and problems with cochlear implants. It is of interest that 8 families reported they had no problems, especially the response of no problem from deaf parent. Specifically, it was detailed in table 19.

As a result, the research hypothesis of H<sub>5</sub> that there exist differences in the biggest difficulty families have experienced during parenting the children with hearing impairment between two family groups was supported. Among them, the apparent differences between two family groups were mainly from two aspects: (1) two family groups experience different specific difficulties generally. For example, the most salient difficulty for Chinese family was financial burden while the answer of Czech families was communication difficulties. (2) Chinese families seemed to experience more difficulties than Czech counterparts because considerable number of families in Czech group reported that they had no problems. Another point to be mentioned is that a considerable number of families from two family groups experienced the same difficulty, namely, communication difficulty with children.

#### Research question 6

Does there exists difference in the main communication mode which families have used to communicate with their children and the approach through which family has got it between two family groups?

#### The communication modes in Chinese families

Among 107 participant families 105 families reported their main communication mode they had used to communicate with their child. This study categorized the various communication ways into main four types: natural gesture (4 families, 3.8%), spoken language (12 families, 11.4%), sign language (49 families, 46.7%), mixed approach (40 families, 38.1 %). Among them, mixed approach included multiple mixtures of spoken language and spoken language, spoken language and written language, spoken language and body language, lip-reading etc. Generally, the sign language and mixed approach were the main communication modes used by families

to communicate with hearing impaired children. To make it clear, the result was presented in the following figure 3.

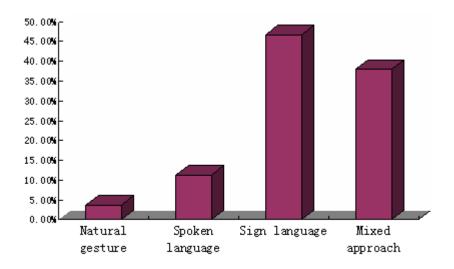


Figure 3 Communication modes in Chinese families

# The approaches through which Chinese families have got the communication mode

Additionally, 74 families report their approaches through which they acquired the communicative skills, mainly sign language. They were three approaches to learn sign language, namely, being taught by their own children (7 families), learning in special school or rehabilitation center (22 families), most of families educating themselves (45 families). From these approaches, it is evident that Chinese parent learned sign language lately than expected theoretically. This result was displayed in the Figure 4.

# The communication modes in Czech families

Likewise 47 Czech families presented their responses to the question of the main communication modes used to communicate with their hearing impaired children. According to their responses, four communication modes which were slightly different from those used by Chinese families had been offered. They were lip-reading (3 families, 6.28%), spoken language (15 families, 31.91%), sign language (7 families, 14.89%), mixture of sign language and spoken language (22 families, 46.81%).

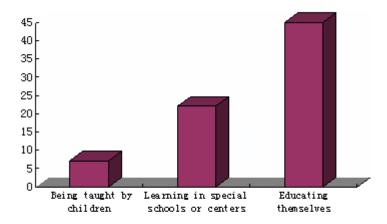


Figure 4 The approaches through which Chinese families acquire the communication mode

The following Figure 5 was used to visualize the communication modes used by Czech families. From the figure, it was evident that mixed approach, including mixture of sign language and spoken language, also mixture of lip-reading and spoken language, or combination of gesture and sign language etc. was the main approach Czech families used to communicate with their hearing impaired children. Additionally, many parents described the children using the sign language at school and using spoken language at home, or another vision of using sign language before cochlear implantation and using spoken language after implantation.

# The approaches through which Czech families have acquired the communicative skills

As for the question where the families had acquired the communicative skills, only 23 Czech families offered their responses clearly. Among them, 14 families reported that they learned sign language at special school, 6 families mentioned their progress in communication with children by practice at home, and the left three families learned their communicative skill through private counsel organization, sign language center and deaf center respectively. From the following Figure 6, it was evident that special school had played a crucial role in helping families acquiring the communicative skill.

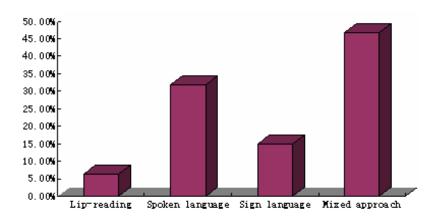


Figure 5 Communication modes in Czech families

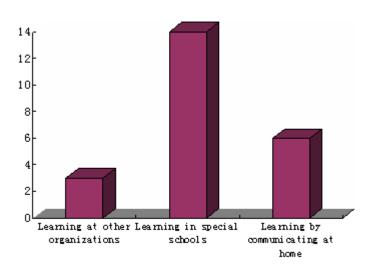


Figure 6 The approaches through which Czech families acquire the communication mode

Comparing the communication mode used by Chinese families and Czech families some commonalities and differences can be obtained from the result above demonstrated. With respect to commonalities, firstly, mixed communication mode, mainly mixture of sign language and spoken language was the most widely used to communicate with hearing impaired children. Secondly, special schools in two countries had played main role in teaching sign language to children and their families. As for the differences, one of salient differences in approaches through which families acquired the communication skills between two family groups was that more Chinese

families reported they acquired their communicative skills by educating themselves or being taught by their children while more Czech families reported they have got communicative skills in special schools. At least this meant that Chinese families had no easier access to sign language than Czech families and started learning sign language later as compared to Czech counterparts.

As a result, the research hypothesis H<sub>6</sub> that there exist differences in the main communication mode which families have used to communicate with their children and in the approach via which family has got it between two groups of families can be accepted partially.

#### Research question 7

# Does there exist difference in family information need while parenting their children between two family groups?

102 Chinese families actively expressed their multiple information needs via questionnaires. In this section of analysis, their needs had been coded into five sorts of

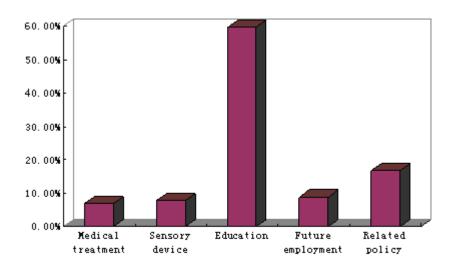


Figure 7 Information needs in Chinese families

information involving medical treatment (7 families, 6.9%), sensory device (8 families, 7.8%), education (61 families, 59.8%), future employment (9 families, 8.8%) and related policy (17 families, 16.6%). It was clear that information need in education, namely how to educate and communicate with their children constitutes the

most part of family needs. According to the specific content in responses, family educational needs mainly included such themes as how to educate child according to his/or her unique characteristics, how to learn well sign language to communicate with child smoothly, seeking for successful example of hearing impaired individual, how to cultivate the positive personality attributes of hearing impaired children and so on. The general distribution of families information needs was manifested in the Figure 7.

#### The information needs of Czech families

38 respondents presented their responses in this question. Two ambiguous responses of "good" and "more care" were excluded from the overall responses. Although only one response was expected in question statement implicitly, some families present more than one responses. To keep internal coherence in statistical analysis, only the first response in this question was regarded as valid response. The last 36 responses had been grouped into information about medical information (4 families, 11.11%), sensory device (4 families, 11.11%), education (22 families, 61.11%), psychological support (5 families, 13.89%) and special response from deaf parent (1, 2.78%). One response from deaf parent was worthwhile being discussed particularly as it have provided a completely different perspective from hearing parent. The deaf parent wrote in questionnaire, "I can not get necessary information for deaf parent, because all the information is for hearing parent." Another kind of information need in Czech families which was different from that of Chinese families was information for psychological support. Five families had expressed the strong desire for psychological empowerment. For example, one parent stated, "I need encouragement to let me believe it will be better." More concrete information was shown in the following Figure 8.

It is not difficult to find that both Chinese families and Czech families had strong need for information about how to educate their children. Because overwhelming majority of respondent parents were hearing, they could not use their own experiences to teach their children, consequently they needed necessary information to help them understand their children, communicate with their children, and make informed

decision in educational placement and hold positive and realistic expectation for children development.

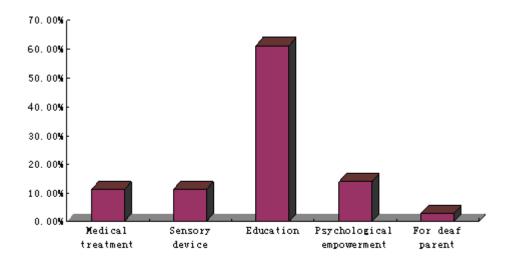


Figure 8 Information needs in Czech families

In general, as a result, the research hypothesis of  $H_7$  that there exists difference in the information families need most while parenting their children between two family groups was refused.

### Research question 8

Does there exist difference in the most effective support perceived by families while parenting their children between two family groups?

### The most effective help perceived by Chinese families

Although from the statement of this question in questionnaire it was mainly focused on the content of help explicitly, many families had reported not only the content but also the source of help. Accordingly the reports of result about this question were divided into two parts, the source of help and the content of help.

### The source of most effective help in Chinese families

94 participant families from China had presented the responses which emphasized the source of the most effective help perceived. Roughly speaking, as demonstrated in the Figure 9, the helps perceived as the most effective help by

Chinese families were mainly from extended family (24 families, 25.5%), friends and relatives (9, 9.6%), special school (19, 20.2%), other governmental agencies such as local Disabled Persons Federation and rehabilitation center funded by government (30, 31.9%), charity (2 families, 2.1%). Additionally, 10 families (10.6%) reported they had not received any help.

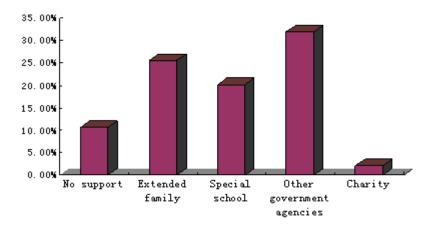


Figure 9 Source of the most effective help perceived by Chinese families

## The content of the most effective help perceived by Chinese families

Among 84 families who reported the helps they had got, 55 families had specified both what the help was and where the help was from. The following table 20 presented more concrete information about the content of help.

**Table 20.** The most effective help perceived by Chinese families

### The most effective help perceived by Chinese families

- Providing opportunities for children to go to school (15 families)
  - e.g.: "we are very grateful for the support of government because our child is offered the opportunity to go to special school." (B24)
- Encouragement, understanding and comforts from spouse, extended families, friends and relatives. (15 families)
  - e.g.: "It was my parent's comforts that help me and my husband to follow through the sorrow of having a hearing impaired." (D2)
- Teaching children their parent sign language and providing speech therapy (10

#### families)

- e.g.: "On every Friday, the special school teaches parents sign language." (C28)
- Economic support by reducing the tuition, providing free of charge compulsory education, other economic subsidy from government, and economic support from extended family. (9 families)
  - e.g.: "The best help from the government is the compulsory education for children free of charge." (B26)
- Funding the cochlear implantation partially or completely. ( 5 families)
  - e.g.: "We are very grateful for the National Cochlear Implants Programme, otherwise it is not possible for my son to use the cochlear implants timely and learn to speak." (D29)
- other help: information etc. (2 families)
  - e.g.: "Information about hearing impairment and cochlear implants" (D28)

# The most effective help perceived by Czech families

48 Czech families presented the responses to the question of the most effective help they had got. Three families were excluded from the range of analysis because of their over-extensive responses such as "special help", "hope and love", "everything". Also some families offered more than one responses. For example, one parent wrote

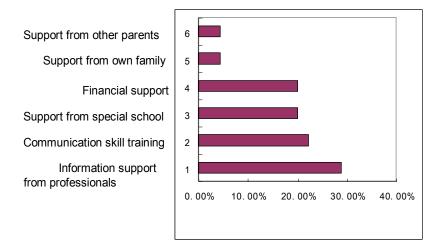


Figure 10 The most effective help perceived by Czech families

in questionnaire: "We get help from speech therapy, learning sign language and being included into deaf community). To keep the internal coherence throughout the whole study, only responses listed first were considered in statistical analysis. Because the responses were diverse and lack of focus, the 45 families' responses were grouped into six categories: 1 information support from professionals such as doctors, teachers, psychologists (13 families, 28.89%); 2 communication skills training such as speech therapy and sign language learning from special (deaf) center (10 families, 22.22%); 3 help from special school (9 families, 20%); 4 financial support for sensory device and associated services from insurance (9 families, 20%); 5 support from other parents (2 families, 4.44%); 6 support from their own family (2 families 4.44%).

The detailed information about support and the source of support was further reflected in figure 10.

Obviously there existed some apparent differences in the content and source of the help or support perceived by two groups of families. For Chinese families, considerable number of families emphasized the help from Government-funded organization, for example, special schools or rehabilitation center. From their view of points, the best help was providing schooling opportunity for their children. In contrast, information support from professionals was more highlighted by Czech counterparts than the support of providing opportunity to attending special school although Czech children get longer duration of compulsory education free of charge. The reason for this result will be discussed in the following section. In general, although Chinese families raised and educated hearing impaired children within circumstance of inadequate support, they demonstrated stronger feeling of being helped.

As a result, the research hypothesis of H<sub>8</sub> that there exists difference in the most effective support perceived by families while parenting their children between two family groups was accepted.

## **Research question 9**

Does there exist difference in family describing their children between two family groups?

98 families from China and 44 families from Czech present various kinds of description about their hearing impaired children. Those responses were mainly description of children's personality characteristics and their personal interest. Despite the questionnaire only asked informants to describe their children with three sentences, many families presented more than 3 sentences. Similar to the way of dealing with responses used previously, in this question only the first response in every sentence was considered as valid response. At last, 289 descriptions from Chinese families and 131 responses from Czech families were drawn out from the overall responses to be discussed further. Analyzing the content of responses, most of descriptions were adjectives used to depict personality characteristics while other response mainly involving the description of personal interests and hobbies. According to the nature of descriptions, they were classified as two types of the positive and the negative. Also the frequencies of adjectives were listed in the parentheses. The more specific information about which words families used was illuminated by the Table 20.

Furthermore, according to whether the number of positive descriptions is more than negative ones, the families are divided into positive families and negative families. Amongst 98 Chinese participant families 20 families are those who are with more negative descriptions than positive ones while 78 families with more positive descriptions. Similarly, amongst 44 Czech participant families, six families are negative families with more negative descriptions while 38 families are with more positive descriptions. Generally, Czech families have higher proportion of 86.36% positive family comparing with proportion of 79.60%.

Additionally, most of Chinese families presented detailed explanation why they used some negatives words to describe their children. For example, a dozen of families or more present further reasons for their description of children's being hot-tempered. According to their words this kind of negative personality characteristic was largely connected to children's difficulty with communicating with people surrounding them. As a specific example, a mother (D16) stated in the questionnaire, "My child is very lovely, except for deficit in hearing loss, he develops well in other areas; He is lively and like watching cartoon; sometimes however when he can not

make himself understood by others, he becomes hot-tempered and bad-tempered."

**Table 21.** The descriptions which families used to describe their children

	Positive de	Top ten		
State	Top ten personality characteristics	Interests and hobbies	negative descriptions	
	intelligent(20)	dancing (8)	hot- tempered(12)	
	sensible (18)	sports (7)	unable to hear and speak (10)	
	sociable (17)	watching TV (7)	disliking playing with normal	
	obedient (16)	drawing (5)	children (10)	
	doing housework (12)	constructive play(2)	difficult with communicating	
China	lively(10)	rope-skipping(2)	with others (7),	
Ciliia	naughty (9)	playing toy car (2)	aggressive (6),	
	lovely (6)	paper-folding(1)	developmental lag (5)	
	studious (5)	taking picture(1)	eccentric(4),	
	caring (5)	playing game(1)	disobedient(4),	
			dependant(3),	
			stubborn(3)	
	intelligent (19)	good at handwork (3)	Hyperactive(3)	
	sociable (9)	sports(3)	emotional (3)	
	friendly (7)	painting (1)	slow in response (2)	
	kind (7)	reading (1)	dependant (2)	
	sensible (4)		stubborn (1)	
Cl	independent(4)		arrogant (1)	
Czech	do well in study (4)		feeling regretful for himself	
	happy(3)		living in his own world (1)	
	hard working (3)		trouble-making (1)	
	goal-seeking (3)		feeling nervous while not	
	extroverted(1)		understanding what others	
			say (1)	

From the data in the table 21, more commonalities than differences in describing their children can be found between two family groups. Both groups of families used more positive words than negative words. Also both family groups emphasized the personality of intelligent, sociable, sensible etc. In general, as a result the research hypothesis of H<sub>9</sub> that there exists difference in family describing their hearing-impaired children between two family groups was refused.

### 4.2 Result of qualitative interview

This part of study was the follow-up of the comprehensive questionnaire above discussed and it aimed to better explore process of adaptation which was less amenable to quantitative comparison. All the results were uniformed in the research question 10 and there no predetermined hypothesis for this question because of its qualitative nature.

## Research question 10

How the resilient Chinese families experience the process of adaptation to the childhood hearing impairment?

# 4.2.1 Characteristics of respondents

According to the research design the main caregivers of children from resilient families judged by their responses in the questionnaire of families with hearing impaired children were invited to participate in the face-to-face semi-structured interview after the analysis of questionnaire responses. Simply put, in this study the resilient families should satisfy the following requirements: 1) accepting well--up till to the time of participation family accepted child's hearing impairment basically and felt peaceful in family; 2) functioning well- involving keeping intact and trying best to meet the members' economic needs, daily care needs, affection needs, educational needs (doing everything affordable and possible to promote children's potential development); 3) expecting well- believing in child's future, believing in family ability to deal with the future potential problems. To be more specific, the level of outcome of adaptation to childhood hearing impairment in questionnaire should be higher than average score 3.97. According to these requirements, ten families were selected and only eight of them would like to take part in the interview with consent because time constraint and personal interest. They were from two educational agencies, the Chengdu Rehabilitation and Education Center (CREC) for disabled preschooler in Chengdu, the capital city of Sichuan Province, and Luxian Special School in Luxian, an agricultural county in Sichuan Province. Among eight families, four of them lived in rural area, two of them were from urban area, and the left two families lived in suburb between urban area and rural area. For the convenience of respondents, all interviews took place in special school or rehabilitation center where the respondent caregivers sent child to special teachers or trainers. The caregivers were encouraged to share their perspectives according to the level of comfort and to focus on the issues of importance to them based on the experience in caring for their child. In order to be confidential and to be convenient for further analysis, the eight participant children were given pseudonym of Bao, Hang, Shuai, Mnan, Wang, Lulu, Luhua, Qiqi. The key demographic and clinical characteristics of the respondent

**Table 22.** Characteristic of participant children in interview study

Name	Age	Gender	Degree of hearing loss	Age at diagnosis	Sensory device	Communication method
Bao	53months	Boy	100dB	6 months	HA & CI	Oral
Hang	45 months	Boy	>90dB	12 months	HA & CI	Oral
Shuai	58 months	Boy	>110dB	45 months	НА	Mixed
Mnan	37 months	Boy	>110dB	20 months	НА	Natural gesture
Wang	48 months	Boy	>110dB	25 months	CI	Oral
Lulu	72 months	Boy	not clear	12 months	None	CSL
Luhua	132 months	Girl	not clear	12 months	None	Written and CSL
Qiqi	92 months	Girl	110 dB	13 months	НА	Natural gesture

Note: HA=Hearing Aids; CI=Cochlear Implants; Mixed=Natural gesture plus spoken language, CSL=Chinese Sign Language

**Table 23.** Demographic characteristics of respondent families in interview study

Name	Caregiver	Parental hearing	Community type	Educational attainment	Family income
Bao	Grandma	Normal	Urban	University	Middle
Hang	Grandma	Normal	Suburb	Middle school	Low
Shuai	Aunt	Normal	Rural	Middle school	Low
Mnan	Mother	Normal	Urban	University	Middle
Wang	Grandma-in-law	Normal	Suburb	Middle school	Low
Lulu	Mother	Normal	Rural	Middle school	Low
Luhua	Mother	Normal	Rural	Middle school	Low
Qiqi	Mother	Normal	Rural	Middle school	Low

Note: educational attainment =highest educational attainment among family members.

families and their children were detailed in Table 22 and Table 23.

#### 4.2.2 Results of interview

Based on the developmental process of families experiencing children's hearing impairment, the findings of this study were formulated into the following themes: diagnosis and family reactions to the diagnosis, the meaning of childhood hearing impairment as a significant risk, rationale for decision making in communication mode sensory device and educational placement, strategies of family used to cope with children's handicaps in terms of the shared experience from the main caregivers of eight participant families.

## 4.2.2.1 Diagnosis and family reactions to diagnosis

## Diagnosis and drive force for diagnosis

Early and accurate identification of hearing loss is critical to the child's overall development and family adaptation to childhood hearing impairment. All respondent families expressed the view that newborn hearing screening services should be desired to be an important part of overall support services for children with hearing loss. However, in reality the diagnoses or identifications of hearing loss in eight families proceeded with in their own way differently and were driven by different forces.

Parents were often the most effective identification sources. Luhua, the eldest child of among seven children, who was 11 years old from the Luxian countryside, her hearing loss was identified around her one year old because of her responsive mother. "I felt she had problem in hearing by intuition. She appeared to have no response to my voice. So I and my husband sent her to the affiliated hospital of Luzhou Medical College" she stated, "but up till to now, I did not know exactly the degree of hearing loss. I simply remembered that the doctor told us 'your child has severe hearing loss'" Like Luhua, the hearing loss of Lulu and Qiqi was also firstly identified by his parents because of their having no response to sound and diagnosed in hospital after one year old.

Mnan's mother shared her suspicion and made a slight complaint against the

doctor's suggestion with the interviewer: "I had some suspicion about his hearing around his age of one and half years because he can not speak. Then I went to the local hospital near my home and told the doctor my suspicion of his lag in language development and communication problem with us. After simple observation and comparison with behavioral checklist of autism, the doctor simply told me that he had no sign of autism and let me go on with observing his behavior. With the hope that he was just a boy opening mouth later, we delayed his diagnosis till he was two years old."

Both Wang's grandma- in-law and Shuai's aunt recognized the two children's hearing loss earlier by their experience of parenting children, yet because of their parent's self deceiving the diagnosis of two children's hearing loss were delayed. As Wang's grandma-in-law recalled: "when I told my suspicion of Wang' hearing loss to my son-in-law and my daughter, they self-deceived themselves that both of parent are normal, there was no reason for his deafness. At last, supported by the more apparent signs of no response to human voice and no locating reaction to sounds, more importantly, moved by my determination, the diagnosis was implemented when he was 25 months old."

With the emergence of implementing newborn hearing screening in China after entering new century, some children benefited from such new technology revolution. Both Bao and Hang' were screened as positive in hearing loss which was one part of newborn disease screening paid by family at their birth. At last Bao's hearing loss was diagnosed accurately when he was six months old while Hang got his diagnosis when he was twelve months old.

Putting together the data many factors can be found to contribute to the time of diagnosis of children hearing loss. There is no doubt that hearing technique is important factor, but more important drive force for early diagnosis is responsiveness of caregivers and attentions paid to children's health.

## Family reactions to the diagnosis

Eight families in this study were families of parents with normal hearing. Children's hearing losses were completely unexpected to them and created rigid family risk. Though some families had some suspicions of children hearing loss earlier, all eight families demonstrated various kinds of intense negative emotional reactions to the diagnosis. For example, when Hang's grandma was asked how her family reacted to the diagnosis, she stated: "The whole family was overwhelmed with the bad news and all the families members, father, mother, and grandparents, wept their heart out." Further she explained: "It was unfair, our families didn't do anything evil, why we were punished by being given a child with such a handicap?" According to the parent experience, the most salient reactions of eight families and the focus reasons for their reaction were detailed in Table 24.

**Table 24.** The most salient reaction to diagnosis and the focus reason

Family/a nama	Most salient reaction	The focus reason for reaction		
Family's name	to diagnosis	The focus reason for reaction		
Bao	Despair	All family members have no experience with deafness		
Hang	Grief	It's unfair, why we are given a child with deafness		
Shuai	Denial	The child will be normal over time		
Mnan	Shock	We have some suspicion but the diagnosis beyond my		
		expectation		
Wang	Anger	Why our child is abnormal while others not		
Lulu	Grief	Deafness means both child and parent have no future		
Luhua	Grief	Both our families have no history of deafness and it is		
		shameful to speak to others		
Qiqi	Collapsing	Why our fate is like this?		

# 4.2.2.2 Childhood hearing impairment as a significant risk for family Families' perception of meaning of childhood deafness to family

As a chronic health condition, the impact of haring impairment can not end at particular time point. After several years struggling with childhood hearing impairment, what it meant for these families to have a child with such handicap? When eight participant families were asked to use one sentence to describe how they

view childhood hearing impairment, their answers were associated with the meaning making of childhood deafness explicitly or implicitly. Overall, all of these Chinese families held the experience that the childhood deafness created a significant risk for families which is related to intense stress level and multiple family difficulties and immersed the families in the negative emotional climate (see Table 25)

**Table 25.** Sentences used to describe the meaning of childhood hearing impairment

Family's name	The sentence used to describe the meaning of childhood deafness
Bao	It is really a challenge, but not a tragedy.
Hang	It means all families must live a hard life
Shuai	It means more money demand, more money is beneficial for his future
Mnan	More responsibility, duties and burden
Wang	It is the debt we owed in the preexistence, we must pay back.
Lulu	It means more money and time demand, I feel depressed whenever when I think of his deafness.
Luhua	It is lasting worry all our lives and eternal pain for me and my husband.
Qiqi	It means I must take care of her till to the time of my death

The responses from families above listed demonstrated that having a child with hearing impairment was still a stressful event in their life. However, what specific difficulties and additional burden beyond normal difficulties and challenges they have experienced constitute another important issue to be addressed in the interview research.

#### Difficulties families have experienced while parenting the children

While the author of this dissertation working with the data of conversations, the main issue or theme that kept coming out in the mind was "difficulty" and experiencing difficulty was a constant day-to-day affair for the eight families. As the interviewer stated and recalled the impression of conducting interview, "the deepest impression of interview was that all participant caregivers looked fine and strong on the outside, but when they sat down to talk, all caregivers wanted to cry." Indeed, every difficult family was difficult in its own way.

### Difficulty in communication with children

Because of the direct impact of hearing loss, eight caregivers expressed the more or less frustrations with communication with children. For Shuai, who was 58 months old, with profound hearing loss, but without systematic learning of sign language and without help of appropriate hearing device, his aunt described a large amount of experience about their communication difficulties: "sometimes he could understand what I said, sometimes he could not. Because of his severity of hearing loss, most of time he could not hear what I said. We used natural gesture and guess to communicate. It was more difficult for him to express his ideas. Every time when he understood what I said, he would nod with smile. But when he did not understand what I said, or when he could not make himself understood by me, he was angry and bad-tempered. I often got frustrated when I saw my nephew being frustrated." For Mnan, who was 37 months old, the youngest of seven children, his mother was planning for his use of cochlear implants to address the problem of communication. She stated, "After his hearing loss was diagnosed, we firstly considered his use of hearing aids. But till to now, it did not work well. At present I used natural gesture to communicate with children. Because he was very young, he could not hear well, speak well and understand well. Sometimes he understood the simple things I said, but for more complicated meaning, he had difficulty. When I had to tell something important to him, I used body language to let him understand or teach him hand by hand and force him to exercise again and again." Similarly Qiqi's mother said, "Although she used hearing aids, but it can not work. Both her sign language and mine are limited, when I can not make me understood, I am very sad." Lulu's mother also commented the hardship of communication with children. But with the growth of children, new communication means of the written language to be used in communication. Luhua's mother mentioned improvement in communication between them by writing, "When Luhua was young, I experienced the frustration with communicating with her. But after she attended special school, he learnt sign language, and she taught me the sign language, so we can communicate more complicated meaning. Now she could write, we often used writing to express our ideas, so we felt communication between us

easier." For three children with cochlear implants, their communications were in different context. Bao, who was implanted cochlear implants (CI) at the age of 22 months old, with the time of 31 months use of CI, having going through the long time of adaptation to CI and hearing speech training, he could understand the majority of what parent and teacher said. For Hang and Wang's families, they were struggling with exercising hearing and speaking to benefit more from hearing and speech training after the average 18 months of use of cochlear implants.

# Difficulty in family economy

Even in western developed countries, some families report difficulty meeting the financial demands related to equipment or service including the cost of sensory devices, therapy, and early intervention programs etc. (Jackson et al., 2008). For the eight Chinese families from China, economic burden was a frequent difficulty of families experienced following the communication difficulty.

Bao was a boy from a middle income family. His parents had job with stable income, and his grandparents could get pension because of retirement from the work. But the financial burden resulted from his hearing loss almost put his family into poverty. When asked the details of the money spent by his grandson, Bao's grandma recalled: "firstly, my family paid the expense of newborn screening including hearing screening, then the family pay the money for the comprehensive audiological evaluation. I could not remember the exact money because it was paid by my son. After audiological evaluation, as a result of doctor's suggestion, we spent 15,000 RMB (about 1500 €) to buy hearing aids for Bao. But Bao did not benefit from this expensive device and he still had no any response to sound stimuli. Afterwards we were told that maybe cochlear implants could work. However it was much more expensive than hearing aids, with price ranging from more than 140,000 to more than 200,000 RMB (about 14,000 to 20,000 €). Despite the price was far beyond the family saving, but with the belief that we should do everything we can to maximize Bao's development, we decided to sale our house for it. It was really lucky that later Bao became one of qualified targets of National Cochlear Implants Program organized by the China Disabled Persons Federation and funded by Mr. Wang Yongqing, a famous industrialist from Taiwan. My family only paid more than 40,000 RMB (about 4,000 €) for service related to cochlear implants operation and consequent hearing and speech training. However, comparing the money spent with our income, we still regarded it as a large amount expense."

Not as fortunate as Bao's family, Hang's family was deep in debt because of Hang's use of Cochlear implants. According to the description of Hang's Grandma, when he was born in hospital, he was given newborn hearing screening and was tested as positive in hearing loss. When he was one and half years old, he was sent to hospital to test hearing loss and was diagnosed with profound hearing loss of more than 110 dB. To help Hang's hearing, his family rent a hearing aid from the Chengdu Rehabilitation and Education Center with a small amount of money. But hearing aids did not bring any gain in hearing. They were then told that cochlear implants maybe help Hang. At that time, the cochlear implant made by Australia was well-known in local deaf community and its price was 148,000 RMB (about 14,800 €). Compared with the average overall income of 10,000 RMB (about1,000 €) annually, the cochlear implants was far beyond the family's financial affordability. However, the family still firmly made up their minds to implant the cochlear implants with the belief that they would do everything beneficial to their child at all costs. With the allowance of 56,000 RMB (about 5,600 €) from the Chengdu Disabled Persons Federation, eventually the family cost 92,000 RMB (about 9,200 €) for the operation of cochlear implant in 2008. Most of the money was borrowed from their relatives. One child's hearing loss let the whole extended family fall into debt.

Wang's family had similar experience to Hang' family. At present they were in heavy debt because of using cochlear implants. As for other three families, namely, Mnan's family, Lulu's family and Luhua's family, their economic conditions were depressed by children's hearing loss to larger or less extent. As main caregivers and mothers of three hearing impaired children, they had to stay at home to take care of children with the notion that hearing impaired children were more dependant on parental care than hearing peers. Because of only one breadwinner in families, the family income reduced. As Lulu's mother stated: "I could not go to city together with

my husband to earn money like other mothers. My husband worked in city as a migrant worker all the year. He was the only breadwinner in my family. Because of my son's deafness, I could not leave him to his grandma. So my family economic condition was worse than other families who had more people to earn money in this village." The only family unaffected apparently by child's hearing impairment was Shuai's family. His family rented hearing aids from the CREC. His father had applied for National Cochlear Implants Program for him, but was rejected eventually. At last he gave up the idea of implanting cochlear implants to his son because he thought it was not cost—effective.

In sum, the economic difficulties were mainly due to three reasons: the first was expense for purchasing sensory devices for children, cochlear implants or hearing aids; the second was expense for hearing-loss-related medical diagnosis and treatment, and associated services; the third reason was that one of the parents, mainly the mother, had to stay at home to take care of the child and the financial situation of a family dramatically worsened compared to the situation when both spouses contributed to the family budget.

# Difficulty in access to intervention services

Due primarily to the large population of the country and the associated financial constraints China was facing there were few intervention programs which provided services, for example, information about hearing impairment and sensory device, funding sensory devices, social support to help family accept hearing loss, teaching sign language, etc. for the hearing impaired children and their families, if any, they were far from being accessible. In this study, Lulu, Luhua, from rural area, had never used hearing aids and cochlear implants despite their profound hearing loss, and their families reported they had never get any free social support from governmental agencies and professional institutions. Qiqi, despite her access to donated hearing aids, but due to the quality of the hearing aids itself or lack of associated services, hearing aids was one kind of ornaments which was of no practical use to her. These children only could communicate with people surrounding them by sign language after they learnt in special school. Mnan's mother was worrying about the surgery of cochlear

implants for his son but she only could get some information from parents. The main regular intervention services that the other four families from Chengdu city could get were hearing aids for rent and hearing-speech therapy provided by CREC for disabled children. But the service of hearing-speech therapy was not easy accessible for Hang's family and Wang's family who lived in suburb and Shuai's family who lived in rural area. Hang's grandma shared her tough experience with interviewer, "because my family fell into debt for cochlear implants, all family members had to save money as much as possible. It was valuable that CREC could provide the associated hearing and speech training after cochlear implants, but it was extremely far from my home. On every Monday to Friday, I and Hang got up at 6 o'clock and walked one hour to bus stop, then after one hour's bus trip we could got to CREC to start training. When Hang received training, I either stayed at rest room or went out to wander in streets. Then at 4 o'clock in the evening we went back home following the same path. This life was hard, but it had lasted for more than one year, so we were already accustomed to it."

# 4.2.2.3 Rationale for decision making in communication mode, sensory device and educational placement

Raising and educating children with hearing impairment mean parent must make additional decisions in sensory device, communication mode, and educational placement. It had been commonly recognized that childhood hearing impairment created additional family difficulty with making decision in communication mode, sensory device and educational placement. According to the previous related researches, the factors influencing decision making were mainly from parents' desire, information and health and safety concerns (Jackson, 2008). Working with the conversions, the common parents' desire which underpinned the family decision was that these families would like to do everything they could at all costs to maximize children's development. As an example discussed earlier, Hang's family resolved to implant the cochlear implants for Hang despite it made the whole family fall into debt.

With respect to making decision in communication mode, it was demonstrated

that no family mentioned the difficulty in making decision in choosing communication mode. All families expressed the common desire to maximize their children's hearing and speaking ability. When these caregivers were asked to detail how they dealt with the difficulty in communication between them and children, five caregivers told interviewer that their families insisted on using spoken language mixed with natural gesture to communicate. As stated in Shuai's grandma' words, "The hearing and speech training provided by CREC was in the form of oral mode, we must help Shuai exercise it at home. So we tried our best to communicate with him in spoken language." While these families attempted to improve their children's hearing and speech ability, Lulu's mother had taken initiative to educate herself sign language by reading book Chinese Sign Language, Qiqi's mother were trying to learn more sign language from special school and the older children, Luhua could taught her mother using sing language to communicate with her. In this study, no family really mastered sign language to the degree of communicating with children fluently, however, it seemed natural for these families choosing sign language as their communication mode when there is no possibility of their children using spoken language.

As for the choice of educational placement, the decisions appeared to be dependant on the sensory devices used. All families expressed it was ideal for their children to go to normal school and meanwhile they all reported it should be more wiser decision for their children to attend special school when children can not communicate with their peers and teachers by normal spoken language. Four families of younger children using or planning to use cochlear implants expressed a consistent comment that regular school was better placement than special school. To a larger extent this consensus could be put down to lack of understanding of special school. As Wang's grandma said, "I did not know special school and I felt it was not good. I never thought of sending him to special school." Mnan's mother emphasized that the purpose of implanting cochlear implants was the opportunity to attend regular school. She stated, "Regular school was certainly better choice for my children. But if he could not get good hearing by cochlear implants, the special school was acceptable.

Yet in that case, the money we spent in cochlear implants was wasted." In contrast, four families of children without using cochlear implants had another consensus. Luhua's mother said, "The special school was beneficial for my daughter. There she has learned sign language and got literacy. She also could communicate with peers with similar experience in special school." Similar to Luhua's mother, Shuai's aunt, Lulu's mother, Qiqi' mother emphasized the importance of attending to special school. As stated in Qiqi's mother words, "Special school is better for Qiqi, because she can not hear and other children don's know sign language, certainly she will meet communication difficulties, and have low self-confidence." In their opinion, the best choice in educational placement for children who could not communicate by oral approach was special school where they could communicate with sign and got education appropriate to them.

With respect to decision making in sensory devices, it was another complicated story. Five of eight children had ever used hearing aids. Bao's family had bought hearing aids for Bao, however it did not work, afterwards they decided to use cochlear implants. Hang, Shuai, Mnan had ever rented hearing aids from Rehabilitation center, but their caregivers reported it did not work either. Qiqi had got donated hearing aids, also it did not improve her hearing. This condition of hearing aids not functioning partially was due to their severe hearing loss, partially due to the quality of the hearing aids or lack of associated service to teach family using the hearing aids.

For three families of children using cochlear implants making decision in sensory implants was also not fully evidenced-based. Lack of appropriate information from professionals, they made decision by trial and error and experiences from other parents. When asked why at last they chose cochlear implants as sensory device, the explanation from Bao's grandma and Hang's grandma answer was: "It was result of trial and error. When hearing aids could not work, we only could choose cochlear implants. We were not sure its effect, but it was the last hope." However, Wang's family was another case. Wang's grandma stated, "Wang did not go through tryout of hearing aids before he was implanted cochlear implants. When we first time went to hospital to diagnose his hearing loss, we had met and talked with a parent of child

who firstly used hearing aids and then was implanted cochlear implants when hearing aids did not bring great gain in hearing. When we went to hospital second time to get diagnosis we met another parent of child with cochlear implants and asked its effect, we were told it was not ideal but better than nothing. After that Wang's father searched some information from internet. At last, the family decision was made that cochlear implants would be implanted without trying of hearing aids to avoid the money being wasted." When participating this study, Mnan's mother was considering his son's surgery of cochlear implants and had somewhat worry about the invasive nature of surgery. However, regardless of her health and safety concern, her decision had been firmly made. Taken together, the main factor which contributed to the decision making in cochlear implants was the family financial status. As Wang's grandma stated simply, "If family have money, implant cochlear implants; if family have no money, let him/her attend special school." In her opinion, thing was simple like this, cochlear implants means normal hearing and going to regular school.

In sum, the rationale for Chinese families' making decisions in sensory devices, communication mode, educational placement largely depends on the family economic status, the access to intervention services, the information from professionals and parents etc. Generally, due to lack of adequate information support, the poor family economy status and no easy access to intervention services, there is little possibility for these families to make informed decisions.

#### 4.2.2.4 Strategies of family coping with childhood hearing impairment

Living within a social context which was of no solid social security system, these Chinese families used their unique strategies to deal with various life challenges or difficulties caused by childhood hearing impairment. Although the childhood haring impairment, especially severe or profound hearing loss, was difficult to accept for these Chinese families who held high expectation for their children, finally they accepted and got control over it. The following storyline was demonstrated by integrating the relevant concepts appeared in the conversations.

Bao's family was the most resilient case among the eight families according to the understanding of resilience previously discussed. This family completely consisted with the standard of accepting well, functioning well and expecting well. When Bao's grandma was asked how her family went through these years, she elaborated their experience of restructuring their family to gear toward optimizing Bao's potential in behalf of her family. She stated with a bit pride: "In the early time when we were told the diagnosis we really felt the sky collapsed. We embraced together and cried. He was the only child in this extended family. We felt extremely unprepared for his hearing loss and uncertain about his future. Fortunately my family was closely connected. My son and my daughter-in-law never quarreled for child's hearing loss. To reduce their time demand I and Bao's grandpa took initiative to be responsible for taking care of Bao's life while my son and my daughter-in-law went on with their work to earn more money. Before the child was born, my daughter-in-law had planed to stay at home to care her child by herself after child's birth. Things changed greatly because of hearing loss. Firstly we were overwhelmed with unexpected handicap, then with the challenge of a large amount of money for hearing aids and followed by hearing aids' failure. More fortunately, we were informed the National Cochlear implants Program by the CREC and got the donated cochlear implants after his passing multiple examinations including intelligence test, hearing and speech test and test of adaptability to cochlear implants. After using cochlear implants, Bao also could go to the CREC to receive free service of hearing speech training on week days. Over years all family members tried our best and didn't miss every opportunity for the good of Bao. In the daytime of every weekdays his parents go to work while I and his grandpa take him to go to park or go to CREC to receive hearing and speech training. At night his parents help him exercise what he has learnt at center and we couple could have a sound rest. This process was not easy but fruitful. Before Bao attended regular preschool he was assessed by the professionals in CREC as a top hearing-impaired child with high intelligence, second grade of speech ability, a degree which is understood as with capability of communicating with people around them basically. Speaking of Bao's almost typical level of development, we really wanted to express thanks to those who gave us help. They were CREC and their teachers in CREC, those parents with similar experiences

to us, our neighbours and relatives, Mr. Wang Yongqing who donated the cochlear implants, and all families members who stood together to turn the tragedy into comedy. We all hoped that Bao would be contributing member to redound upon society."

Other Six participants expressed the similar experience of difficulty in parenting and at last adapting to the challenges positively. Wang's grandma-in-law accepted Wang's handicaps as her family's destiny. "His coming to the world was asking us to pay the debt we owed in previous existence. Now all the families were working together to earn more money for clearing debt due to cochlear implants and preparing for his future." Hang's grandma accompanied by Hang had been walking in the long distance between CREC and their home day after day while Hang's parents were busy with earning more money for his future life. Shuai's aunt repeated again and again that Shuai's parents should devoted more time to take care of their son by themselves. However, Shuai's parents were occupied with their business with belief that enough money could guarantee Shuai's security in future life. Mnan's mother did not worry about family economy because of higher income from her husband and she was planning the operation of cochlear implants for her son with optimistic expectation that cochlear implants would help Mnan greatly. Lulu's mother from countryside were educating herself Chinese sign language by reading book- Chinese Sign Language- to overcome the communication barrier between her and her son. Similarly, Luhua' mother, also from countryside, felt gratified with her daughter who had learned sign language in special school and could communicate with her fluently using language and writing. Qiqi's mother had become more optimistic while parenting her hearing impaired daughter. When she was asked how she accepted her daughter's hearing loss, she stated, "Now I feel much better than before, not as pessimistic as before. No matter what condition it is, the life will go on. Looking at children in earthquake area, they have lived bravely with their disabled body, and I should not complain my life. Despite she is deaf, however she has normal body, can eat and dress normally. Nevertheless, returning to our topic, parenting this child need spend more energy and efforts." Generally, all these families went through the hoops and were functioning

well. Despite they all worried about their children's future, they all believed that their children should have their own future.

More specifically, the eight families used various kinds of strategies to cope with the reality of having a child with hearing impairment. The strategies which these families used to cope with life challenges were categorized into strategies of shift in focus of family life, accepting what can not be changed, cooperative parenting, making using of social resources, taking concrete steps towards goals.

Shift in focus of family life. Following the intensive emotional reactions to the diagnosis of children's hearing loss in the early days, several families had experienced the common shift in focus of family life to adapt to the reality of having a child with hearing impairment at home. Generally all the shifts geared their families towards experimenting with various kinds of methods to help child hear and maximizing the children's potential. For example, Bao' grandama stated, "Before Bao was born, all my families were considering how to earn more money and live better life. After the diagnosis of his hearing loss, the life focus of all of us was changed to look for methods of helping him hear." Similarly, Wang's grandma-in-low described, "After we knew the result of diagnosis, we immediately began to ask about cochlear implants". Qiqi' mother said to interviewer, "After diagnosis, we do not believe in it. We had gone to many hospitals try to cure him by medicine, but it did not work. We also used some superstitious activities, it did not work either. Now we had to work hard to earn more money for his future." Mnan's mother commented, "Before we knew his hearing impairment, I tried to go to work and improved my quality of life, after his hearing impairment was diagnosed, I chose to stay at home taking care of him, taking part in his therapy and education."

Accepting what can not be changed. All but one caregiver expressed complete acceptance of children's hearing loss. Seven families explained the reason for their acceptance. Bao's grandma stated, "Although his profound hearing loss let us in hot water in the early days, eventually his loveliness and striking progress after using cochlear implants let us out of it. Now I did not think it was very bad thing." From another prospective, Hang's grandma explained her acceptance. She stated, "Now that

it was our fate, we just accepted it." Similarly, Lulu' mother felt children's handicap was his destiny. Mnan' mother and Luhua's mother shared the same idea, as they stated, "It is the irreversible reality, you can not change it but just come to terms with it." Qiqi's mother stated, "Despite of her hearing impairment, she is my daughter. Now that it is my fate, I accept it. Looking at the children disabled in earthquake, she has leg and hand, why not be more optimistic?" Only Wang' grandma reported the partial acceptance of her grandson's handicaps, as she described, "Sometimes when I felt tired, I could not accept it. But I knew accepting reality was helpful for all of us."

Cooperative parenting. The category of cooperative parenting discussed here meant two or more caregiver taking part in fostering children. In terms of the shared experience from participant families it greatly reduced the increased time demand and physical fatigue resulted from additional burden of caring handicapped children. In this study, five of eight hearing-impaired children were co-fostered by parents and caregivers from their extended families. Only Lulu, Luhua and Qiqi from therural area, were mainly brought up by their mothers while their father, the main breadwinner of families went to cities as migrant worker to earn money.

Mobilizing social networks. When asked what supports from social networks families had got to help them cope with the children's hearing impairment, Bao's family and Hang's families reported the financial support from government organization represented by local Disabled Persons Federation and associated speech therapy, Qiqi 's mother reported she had contact with other parents and got some emotional support from them. The other five families expressed that they did not get adequate support from social networks which were understood by participants as public welfare agencies. In fact, all eight families utilized more or less supports from inside and outside of families demonstrated in their conversations. Analyzing their experience, families had got economic, emotional, and parenting support from extended family, relatives, other parents with similar experiences, rehabilitation center (CREC), special schools, regular preschools. Table 26 detailed the main sources of support which families had got.

**Table 26** The main social resources of support which families had got

Social	Qiqi's	Bao's	Hang's	Shuai's	Mnan's	Wang's	Lulu's	Luhua's
resources	family	family	family	family	family	family	family	family
Extended families		•	•	•	•	•	•	
Relatives		•	•		•			
Other parents	•	•	•	•	•	•		
Rehabilitation center		•	•	•	•	•		
Special school	•						•	•
Regular preschool		•						

Focusing on goal and taking concrete steps. All eight families held the hope that their children would not have a not very bad future and could survive, be independent on others in adulthood. In order to reach their hope, all families took their own steps. The common point across families was earning more money for children's future. Others concrete steps included buying or renting hearing aids, implanting cochlear implants, implementing family training, participating in hearing and speech training, learning sign language etc. Table 27 listed the concrete steps families taken toward children's future.

Table 27 Families' steps taken towards children's future

Steps	Qiqi's	Bao's	Hang's	Suai's	Mnan's	Wang's	Lulu's	Luhua's
towards future	family							
Using hearing aids	•	•	•	•	•			
Using cochlear implants		•	•			•		
Family training		•			•			
Hearing and speech training		•	•	•	•	•		
Learning sign language	•						•	•

Earning more money • • • • • • • •

As a result, we can see that the childhood hearing impairment adversely and completely impacted on the life of the eight families. However, the eight families still kept family intact, after intense negative emotional reactions they learnt to come term with it, got more acceptance and did everything affordable and possible to promote their children development.

#### 4.3 Discussion

### 4.3.1 Family positive adaptation to child's hearing impairment and influential factors

The findings of the present study suggest that two group of families from two different social contexts were resilient with positive adaptation to the challenges of parenting their child with hearing impairment based on the conceptual framework of family resilience as a systematic structure consisting of significant risk of childhood hearing impairment, the transactional process of risk factor and protective factor, and the good outcome positive adaptation. Firstly, childhood hearing impairment constituted the significant risk to families due to its impacts on family life by increasing financial burden, strong feeling of fatigue and influencing parent-child communication etc. This result generally was consistent with past studies. For example, as argued by Hintermair (2000b), when reviewing the relevant literature, it was found that any disability, whether it will be mental or physical, was unanimously regarded as a considerable stress potential for the parents. However, despite the risky exposure to childhood hearing impairment, the families from two countries have scored 3.97 point, a higher score than the boundary value of 3 point between positive and negative adaptation in the outcome of adaptation. It meant that family basically accepted the reality of having a child with hearing impairment, functioned well by keeping closer family relationship and not deteriorated marital relations, having made best efforts to promote their child's communication and learning, furthermore, expected well for child's good future and belief in family's ability to deal with future

problems despite exposure to the severe negative impacts of hearing impairment. This result of positive adaptation was further validated in families' positive description of their children. 81.69% families had used positive words to describe their children personality and behavior. As one parent stated, "he is normal child, only difference is he can not hear." This finding provided strong evidence with researchers and practitioners that although family life will be influenced intensively by childhood hearing impairments, however there is good reason to believe that hearing impairment do not create any insurmountable obstacles to family positive life.

The further analysis of correlation between the level of adaptation and social stigma, family characteristic, the impact of hearing impairment, change in family belief, social support and family perception of childhood education and development showed that the good outcome of adaptation was positively correlated to family characteristic, social support and change in family belief and negatively correlated to impacts of hearing impairment on family and social stigma. It is not really surprising that family resilience was positively related to family characteristics and change in family belief. These results further validated previous findings on family resilience that family coherence, family open communication, family meaning-making play important role in reducing the adverse impacts of risk (Patterson, 2002, Walsh 2003, Australian Family Action Centre in 1999). In like manner, the result of this study showed that social support played an important role in protecting families from being damaged by the risk of childhood hearing impairment. This result was also consistent with the findings of numerous previous studies (e.g. Strong, 1992; Yoshinaga-Itano, 2000; Hintermair, 2000a). As a significant risk, childhood hearing impairment had influenced families' economic status, leading to communication difficulties and feeling of fatigue etc., consequently it was understandable that it was negatively correlated to the level of family adaptation. Simply speaking, the heavier childhood hearing impairment impacts on family life, the lower level of family adaptation was demonstrated.

With respect to social stigma, according to Dovidio et al. (2003) stigma was a social construction that involves at least two fundamental components: (1) the

recognition of difference based in some distinguishing characteristic, or "mark"; and (2) a consequent devaluation of the person. The experience of being stigmatized inevitably results in deep-seated, negative, and even pathological consequences for the stigmatized individual. The idea is further validated in this study from the significant correlation between social stigma of hearing impairment, more specifically, family being teased by others because of childhood hearing impairment and childhood hearing impairment meaning no bright future and family positive adaptation. From this point, it is evident that the impacts of hearing impairment on family life are not only from hearing impairment itself, but also from its social meaning.

### 4.3.2 No significant difference in overall level of family adaptation but apparent difference in adaptation pattern between two family groups

The findings of this study show that there was no significant difference in overall level of family adaptation to child's hearing impairment between two family groups. Generally, both family groups tended to highly agree the statements that their families were characterized by close relationship and mutual support and that best efforts has been made to promote the child's communication and learning in their families, highly disagree the statement that because of their child's hearing impairment, their marital relationship has deteriorated. These results meant two group families function normally risk exposure to children's hearing impairment.

However, further examining the family's stress level and the changes in acceptance and family relationship, the results show that Chinese family group demonstrated significant difference in adaptive pattern from Czech family group. Specifically, Chinese families tended to agree the statement that parenting a child with hearing impairment has been linked to chronic sorrow and grief while Czech group tend to slightly disagree that statement. However, over time Chinese families had experienced more changes in acceptance compared with the early days when hearing loss was diagnosed and family relationship had become closer compared with Czech families. Summarily, Chinese families' adaptation to the child's hearing impairment was different from Czech families' in two aspects: (1) The former is like roller coaster while the latter keep more stable adaptation; (2) Compared with Czech families'

adaptation to childhood hearing impairment, Chinese families' adaptation is a kind of adaptation of similar level yet with more stressful experience. Theoretically, the result of positive adaptation accompanying with stressful experience is not a new thing. Masten et al (1994, in Luthar 2000) had distinguished among three groups of resilient phenomena: (1) at-risk individuals or families show better-than-expected outcomes, (2) positive adaptation is maintained despite the occurrence of stressful experience, and (3) there is a good recovery from trauma. As other handicaps, child's hearing impairment is irreversible and has no recovery, for most of families, stressful experience is inevitable to appear recurrently. The family's subjective appraisal of stressful experience while exposure to risky condition depends on many factors, such as family's expectation for children, social support enacted and social security for child's future life. This point also was consistent with previous studies (Kumpfer, 1999; Luthar, 2000; Patterson 2002b) and to be discussed further.

# 4.3.3 Differences in impact of hearing impairment, social support and social stigma may contribute to the difference in stress level between two family groups.

According to Kumpfer (1999), resilience is holistic and dynamic process of interaction between individual or family and its risk environment. Undoubtedly, the child's hearing impairment was a significant risk for overwhelming majority of families in both China and Czech. However two groups of families were similar in outcome of family adaptation but differ in the stressful level due to different internal protective factors and contextual factors. This result was supported by the results of exploration on the difference in impacts of hearing impairment on family life, social stigma and social support.

Firstly, the findings of this study show that both Chinese families and Czech families had experienced the impacts of children's hearing impairment but Chinese families experienced more adverse influences. First of all, both of them had experienced difficulty of communication with children and Chinese families were affected more heavily. In addition, Chinese families had experienced higher increased economic burden and feeling of great fatigue compared with Czech families. This

kind of impact was further validated by the result of the followed open-ended question, the first biggest difficulty for Chinese families was financial burden, and many parents had feeling of fatigue because they must assume double responsibility of working and taking care of child. As a Chinese parent (C6) wrote, "I feel tired and can not work normally because every day I need send him for speech therapy and have to take him back after my work." In contrast, one Czech parent (Olomouc 03) stated, "I feel convenient that I can stay with him at home when I need." Theoretically, communication difficulty between family members and hearing impaired children can be attributed to the primary effects of hearing impairment. However, the economic burden and feeling of fatigue were mainly not caused by hearing impairment itself. The difference in these aspects should be expounded from other perspectives.

Secondly, Chinese families and Czech families also lived in slightly different social attitude context. According to their responses in item 2 and item3, both groups of families tended to disagree with the statements that child's hearing impairment meant no bright future and family is teased by other people because of hearing impairment. However, the further result of statistical test for significant difference show that there existed significant difference in the level of stigma between two family groups. In other words, Czech families live in a lower level of stigma relative to Chinese families.

Thirdly, the results of this study clearly show that there was big gap in social support from social security system for families of children with hearing impairment between two countries. The gap manifested in the following aspects: (1) The result of hearing-loss-related characteristics suggest that Chinese participant children demonstrated apparently later time of using hearing aids, lower rate of using hearing aids, cochlear implants and receiving sign language learning and associated therapy. (2) The results of payers of children's hearing aids, cochlear implants and therapy also demonstrated almost completely different situation in two family groups. The expenses of hearing aids, cochlear implants and associated therapy in Czech are almost completely paid by health insurance, only few families pay partially when they are dissatisfied with the quality of hearing aids paid by health insurance or second

cochlear implantation. In sharp contrast, in China almost all these expenses are mainly paid by family completely or partially, only few families benefited from government funds and donations. (3) The further findings of support from extended families, information support from professionals, the community supports of free choice in special school and regular schools, the access to self-help parent group also show that Chinese families had adapted to child's hearing impairment within a circumstance of inadequate support as compared to Czech counterparts. (4) Some Czech families explicitly or implicitly have mentioned the existence of other sources of support in finance for example, some parent mentioned the convenience of staying at home when needed or possibility of half work day. Although those supports were not perceived as the most effective help by most of families, they should have played important role in supporting families especially disadvantaged families. According to relevant document research, one important source for Czech families of children with and without hearing impairment is family benefits. According to family policies in Czech, families with children receive financial support generally in three stages and in two forms of transfers and taxation. Transfers represent direct financial support from the govern government. The first transfer family generally receives from the state is a birth grant, the one-time benefit generally covering costs connected with childbirth. Maternity benefits are paid during the period shortly before and after birth. A child-rearing allowance or parental allowance is paid to the parent who provides care for a child usually up to the age of 2 to 4 years. A child benefit is paid to families with children usually up to the end of the child's compulsory education. Because of these pro-family policies, families have lower income loss due to parenthood. It is even beneficial to stay at home to take care of the child for the families with very low income (Švarcová et al., 2009). In the event of a disability, certain state social support benefits are awarded for longer periods of time (e.g. parental allowance) or in increased amounts (Ministry of Labour and Social Affairs, Czech Republic).

In sum, the protective factor of social support and lower level of social stigma of hearing impairment in Czech may mediate the impact of hearing impairment on family life and likely contribute to the lower level of family sorrow and grief while facing children's hearing impairment. By contrast, Chinese families were heavily impacted due to lack of adequate social support from social security system.

### 4.3.4 Protective factors which can contribute to Chinese families's positive adaptation while lack of adequate support from social security system

It may be an intriguing question that how Chinese families positively adapt to children's hearing impairment despite lack of adequate support from social security system and the presence of higher level stigma relatively. From their response in the outcome of adaptation, this family group had scored 27.81 points in 7 items with average value of 3.97 in every item. This result meant generally they responded the seven statements relevant to the outcome of family adaptation positively. Statistically this result was very similar to that of Czech family group. The further analysis of influential factor contributing to this result suggest that Chinese family group got higher than moderate score in items examining family characteristics, namely, family's self efficacy of ability to face the challenge of child's hearing impairment, family characteristic of close relationship and mutual support, family sharing emotions and opinions together to educate their children. To some degree one inference may be drawn from this result was that child's hearing impairment had no significant influence on family relationship in Chinese families. Despite increased financial burden and communication difficulties with children etc. due to childhood hearing impairment, the Chinese families keep the cohesive family relationship. To a lesser or larger degree it seemed that the risky situation makes family relationship closer because of open communication of sharing emotion and ideas. This result was consistent with some researches on Chinese culture. For example, Ju and Chu (1996) have argued that for thousands of years, close family relations had been a major cornerstone of traditional Chinese culture. According to Xu et al. (2007), an outstanding expert in Chinese family, one of the salient features of Chinese family was family cohesive support while facing challenges and family stressful events.

Also, the result of factor of change in family belief demonstrated that Chinese families tended not to believe in destiny, they had become more optimistic about future, more tolerant toward difference, more altruistic to others while parenting the children with hearing impairment. Theoretically this positive change in family belief was not inconsistent with previous results. Previous literature on the adaptation of families of children with chronic health conditions had indicated that these families coped with child's disability by attributing positive meanings to their situations, defining them as manageable, and making efforts to regain a sense of control (King et al, 2006). Additionally families gained a greater understanding of themselves through the experience of raising a child with a disability, and learned about patience, acceptance, tolerance, perseverance, compassion, and unconditional love. Grant et al (2007) argued that despite the persistence of research-based accounts that depict families with intellectually disabled children and adults in pathological term, there was mounting evidence that caregiving could have positive attributions and rewards. Although few researches on hearing impaired families had been conducted in the framework of resilience, few researches have been concerned with family belief changes while parenting hearing impaired children, the result of this study can be supported by the associated studies in the area of family coping childhood disability.

Further more, the results relevant to social support for Chinese families show a bit inconsistence between the results of questionnaire and open-ended question. In the questionnaire survey the results of factor of social support show that Chinese families tended to agree that families got help from extended families and relatives and disagree that they have got information from professionals, had free choice in placing children in special school and regular school, had no access to parent self-help group, had no adequate financial support from national welfare organization. Put simply, the results fully demonstrated the current condition of inadequate social support for family, especially for disadvantaged families in China. However, in later responses of open-ended question about the most effective help the families have got while parenting their children most of families (89.4%) reported they have got some help from extended family, special school and other government agencies. To be more specific, many families emphasized the expense reduced or free of charge in education. Seemingly, these two results were inconsistent mutually, in essence they were not contradictory. The former had reflected the general condition of lack of

adequate social support whilst the latter had spoken some latest changes of social support taking place in China. The stronger feeling of being supported within general condition of inadequate social support is more likely the outcome of comparison with the past situation. Summarily, the latest changes can be collected as four aspects as follows: (1) government building more and more special schools to provide schooling opportunities for children with hearing impairment. For example, in effort to build more special schools in relatively underdeveloped area of middle and western part of China, the Chinese state council issued the national document named the Guideline of Further Quickening the Development of Special Education in 2009 and stipulated that at least one special school must be built in the county with population of 300,000 to guarantee the children with special needs have opportunity to receive compulsory education. (2) Government providing children with special needs with compulsory education free of charge since 2006. In China, the Compulsory Education Law of the People's Republic of China was passed in 1986. According to this law, schools are required to accept children with special needs and school entrance rates of students with disabilities have become an important area of attention during official district inspections (Deng, Poon-Mcbrayer, & Fransworth, 2001). This law first created a national special education system which enabled children with special needs to have access to a nine-year mandatory education. However, due to the large population of the country and the associated financial constraints the country was facing the expense of the compulsory education was paid by families. After constant and rapid economic growth in recent decade, in 2006, one of important changes in compulsory education took place. According to new revision Act of Compulsory Education, all the appropriate-age children, including children with disability have right to receive free-charge compulsory education. (3) Special school providing sign language curriculum with hearing impairment and their families for children as an outcome of new curriculum reform. In the long history of hearing-impaired education the oral approach has continued to be the dominant approach promoted by Chinese government and by educators in China despite everyday practice in schools for the deaf and hard of hearing has long entailed the use of "signed language" (Lytle et al,

2005). However, with the issue of new Experimental Program of Curriculum Setting of Compulsory Education in Deaf School (2007), deaf children's communication and social interaction have been paid increasing attention and more and more importance is attached to teaching children learning to communicate with people surrounding them. As a result, sign language has been taught to children and their parents in some special school. These changes have manifested in families response to the open-ended question and qualitative interview data. (4) A great deal of efforts having been made to provide intervention service for children with hearing impairment. For example, in 2004, the National Lottery Public Welfare Fund was started to guarantee that certain amount of money would be used to help children from low-income families to benefit hearing aids and hearing services. This fund also addresses services such as fitting hearing aids, tailoring ear molds, providing batteries, drying capsules and repairs, and subsidizing some training. In 2009, the government has stated that it would plan to spend 400 million Yuan (Chinese dollar) from central finance to implement the China Disabled Persons Federation Salvage Rehabilitation Program. It is reported that according to this program 1,500 children, ranging from 1 to 5 years old with severe-to-profound hearing loss, will be offered cochlear implants and associated services without any charge during 2009 to 2011.

### 4.3.5 Resilient Chinese families used some effective strategies to cope with childhood hearing impairment for children's better future

The results of qualitative interview further supported the result of the Chinese families' positive adaptation to childhood hearing impairment with considerable level of stressful experience. The result of qualitative analysis of the thick experience from eight hearing-impaired families show that childhood hearing impairment had overwhelmingly affected the family normal life, some families falling into debt deeply for children's cochlear implantation, some families willing to sale house or move room for their child's cochlear implantation and associated therapy and some fathers leaving their home to go to city to earn more money for children's better future. In addition to financial demand caused by childhood hearing impairment, several families taking part in interview commonly experienced the communication

difficulty with children mainly due to limited sign language and lack of knowledge of how to educate hearing impaired children. Despite inadequate support from social security system, these families were battling against childhood hearing impairment by their own efforts. They had tried their best for their benefit of their children with the price of losing their own happiness. Shifting life focus, accepting what can not be changed, mobilizing all potential resources inside and outside family, taking concrete steps towards goal including learning sign language by themselves were main effective strategies these resilient families had used to adapt to the risk of childhood hearing impairment. What was the impetus behind these behaviors with the nature of self-sacrifice, it can probably be attributed to the deepest love that Chinese parents hold towards their children.

#### 4.3.6 Implication for intervention services in China

The result of this study suggest again that social supported played crucial role in protecting families from being heavily impacted by childhood hearing impairment. Because of lack of inadequate social support in China, Chinese families adapt to the childhood hearing impairment with heavy stressful experience. However, they had tried their best for the benefit of their children. Financial burden, communication difficulty with their children, lack of appropriate information support, especially how to educate hearing impaired children from professionals etc. were main challenges facing them. Although in short period of time it is impossible for dramatic changes occurred to provide adequate financial support for families of children with hearing impairment, some realistic initiatives remains to be taken practically.

Some limitations in intervention services in China, especially early intervention programs have been found in the study. Early intervention, commonly called early rehabilitation in China, referred to a series of services provided to children from birth to six years of age who are at-risk for developmental problems or children who have been determined to have an established disability such as hearing impairment. Although there was recognition that early intervention for young children with hearing loss was important in the 1980s in China, there were few programs serving deaf children and their families due primarily to the large population of the country

and the associated financial constraints the country was facing. Few intervention programs, if any, narrowly focused on the child's audiotory-oral therapy. Additionally, there was considerable disparity in development between rural and urban areas. However, as the economy has grown, the Chinese government has invested more money in education, especially programs for children with special needs. The government has mobilized a network of social resources, public and private sector agencies, spearheaded domestic programs, and utilized international supports to place an emphasis on supporting young children with hearing loss. According to the latest official document, "The Proposal on Furthering China Special Education" jointly issued by eight departments of government including the Ministry of Education and The China Disabled Persons Federation (2009), early intervention was first proposed officially and was included as the integrated special education system. Also, early intervention for children with hearing loss is getting more attention and developmental opportunities than ever. In effort to provide more services which is suited to family needs, according to the result of this study, some recommendations are put forward to inform the early intervention programs implementing in China.

Be sensitive to families' needs. From the experiences shared by participant families, strong evidences supported the established recognition that childhood hearing impairment belongs not just to the child but to the entire family. Families' communication difficulty, financial demands associated with sensory devices and lack of information to making informed decision, strong desire for information associated with hearing-impaired education were the most urgent issues which the early intervention programs should make efforts to address. To solve the main difficulty of communication, it is time to stop controversy of oral-auditory mode and manual-visual mode. The starting of sign language teaching from special schools are welcome to most of families, especially for families from rural area to whom hearing aids and cochlear implants are not affordable, however it is too late to avoid the damage of parent-child interaction and relevant behavioral problems and negative personality development, such as bad-temperedness and aggressiveness. Consequently,

although at present intervention services for hearing impaired children have been predominated by the auditory-verbal communication model, there are more children who may benefit from a more comprehensive communication approach such as total communication (e.g., signing, speaking, finger-spelling). Consequently it is expected more early intervention programs which should assume a comprehensive developmental approach, offer services that are integrated between medical and education facilities, involve families as the cornerstone of helping children reach their optimal level in cognitive, language and social emotional development.

·Make supports more accessible to all families from urban and rural areas. Because of poverty many hearing impaired children from urban and rural poor families can not use the hearing aids, let alone use of cochlear implants. Till to now, the limited early rehabilitation programmes are based on the oral-auditory hearing and speech training, however, these programmes can not satisfy the needs of most children without hearing aids and cochlear implantation. So it is desirable that some programmes can be more sensitive to the needs of families from rural area and it is hoped that more attentions should be paid to these children who are most vulnerable and disadvantaged while the government seeks to reach higher standard and expectation in development of special education.

Provide non-biased informational supports pertaining to medical, education, technical, and communication. Especially help family develop informed decision-making and realistic expectation in cochlear implants. According to the result of interview, many families regarded cochlear implants as catholicon which can resolve all the troubles concerning hearing loss. Even in very poor condition, some Chinese families took a gamble to help their children using cochlear implants regardless of the uncertain outcomes, high cost and potential safety and health risk of cochlear implants. However, if some families have used all family savings for cochlear implants without expected good outcome, it will lead to heavier accumulating effects of hearing impairment.

Provide psychosocial support by building parent self-help group, initiating deaf

parent workshop etc. Talking with other parents with similar experience can help these families deal with the heightened stress levels associated with hearing loss diagnosis, information gathering, parenting, time and financial demands, worries about future etc. Especially, it will be of particular help for families to build new hopes and dreams by contacting with some successful deaf examples. Compared with high price of qualified sensory devices, building family self- help group maybe one of more cost effective and practical intervention services at present condition of inadequate financial power.

#### 4.3.7 Research limitations

Reflecting the research process of this study we sensed that each research conducted was compromise between ideal plan and reality. This study mainly consisted of two parts of questionnaire survey and qualitative interview. The main limitations of this research can be analyzed from four aspects: firstly, there was disparity in number of research samples from Chinese families and Czech families due to language barrier, constraints of time, energy, availability of subjects. This study got double respondents in questionnaire survey in China of that in Czech, so some difference in result can not be excluded from the sample errors. Also the in-depth interview was only conducted in China, no equivalent data can be used to compare the coping strategies used by two family groups. Secondly, because of language barrier, the researcher of this study only know Chinese and English, with the help of translation, the questionnaire survey can be conducted in Czech. However, it is difficult to keep cultural correspondence in translation and data analysis. Thirdly, despite lack of clear regulations on the number of participants in qualitative research, "it was safe to state that the researchers should continue to collect and analyze data until theoretical saturation takes place." (Corbin & Strauss, 2008, p.324). It was clear that eight families were far from the status of theoretical saturation. Fourth, because of variation in understanding of resilience and family resilience, the term of family resilience is operationalized as a comprehensive structure of significant risk, the process of risk factor and protective factors and the positive adaptation to risk condition. Also the family's positive adaptation was inferred according to the outcome

of accepting well, functioning well, and expecting well from the perspective of process. Although it is understandable and usual practice for researcher to operationalize the specific term in specific research, the author of this dissertation still beg questions and further explorations in how to assess the family resilience in specific condition. However, despite of the limitations above mentioned, through the limited participant families, some valuable results have been obtained and some voices from hearing-impaired families have been heard. Considering the heterogeneity and large number of hearing-impaired population in China and in Czech it is desired that more families from culturally and linguistically diverse backgrounds with children of different age, different severity of hearing loss and in different educational placement will be involved in future researches and more varied voice will be heard.

#### 5. Conclusion

The purpose of this study is to examine how families from two different social contexts, China and Czech, adapt to the risk of childhood hearing impairment and explore the process of resilient families adapting to such risk condition positively. Based on a large body of literature on resilience and family resilience, in this study the term family resilience was operationalized as the construct of the process through which family adapt to the reality of having a child with hearing impairment. It mainly included three parts: the impacts of hearing impairment as a significant risk on family life, the transactional process of hearing impairment and protective factors or supportive factors, and outcome of positive adaptation to the childhood hearing impairment according to the criteria of family accepting hearing impairment, functioning, and expecting for the child's future.

To reach the purpose of research, this study adopted the combination of quantitative research and qualitative research to examine the outcome and process of family adapting to the reality of having a hearing-impaired child in family. A sample of 160 families from China and Czech were selected to take part in questionnaire survey and eight Chinese families were invited to take part in semi-structured interview. Questionnaire including open-ended and closed ended questions were developed to investigate the factor of outcome of adaptation, the impacts of childhood hearing impairment on family life, the social stigma associated with hearing impairment, protective factors of family characteristics and social support, and family perception of hearing impaired education and children's development. The following conclusions were drawn from the results and discussions above conducted:

(1) Overall, two groups of families from China and Czech were resilient with

positive adaptation to childhood hearing impairments after more than ten years struggling with them;

- (2) Generally the level of family adaptation to childhood hearing impairments were positively correlated to family characteristics, change in family belief and social support while being negatively correlated to impacts of hearing impairment and social stigma;
- (3) Chinese families and Czech families did not demonstrate significant difference in outcome of positive adaptation but apparent difference in adaptive pattern because of Chinese family's showing much higher stressful level and displaying more change in acceptance than the early days after diagnosis as compared to Czech counterparts;
- (4) There existed big gap in intervention service including using hearing aids, cochlear implants, receiving therapy and other social supports including financial support for sensory devices, sign language learning opportunity, information support from professionals, the community supports of free choice in special school and regular schools, the access to self-help parent group etc. may contribute to the difference in subjective appraisal of stressful level between two family groups.
- (5) Due to lack of adequate social support, Chinese family were more significantly impacted by childhood hearing impairment ,specifically demonstrating in family economy burden, communication difficulty and educational puzzle etc.
- (6) Despite adverse impact of childhood hearing impairment, the protective factors including Chinese family's cohesive family relationship, open communication, and change in family belief including becoming optimistic, altruistic and tolerant toward difference, and higher feeling of being helped may contribute to the outcome of Chinese family positive adaptation.
- (7) Faced with the reality of having a child with hearing impairments, Chinese resilient families used the coping strategies of shifting life focus, accepting what can not be changed, mobilizing all potential resources inside and outside family, taking concrete steps towards goal including educating sign language by themselves and working harder to earn more money for child's future etc. and their experiences

demonstrated again that childhood hearing impairment did not created the barrier which is insurmountable and that within appropriate support every family can be resilient despite risky exposure.

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#### **Appendix**

#### Appendix A Questionnaire in English

Questionnaire of Families with Hearing Impaired Children

Dear children's parents or other caregivers,

The birth of a child with hearing impairment is a great challenge for most of families. At present more and more attentions are being paid to how to support family advance the development of children with hearing impairment. This investigation being conducted and concerning the families' difficulty in parenting the children with hearing impairment and their adaptation to the reality of having such children just serves this purpose. As a main caregiver of your child, your responses on behalf of your family, will help me better understand the life experience of family of children with hearing impairment and inform professionals, policy makers, and other people serving the hearing impaired children how to better support families. We ensure you that the questionnaire is absolutely anonymous and is only used in the research. Thanks for your cooperation.

Yours sincerely
International PhD program research group
From Institute Special Education Studies
Faculty of education
Palacky University
Czech Republic

Partl Information data about informant

#### Please circle and fill the data pertaining to you

- I am: 1. a man 2. a woman
- I am child's: 1. father 2. mother 3. grandparent 4. other caregivers, such as baby-sister/sibling.....
- I reside in: 1. town/city 2. village
- my education: 1. illiterate 2. primary 3. secondary 4. university
- how long have I been taking care of the hearing-impaired child:
  - 1. within 1 year 2. 1-2 years 3. 2-3 years 4. more than 3 years

## Part II Information data about the hearing-impaired child in your family, Please circle and fill the data pertaining to your child

- the age of child is:....months
- the child is a 1. boy 2. girl
- the child's parents is: 1. in marriage 2. separated 3. divorced 4. cohabited
- the hearing of the child's parents: 1. normal 2. deaf 3. one normal and one deaf
- the economic condition of family: 1. lower income 2. middle class 3. higher income
- the highest educational level of your family members:
  - 1. illiterate 2. primary 3. secondary 4. university or higher
- your family often attends religious activity: yes/ no your religion is:
- the child is: 1. only child in family 2. one of two or more children in family
- the degree of your child's hearing loss:
  - 1. 26~40 dB 2. 41~55dB 3.56~70dB 4.71~90dB 5.91~110dB 6. >110dB

- 7. not clear
- the exact time of child's hearing diagnosis:....months old.
- the onset at which hearing loss occurred:
  - 1. birth 2. within 1 year old 3. 1-3 years old 4. after 3 years old 5. not clear
- the age when child began to use hearing aids: \_\_\_\_\_ months old.
- the child's hearing aids was paid by:
  - 1. government 2. family completely 3. healthy insurance 4. family partially
  - 5. donation
- the age of child's using cochlear implant: \_\_\_\_(years)\_\_\_\_(months) old.
- the child's cochlear implants was paid by?
  - 1. government 2. family completely 3. healthy insurance 4. family partially 5. donation
- has child received systematic training of sign language: 1. yes 2. no
- the communicative model with which your child uses to communicate:
  - 1. natural gesture 2. sign language 3. spoken language 4. mixture of sign and spoken language
- types of therapy received by your child:
  - 1.medication 2. speech therapy 3. social skill training 4. sensory integration 5. none
- the therapy received by child was paid by:
- 1. government 2. local government 3. family completely 4. family partially 5. donation
- the child's present educational placement:
  - 1. at home 2. specialized preschool 3. regular preschool 4. regular school 5. special school
- the expense of child's special preschool education is paid by:
  - 1. government 2. family completely 3. family partially 4. social donation

Part III Information data about your family raising the child with hearing impairment. Please circle the statement which best applies to you.

1	1 7	1 2	1 1	5
1	<u> </u>	)	l <del>4</del>	J
		-		_

	ng a child with he							
	o chilomic soffow and		t has been	1	2	3	4	5
	nily has always be	-	her people	1	2	3	4	5
	because of my child's hearing impairment  My child's hearing impairment means the child will no					3	4	5
	id's nearing impairn ight future	nent means the ch	na wiii not	1	2	3	4	3
		d'a bassina issue	imma saat aass	1	2	3	4	5
ا ا	the reality of child	u's nearing impa	irment, my	1	2	3	4	3
<del>                                     </del>	tend to be a fatalist.	family's shility (	a face the	1	2	3	4	5
	gly believe in my	-	o race the	1	2	3	4	3
<del>                                     </del>	ge of child's hearing			1		2		
l -	nily is characterize	d by close relati	onship and	1	2	3	4	5
+	support	1.11.1 41 1.	C	1				
	the time of parentin		egree of my	1	2	3	4	5
+	r (readiness to help o		0					
l 1	the time of parentin	•	egree of my	1	2	3	4	5
+	ce toward difference		2442					
l	the time of parentin	g my child, the de	gree of life	1	2	3	4	5
-	m increased							
	the time of paren		often feel	1	2	3	4	5
<del>                                     </del>	ty in communicating							
11. Parent fatigue	ng my child make	me have a feelir	ng of great	1	2	3	4	5
12. Becaus	e the child's hearin	g impairment, the	e economic	1	2	3	4	5
status	f my family has dete	eriorated						
13. The su	port from my exten	ded family and oth	er relatives	1	2	3	4	5
often l	elp me greatly.							
14. Becaus	e of my child's hea	ring impairment,	my marital	1	2	3	4	5
relatio	ship has deteriorat	ed						
15. To edu	cate the child with h	nearing impairmen	t, we often	1	2	3	4	5
share 6	notions and opinion	s together in my fa	mily					
16. In my	amily parenting the	child with hearing	loss means	1	2	3	4	5
provid	ng best care and prot	ection						
—	nily can often get ne		n related to	1	2	3	4	5
l	impairment from pr	-						
<u> </u>	ld can choose to att		reschool or	1	2	3	4	5
	preschool age-appro							
H	nily has access to s			1	2	3	4	5
	impaired children		_					
+	re learning sign lang	guage is of no be	nefit to my	1	2	3	4	5
child's		- <del>-</del>	,					
	ve that mastery of	f spoken languag	ge is most	1	2	3	4	5

	fundamental educational goal for my child.					
22.	The mutual communication of the family members has	1	2	3	4	5
	been affected by the child hearing loss					
23.	The financial support from welfare is high enough to	1	2	3	4	5
	meet the special needs of the child with hearing					
	impairment					
24.	Best efforts has been made to promote the child's	1	2	3	4	5
	communication and learning in my family.					
25.	Comparing with the early days after diagnosis of hearing	1	2	3	4	5
	impairment, there is more acceptance and peace in my					
	family at present.					
26.	Up to now my child does not show developmental lag	1	2	3	4	5
	relative to same age peers.					
27.	Nowadays my family believes that my child will have	1	2	3	4	5
	bright future and be a beneficial member in society in the					
	future.					
28	My family relationship has become closer during	1	2	3	4	5
	parenting the child with hearing impairment					
29	My family has ability to deal with the children's	1	2	3	4	5
	difficulties and problems in coming years.					

#### PART IV Write the answer freely

1. Write out the biggest difficulty your family has experienced during your parenting th child with hearing impairment:
2. Write out the main way your family has used to communicate with your child and th place where you got it:
3. Write out the information your family need most while parenting your child:
4. Write out the most effective help your family have got while parenting your child:
5. Please describe your child with three sentences:
(1) I think he/she

is	
(2) I think he/she is	••••
(3) I think he/she is	

At last I would like to thank you for your completing this questionnaire. I believe the results of this investigation will help us understand your life challenges and help professionals move toward improving services for children and families.

#### Appendix B Questionnaire in Czech

Dotazník pro rodiče dětí se sluchovým postižením

Vážení rodiče a pečovatelé,

narození dítěte s vadou sluchu je velkou změnou v životě většiny rodin. V současné době je stále více a více pozornosti věnováno otázce, jak podpořit rodiny a především vývoj dětí se sluchovým postižením. Toto šetření je prováděno proto, aby bylo možné lépe charakterizovat problémy týkající se rodiny a rodičovství dětí se sluchovým postižením a možnosti adaptace na život s dětmi se sluchovým postižením.

Vaše odpovědi mi pomohou lépe pochopit životní zkušenosti rodiny dětí se sluchovým postižením a informovat odborníky, politiky a další osoby pracující v oblasti péče o děti se sluchovým postižením o speciálních potřebách a jejich rozsahu.

Prohlašuji, že dotazník je zcela anonymní a výsledky budou použity pouze pro výzkum. Děkuji za vaši spolupráci.

S uctivým poděkováním

studentka doktorského studijního programu speciální pedagogika Ústav speciálněpedagogických studií Pedagogická fakulta Univerzita Palackého v Olomouci

#### Část I. základní údaje

(Prosím, zakroužkujte nebo doplňte údaj, který podle Vás odpovídá pravdě.)

vztah k dítěti se sluchovým postižením
1. otec 2. matka 3. prarodič 4. pečovatel
bydlíme: 1. město 2. vesnice
moje vzdělání: 1. základní 2. střední 3. vysokoškolské
o dítě se sluchovým postižením pečuji:
1. do 1 roku 2. 1-2 roky 3. 2-3 roky 4. více než 3 roky

Část II. Informace o dítěti se sluchovým postižením v rodině (Prosím, zakroužkujte nebo doplňte údaj, který se týká dítěte a považujte jej za pravdivý.)

1. doma

• věk dítěte: .... roků .... měsíců pohlaví dítěte: 1. chlapec 2. děvče • rodiče dítěte jsou : 1. manželé 2. žijí ve společné domácnosti 3. odděleně 4. rozvedeni • rodiče jsou : 1. slyšící 2. sluchově postižení 3. kombinace obojího • příjem rodiny je 1. na úrovni minimální mzdy 2. na úrovni průměrné mzdy 3. nad průměrem nejvyšší vzdělání v rodině: základní 2. středoškolské 3. vysokoškolské • můžete popsat váš vztah k náboženství? 1. věřící 2. nevěřící • dítě se sluchovým postižením je: 1. jediným dítětem v rodině 2. má sourozence • velikost sluchové ztráty dítěte je: 1. 26~40 dB 2. 41~55dB 3.56~70dB 4.71~90dB 5.91~110dB 6. >110dB 7. nevím • kdy byla u dítěte diagnostikována vada sluchu ....roků... měsíců • kdy se vada sluchu podle vás projevila: 1. do půl roku 2. do 1. roku 3. mezi 1-3 lety 4. po 3. roce věku 5. nevíme • ve kterém věku dostalo dítě první sluchadlo • sluchadlo bylo hrazeno: 1. pojišťovnou 2. jinak (prosím vypište jak) • dítě používá kochleární implantát od věku ..... • kochleární implantát byl hrazen 1. z prostředků zdravotního pojištění 2. jinak (popište prosím jak) • má dítě možnost učit se systematicky znakovému jazyku? 1. ano • komunikace dítěte probíhá užitím: 1. gest 2. znakového jazyka 3. mluvené řeči 4. využití znakového jazyka a mluvené řeči • která terapie byla dítěti nabídnuta v souvislosti s vadou sluchu: 1.medicínská 2. logopedie 3. rozvoj sociálních dovedností 4. rozvoj smyslového vnímání 5. žádná • terapie, kterou dítě dostalo, byla hrazena: 1. zdravotní pojišťovnou 2. z prostředků obce 3. kompletně rodinou 4. rodina částečně 5. sponzorsky • v současné době je dítě umístěno:

2. ve speciální mateřské škole

3. v běžné mateřské škole

4. pravidelně škole

5. speciální škole

Část III. informace o výchově dítěte s vadou sluchu (Prosím, zakroužkujte nebo doplňte údaj, který považujete za pravdivý.)

#### Vzor hodnocení:

1	2	3	4	5
ne, ne	ne	ano i ne	zpravidla ano	vždy ano

1.	Být rodičem dítěte s poruchou sluchu je spojeno se stálou bolestí a žalem.	1	2	3	4	5
2.	Naše rodina vždy trpěla poznámkami z okolí, naše dítě má vadu sluchu.	1	2	3	4	5
3.	Dítě se sluchovým postižením nebude mít nikdy světlou budoucnost.	1	2	3	4	5
4.	Život s dítětem s vadou sluchu mě přivedl k větší odevzdanosti	1	2	3	4	5
	osudu.					
5.	Pevně věřím, že moje rodina je schopna odolávat problémům dítěte s va	1	2	3	4	5
	sluchu.					
6.	Pro naši rodinu je charakteristický pevný vztah a vzájemná podpora.	1	2	3	4	5
7.	Když jsem se stal/a rodičem dítěte s vadou sluchu, míra mé ochoty pom	1	2	3	4	5
	ostatním se zvýšila.					
8.	Když jsem se stal/a rodičem dítěte s vadou sluchu, míra mé tolerance	1	2	3	4	5
	odlišným lidem se zvýšila.					
9.	Když jsem se stal/a rodičem dítěte s vadou sluchu, míra mého	1	2	3	4	5
	životního optimismu se zvýšila.					
10.	Když jsem se stal/a rodičem dítěte s vadou sluchu, začal jsem	1	2	3	4	5
	pociťovat problémy v komunikaci s dítětem.					
11.	Když jsem se stal/a rodičem dítěte s vadou sluchu, dostavil se pocit v	1	2	3	4	5
	únavy.					
12.	S příchodem dítěte s vadou sluchu se ekonomická úroveň naší rodiny zhorš	1	2	3	4	5
13.	Podpora širší rodiny a dalších příbuzných mi velmi pomáhá.	1	2	3	4	5
14.	S příchodem dítěte se sluchovým postižením se můj manželský vztah zhorš	1	2	3	4	5
15.	Při výchově dítěte s vadou sluchu, se často střetnou emoce a rozumné ná	1	2	3	4	5
	v naší rodině.					
16.	V naší rodině se dítěti s vadou sluchu dostává větší péče,	1	2	3	4	5
	pozornosti a ochrany.					
17.	V naší rodině se často pracuje s informacemi o vadách sluchu, které mám	1	2	3	4	5
	odborníků.					
18.	Pro naše dítě nebyl problém s možností výběru speciální mateřské	1	2	3	4	5
	školy nebo běžné mateřské školy pro slyšící.					
19.	Naše rodina má možnost kontaktu a setkávání s jinými rodinami	1	2	3	4	5
	s dětmi s vadami sluchu.					
20.	Nevěřím tomu, že znakový jazyk má pro moje dítě nějaký význam.	1	2	3	4	5
21.	Jsem přesvědčen/a, že mluvená řeč je základním cílem vzdělávání	1	2	3	4	5
	dítěte s vadou sluchu. Věřím, že zvládnutí mluvené řeči je základní					
	cíl také pro moje dítě.					

22.	Vzájemná komunikace členů naší rodiny byla ovlivněna ztrátou	1	2	3	4	5
	sluchu dítěte.					
23.	Finanční podpora, kterou dostáváme, je dostatečně vysoká, aby	1	2	3	4	5
	vyhověla specifickým potřebám dítěte se sluchovým postižením.					
24.	Naše rodina vynaloží veškeré úsilí k podpoře rozvoje dítěte v ob	1	2	3	4	5
	komunikace a vzdělávání.					
25.	Celková situace v naší rodině se od doby zjištění vady do dnešní	1	2	3	4	5
	doby zklidnila.					
26.	Naše dítě nevykazuje výrazné vývojové opoždění ve srovnání s dětmi stejí	1	2	3	4	5
	věku.					
27.	V současné době naše rodina věří, že naše dítě bude mít dobrou budoucné	1	2	3	4	5
	v dospělosti se dobře uplatní.					
28	S příchodem dítěte s vadou sluchu se vztahy v naší rodině zlepšily.	1	2	3	4	5
29	Naše rodina má schopnost vyřešit problémy a obtíže v následujících letec	1	2	3	4	5

#### Část IV. Prosím vypište odpovědi

1. Popište prosím největší problém, se kterým jste se jako rodič/e dítěte se sluchovým postižením setkal/i.
2. Popište prosím nejfrekventovanější způsob komunikace s vaším dítětem a kde jste se tomuto způsobu naučili.
3. Kterou informaci považujete za nejdůležitější pro rodiče dítěte se sluchovým postižením?
4. Kterou pomoc, považujete za nejefektivnější z hlediska potřeb rodiče dítěte se sluchovým postižením.
5. Popište prosím dítě v následujících třech větách.
(1) Myslím, že
(2)
je
je
(3) Myslím, že

je .....

Závěrem bych Vám ráda poděkovala za vyplnění dotazníku. Věřím, že výsledky tohoto šetření nám pomohou pochopit životní problémy rodičů dětí se sluchovým postižením a také pomohou odborníkům ve snaze o zlepšování služeb nabízených těmto rodinám.

#### Appendix C Abstract in German

#### Resümee

Forschung im Bereich der Widerstandsfähigkeit der Familien mit Kindern mit Gehörschaden

Der Gehörschaden bei Kindern hat nicht nur Einfluss auf die Entwicklung des Kindes, sondern greift auch in alle Aspekte des Lebens der Familie ein. In dieser Forschung werden gemischte Herantretensweisen der quantitativen und der qualitativen Forschung benutzt, und es wird untersucht, wie sich Familien aus zwei unterschiedlichen sozialen Milieus, der Chinesischen Volksrepublik und der Tschechischen Republik, an den Gehörschaden der Kinder angepasst haben (insgesamt 160 Familien untersucht). Zugleich wird der Prozess der positiven Anpassung der chinesischen widerstandsfähigen Familien trotz dieser Risikoaussetzung beschrieben. Wegen der wesentlichen Abweichungen in der Definition und im Messen der Widerstandsfähigkeit und in der Widerstandsfähigkeit der Familien in früheren Studien wird der Begriff Widerstandsfähigkeit der Familie in dieser Studie als systematische Struktur definiert, die aus der Auswirkung des Gehörschadens als bedeutenden Bedrohung Familienlebens, einer des aus dem Transaktionsprozess des Gehörschadens und aus Schutzfaktoren und Folgen der positiven, durch Abfindung mit dem Gehörschaden, gute Funktion und Erwartungen entwickelten Anpassung besteht.

Auf Grund dieses Konzeptionsrahmens ist ein Fragebogen erarbeitet worden, dessen Ziel es war, das gesamte Niveau der Anpassung der Familie zu beurteilen und Einflussfaktoren einschließlich der Auswirkung des Gehörschadens auf das Familienleben, des sozialen Stigmas, der Familiencharakteristik im Rahmen der Familienleistungsfähigkeit, des Familienzusammenhaltens und offener Kommunikation, der Änderung des Familienglaubens zum Fatalismus, Optimismus, Altruismus und zur Toleranz zu Unterschieden und Unterstützung der Ausbildung und der Entwicklung des Kindes seitens der Familie und der Gesellschaft zu definieren. Die aus der Fragebogenuntersuchung entstandenen Feststellungen zeigen, dass (1) diese zwei Familiengruppen allgemein widerstandsfähig sind, wenn sie der Herausforderung des Gehörschadens der Kinder entgegenstehen; (2) die Folgen der positiven Anpassung dem

Zusammenwirken der Faktoren der Auswirkung des Gehörschadens auf das Familienleben und das gesellschaftliche Stigma, auf den Familiencharakter, die Änderung des Familienglaubens und Unterstützung seitens der Gesellschaft zugeschrieben werden können.

Ein weiterer Vergleich deutet an, dass chinesische und tschechische Familien keinen wesentlichen Unterschied in den gesamten Folgen der positiven Anpassung aufweisen, dagegen weisen sie jedoch merkbare Unterschiede in den Anpassungsmustern auf, weil chinesische Familien ein wesentlich höheres Stressniveau und mehr Änderungen im Akzeptieren des Gehörschadens der Kinder und im Zusammenhalten der Familie im Vergleich mit den ersten Tagen nach der Diagnose aufweisen, wenn sie mit tschechischen Familien verglichen werden. Die enorme Lücke zwischen den beiden Gruppen besteht in Hilfsdienstleistungen wie z.B. Benutzung der Gehörhilfsmittel, kochlealer Implantate, Therapie und anderer Sozialhilfe einschließlich Informationsunterstützung seitens der Fachleute, Unterstützung seitens der Gesellschaft, die die Wahl einer spezialisierten oder gewöhnlicher Schule oder das Herangehen zu Elterngruppen betrifft, wobei das alles zum Unterschied in der subjektiven Beurteilung des Stressniveaus zwischen beiden Familiengruppen beitragen könnte. Trotz der negativen Auswirkung des Gehörschadens der Kinder und des Mangels entsprechender Unterstützung seitens der Gesellschaft haben vielleicht die Schutzfaktoren zur positiven Anpassung in chinesischen Familien beigetragen, wobei diese Faktoren das Zusammenhalten chinesischer Familien, offene Kommunikation und positive Änderungen im Familienglauben wie z.B. die Tatsache, dass sie optimistischer, altruistischer und toleranter zu Abweichungen werden, und auch die Gefühle, dass jemand ihnen hilft, umfassen.

Nachfolgend sind detaillierte Gespräche verlaufen, in denen reiche Erfahrungen von acht chinesischen Familien beschrieben worden sind, die gegen dem Gehörschaden der Kinder gekämpft und die sich ihm positiv angepasst haben. Die qualitative Analyse der Daten aus den halbstrukturierten Gesprächen hat weiter bestätigt, dass chinesische Familien vom Gehörschaden der Kinder wegen der ungenügenden sozialen Unterstützung seitens des sozialen Systems und der Fachleute ernsthaft betroffen sind, dass sie insbesondere eine hohe ökonomische Belastung, Kommunikationsprobleme und eine kleine Möglichkeit, informierte Entscheidungen in der Sache sensorischer Hilfsmittel, Kommunikationsweisen und Ausbildungsweise zu treffen, aufweisen. In Angesicht der Tatsache, dass sie ein Kind mit Gehörschaden haben, verwenden jedoch chinesische Familien die Strategie der Verschiebung der Lebensorientierung, des Akzeptierens desjenigen, was nicht zu ändern ist, der Mobilisierung aller möglichen Quellen innerhalb und außerhalb der Familie und konkreter Schritte, die auf das Ziel gerichtet sind, wie z.B. Selbststudium der Zeichensprache und eine intensivere Arbeit, damit sie mehr Geld für die

Zukunft des Kindes verdienen, usw. Das alles hilft ihnen, sich mit dem Gehörschaden des Kindes abzufinden und zu zeigen, dass er kein unüberwindbares Hindernis ist.

Nicht zuletzt sind einige Empfehlungen über Hilfsdienstleistungen in China und Beschränkungen dieser Forschung beschrieben.

Schlüsselwörter: Widerstandsfähigkeit der Familie Kinder Gehörschaden chinesisch tschechisch

#### Appendix D Abstract in Czech

#### Resumé

Výzkum v oblasti odolnosti rodin s dětmi s poškozením sluchu

Poškození sluchu u dětí nemá vliv pouze na vývoj dítěte, ale zasáhne všechny aspekty života rodiny. Tento výzkum přijal smíšené přístupy kvantitativního a kvalitativního výzkumu a prozkoumal, jak se rodiny ze dvou různých sociálních prostředí, Čínské lidové republiky a České republiky, přizpůsobily poškození sluchu dětí ve vzorku 160 rodin a probádal proces pozitivní adaptace čínských odolných rodin navzdory tomuto rizikovému vystavení. Kvůli výrazným odchylkám v definici a měření odolnosti a odolnosti rodiny v předchozích studiích byl v této studii termín odolnost rodiny definován jako systematická struktura skládající se z dopadu poškození sluchu jako výrazného ohrožení života rodiny, transakčního procesu poškození sluchu a ochranných faktorů a následků pozitivní adaptace díky vyrovnání se s poškozením sluchu, dobrému fungování a očekávání.

Na základě tohoto koncepčního rámce byl vypracován dotazník, jehož cílem bylo posoudit celkovou úroveň adaptace rodiny a identifikovat faktory vlivu včetně dopadu poškození sluchu dítěte na život rodiny, sociálního stigmatu, charakteristiky rodiny v rámci rodinné výkonnosti, soudržnosti rodiny a otevřené komunikace, změny víry rodiny na fatalismus, optimismus, altruismus a toleranci rozdílů a podpory vzdělání a vývoje dítěte ze strany rodiny a společnosti. Zjištění dotazníkového šetření ukazují, že (1) obecně vzato tyto dvě skupiny rodin jsou odolné, když čelí výzvě poškození sluchu dětí; (2) následky pozitivní adaptace mohou být připsány součinnosti faktorů dopadu poškození sluchu na život rodiny a na společenské stigma, charakter rodiny, změnu ve víře rodiny a na podporu ze strany společnosti.

Další srovnání naznačuje, že čínské a české rodiny nevykazují výrazný rozdíl v celkových následcích pozitivní adaptace, ale zato vykazují viditelné rozdíly v adaptivních vzorcích, protože čínské rodiny demonstrují mnohem vyšší úroveň stresu a více změn v přijetí poškození sluchu dětí a v soudržnosti rodiny v porovnání s prvními dny po diagnóze, jsou-li srovnány s českými rodinami. Obrovská mezera mezi oběma skupinami rodin spočívá v pomocných službách, jako například využití sluchových pomůcek, kochleárních implantátů, terapie a další sociální podpory včetně informační podpory ze strany odborníků, podpory ze strany společnosti týkající se volného výběru zvláštní nebo běžné školy a přístupu

k rodičovským skupinám, které by všechny mohly přispět k rozdílu v subjektivním hodnocení úrovně stresu mezi oběma skupinami rodin; nicméně navzdory zápornému dopadu poškození sluchu u dětí a nedostatku adekvátní podpory ze strany společnosti ochranné faktory

zahrnující soudržný vztah čínských rodin, otevřenou komunikaci a pozitivní změny ve víře rodin, jako například to, že se stanou více optimistické, altruistické a tolerantní vůči odlišnostem, a také pocity, že jim někdo pomáhá, možná přispěly k pozitivní adaptaci pozorované v čínských rodinách.

Následně proběhly podrobné rozhovory, které popsaly bohaté zkušenosti osmi čínských rodin, které bojují s poškozením sluchu dětí a které se mu pozitivně přizpůsobily. Kvalitativní analýza dat z polostrukturovaných rozhovorů dále potvrdila, že díky nedostatečné sociální podpoře ze strany sociálního systému a odborníků jsou čínské rodiny vážně zasaženy poškozením sluchu děti, vykazují především vysokou ekonomickou zátěž, komunikační potíže a malou možnost učinit informované rozhodnutí, co se týká sensorických pomůcek, způsobů komunikace a způsobu vzdělávání. Nicméně tváří v tvář tomu, že mají dítě s poškozením sluchu, využívají čínské rodiny strategie posunu zaměření života, přijetí toho, co se nedá změnit, zmobilizování všech možných zdrojů uvnitř i vně rodiny a učinění konkrétních kroků směřujících k cíli, jako například samostudium znakové řeči a intenzivnější práci, aby vydělali více peněz pro budoucnost jejich dítěte, atd. Toto všechno jim pomáhá se vyrovnat s poškozením sluchu dítěte a ukázat, že není nepřekonatelnou překážkou.

V neposlední řadě byla popsána nějaká doporučení týkající se pomocných služeb v Číně a omezení tohoto výzkumu.

Klíčová slova: odolnost rodiny děti poškození sluchu čínský český