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# How Chinese Hearing Parents Support Their Deaf Children to be Ready for and Educated at Mainstream Schools in Beijing, China

Xirong He

PhD

2016

# How Chinese Hearing Parents Support Their Deaf Children to be Ready for and Educated at Mainstream Schools in Beijing, China

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### **Abstract**

Alongside the social and economic reform of the 1980s, special education and inclusive education have been developing rapidly over the last three decades in China. Despite increasing research on the positive relationship between parental involvement and children's educational achievement, only a limited number of studies have begun to focus on how Chinese parents get involved in inclusive education in China. The aim of this research was to explore how a small group of Chinese hearing parents support their deaf children to be ready for and educated at mainstream schools in Beijing, China.

A qualitative research design combining constructivist grounded theory and autoethnography was applied to this study. Following the guidelines of Charmaz's grounded theory, intensive interviews were conducted with 10 Chinese hearing parents of deaf children in Beijing, China. All hearing parents were interviewed twice, resulting in 18 total interviews plus back-up interviews. Additionally, my own story of being a deaf person growing up and attending regular schools in Beijing, provided autoethnographic reflections on the data and codes.

The analysis of interview data has explored and developed a conceptual theory of parental involvement including three key categories: the effects of parental involvement, parental involvement strategies, and the barriers to parental involvement. Also, these findings showed that Chinese hearing parents' 'tried and tested' strategies for supporting their deaf child to be ready for and educated at mainstream schools and actively removing the barriers to their involvement.

In conclusion, the findings of this research discussed that these parents' attitudes towards deafness and inclusive education could influence their strategies in deaf diagnosis, early intervention, school settings and coaching their deaf child. And these findings suggested that this theoretical model of parental involvement could influence a deaf child's development in self-concept and deaf identity, contributing to the theories and practices of parental involvement and inclusive education for deaf children in China.

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### **Abbreviations**

CDPF: China Disabled Person's Federation

CDPPAT: China Disabled People's Performing Art Troupe

CLB: children left behind

CRPD: United Nations' Convention on the Rights of Persons with Disabilities

CRRCDC: China Rehabilitation Research Centre for Deaf Children

CRMW: children relocated along with migrant workers

CSL: Chinese Sign Language

EFA: Education for All

HIV/AIDS: human immunodeficiency virus / acquired immunodeficiency syndrome

IEP: Individual Education Plan

LRC: Learning in Regular Classrooms

MOE: Ministry of Education

NDRC: National Development and Reform Commission

NGO: Non-Governmental Organization

PRC: People's Republic of China

UNESCO: United Nations Education, Scientific and Cultural Organizations

UNHS: Universal Newborn Hearing Screening

WHO: World Health Organization

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In a word, a PhD study over 7 years tells me that 'a person's character isn't determined by how he or she enjoys victory, but rather how he or she endures defeat'. Thanks to a PhD study, my ability and confidence in conducting research has improved and my willpower has been strengthened.

This PhD thesis is dedicated to my family and to deaf people in China.

### **Declaration**

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the University Ethics Committee on 17<sup>th</sup> December 2009.

I declare that the Word Count of this Thesis is 81,985 words.

Name: Xirong He

Signature:

Date:

### **Chapter 1 Introduction**

### 1.1 Research background and context

China is a developing country with a population of 1.3 billion, and has a different culture and history from developed countries (e.g. USA, UK, etc.). It has experienced rapid development in its economy, society and education since opening its door to the world in 1979. Latterly, China's reform has taken place with the beginning of globalisation, especially economic globalisation (Liu and Yan, 2015). In this environment, globalisation not only promotes economic reform, but also influences national culture and values (Little and Green, 2009; Law, 2007; Liu and Yan, 2015). According to Hall (1992), national culture could be strengthened or threatened by the movement of globalisation. Hall (1992) further pointed out that national culture would become a hybrid of global-local interaction in a modernisation process, although globalisation is dominated by Western power. As far as the labels 'East' and 'West' are concerned, both terms 'are sometimes used to characterise the power structures underpinning policies and the nature of reorientations in different parts of the world' (Adamson et al, 2012, p. 3). However, this distinction is unwieldy and the boundaries of East and West are not a fixed way of looking at a map of the world (Adamson et al, 2012; Hayhoe and Pan, 2001). Thus, Hayhoe and Pan (2001) suggested that the boundaries of East and West are cultural rather than geographical and historical. They also pointed out that the West refers to the cultures influenced by the Enlightenment Europe and Christianity (e.g. Europe, North American, etc.). Furthermore, it is fallible to simply view globalisation as Westernization or Americanization from the perspective of essentialism (Turner and Khondker, 2010). Sayer (1997) asserted that essentialism as reductionism makes it hard to understand the multi-dimensional character of social science. Unlike essentialism, social constructionism claims that knowledge and social phenomena are socially constructed, and these constructions could be revisable (Sayer, 1997). From this perspective, it is suggested that globalization should be recognized as 'a

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<sup>&</sup>lt;sup>1</sup> Developing countries are defined as low income and lower-middle-income economies according to the World Bank Country Classification (http://data.worldbank.org/about/country-and-lending-groups).

multidimensional process' rather than 'a narrow, economic and exploitative process' (Turner and Khondker, 2010, p. 17), which 'impacts on the economic, political, cultural, social and educational dimensions of human activities in an increasingly interconnected and interdependent world' (Law, 2007, p. 18).

In terms of the relationship between education and globalisation, Little and Green (2009) suggested that education plays a vital role in enhancing the importance of knowledge and skills to engage with the global market. With the influence of globalisation, inclusive education has become a global agenda in the field of the education for children with disabilities across the developed and developing countries over the past thirty years. This agenda is reflected in the Salamanca Declaration, the Dakar Framework for Action, and the United Nations Convention on the Rights of Persons with Disabilities and so on, as discussed in the Literature Review Chapter section 2.1.2. Furthermore, Barton and Armstrong (2008) claimed that inclusive education refers to a diverse international movement, based on the fact that the terminology of 'inclusion' cannot simply be applied across countries with different cultures and languages. And what is more, inclusion is a slippery concept that is constructed and interpreted with different meanings to different people in different systemic, socio-economic and cultural contexts (Booth, 1995; Dyson and Millward, 1997). For example, the term of inclusion in the English context may imply more equity or social justice than that in the non-English discourse (Barton and Armstrong, 2008). Therefore, the notion 'inclusion' should be seen as a multidimensional process of removing the barriers to all kinds of marginalisation and exclusion in education, rather than representing universal ideology and shared values (Barton and Armstrong, 2008).

It is argued that Education for All (EFA) is strongly connected to national economic development and is influenced by global economics (UNESCO, 2000). Furthermore, Peters (2003) stated that financial support of the education for children with disabilities is the most important factor for all countries, regardless of available resources and training programmes. To take an example of Chinese education, the education of children with disabilities, either through special education or regular education, has been developing fast within China's economic reform. In this way, educational reforms for disabled children have been quickly promoted through the

implementation of several important laws for the disabled since the 1980s and the 1990s, such as the Compulsory Education Law (1986, 2006), the Law on the Protection of Disabled Persons (1990, 2008), the Regulations on the Education of the Disabled (1994) and so on. Furthermore, Artiles and Dyson (2005, p. 42) asserted that 'inclusive education is both an outcome of global economic trends and itself an instrument of the globalization of educational policy and ideology'. In other words, inclusive education has become to be a global education for children with disabilities across different countries. This approach not only enhances the educational development in developed countries, but also creates a global vision for developing countries. In response, Learning in Regular Classrooms (LRC) was introduced to offer opportunity and access to education for children with disabilities, particularly students with hearing, visual and/or intellectual impairment (Deng and Manset, 2000). Furthermore, LRC has been developed into a form of inclusive education for students with disabilities over the last 20 years (Ministry of Education, 2008). Therefore, the localized term LRC has begun to coincide with inclusive education in a global movement in the 21<sup>st</sup> century, as discussed in the Literature Review Chapter section 2.1.3.

### 1.2 Origin of research

Any research related to deaf education draws my attention because of my personal experience of being a profoundly deaf person who has grown up in a deaf and hearing world. I have included my personal story in the Appendix 10, but will briefly introduce myself here.

I was initially hearing at birth. Unfortunately, I became deaf at nearly 1 year old following an injection of 'Garamycin' to cure my high fever. It was a shock to my family, who were all hearing. I started to spend a large amount of time in hospitals with my parents in order to attempt to cure my deafness. At five years old, my parents were able to afford to buy me a pair of hearing aids. One year following this, I was educated in a deaf school with a pre-school classroom to receive listening and speech training. During this period in the deaf school, I worked hard with a teacher through one-to-one classes and learned Chinese words with deaf peers in group

classes. After school, my parents coached me in order to develop my language skills. My language improved a lot, compared to my deaf peers, through my intensive training in listening and speech with my teachers and parents. When I was 7 years old, my parents encouraged me to study at a local regular school. The journey of studying at a mainstream school was not easy for me. At the mainstream school, I was the only deaf student in my class, and I worked hard to learn and understand what teachers and hearing peers said. Meanwhile, my parents continued to be dedicated to me and offered great support while I was learning at the mainstream school.

When studying an undergraduate degree at Beijing Union University, I started to learn knowledge related to deaf education. After four years, I came to Northumbria University to study a Master's degree and then a doctoral degree. These learning experiences at university increased my professional knowledge of deaf education.

In keeping with my personal and professional experiences, I started to explore potential approaches and strategies of parental involvement for deaf children and this developed as the main topic of this PhD study.

### 1.3 Statement of study aim and research questions

The aim of this study is to explore how a small group of Chinese hearing parents support their deaf children to be ready for and educated at mainstream schools<sup>2</sup> in Beijing, China.

To shed light on the research problem, the following research questions are addressed:

1) How do Chinese hearing parents experience and deal with their child's deafness

<sup>2</sup> Mainstream schools in China mainly refer to Learning in Regular Classrooms (LRC). The term

LRC is not often used in academic research in developed countries (e.g. USA, UK, etc.), so it is suggested that terms like LRC, mainstreaming, integration and inclusion can be used interchangeably in this PhD thesis.

from birth through to early school age?

- 2) How do Chinese hearing parents support their deaf child to be ready for mainstream school in Beijing, China?
- 3) How do Chinese hearing parents help their deaf child to be educated at mainstream schools in Beijing, China?
- 4) What issues and challenges do Chinese hearing parents face in the process of raising their deaf child on the journey to a mainstream school? How did they deal with any arising issues?

### 1.4 Structure of the thesis

This thesis will be divided into seven chapters as below:

Chapter 1 briefly states four areas including research background and context, the origins of the thesis, the statement of study aims and research questions as above, as well as the structure of thesis as below.

Chapter 2 illustrates and reviews the academic literature available on three subjects: inclusive education in China, deafness and deaf education in China, and parental involvement in China.

Chapter 3 discusses symbolic interactionism as the philosophical stance of the qualitative research design, which combines constructivist grounded theory and autoethnography. It will also address the ethical considerations of this methodological approach.

Chapter 4 explains how this study was carried out with a small group of Chinese hearing parents of deaf children in Beijing, China, with reference to the research aim and questions. It also illustrates the process of interview data collection and analysis following the guidelines of Charmaz's grounded theory (2006, 2014). Finally, issues of qualitative validity and reliability are addressed.

Chapter 5 provides a detailed description of data analysis and interpretation.

Following the approach to constructivist grounded theory, a conceptual theory of parental involvement emerges, including three key categories: the effects of parental involvement, parental involvement strategies and barriers to parental involvement.

Chapter 6 provides critical discussions of the data analysis and conceptual theory related to the existing literature and research. It also identifies the important link between the model of parental involvement and deaf identity.

Chapter 7 provides a conclusion to this thesis through three sections: the contributions to knowledge, a critique of the research and recommendations for further research.

### **Chapter 2 Literature Review**

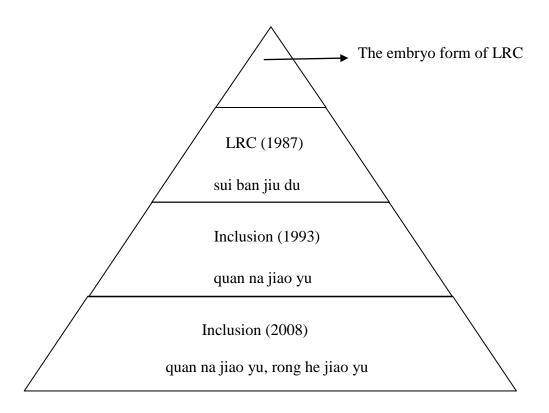
The Literature Review Chapter begins with an outline of the development of the concept of inclusion, alongside its Chinese version, 'Learning in Regular Classrooms' (LRC), which has developed since the 1980s. Following this, the subject of deafness and education for deaf children in China is outlined. Then, an overview of parental involvement for children with hearing impairments in China is discussed from the perspectives of inclusive education and deafness. Lastly, the gap between policy and practice is presented.

### 2.1 The development of inclusion in China

The aim of this section is to highlight the history and development of inclusion in China as shown in Figure 2.1 below.

The Chinese version of inclusion can be traced back to the implementation of Learning in Regular Classrooms (LRC) in 1987, where two different regions of China piloted education of children with visual and hearing impairments in mainstream classes. The worldwide version of inclusion was introduced in China via the 1993 Harbin Declaration, yet the term inclusion was used as a narrow concept which only referred to special education. In the 2000s, the concept of inclusion was broadened in China. According to a document reported by the P.R. China and Chinese National Commission for United Nations Education, Scientific and Cultural Organizations (UNESCO) in 2008, inclusion in education has broadened to encompass education for migrant workers' children, education for ethnic minorities and special education for specific disabilities. Over the last three decades, LRC has been integrated into the concept of inclusive education in China.

Figure 2.1 The development of inclusion in China (1980s-2010s)



### 2.1.1 Learning in Regular Classrooms (LRC) background and its policy

Sui ban jiu du<sup>3</sup>, literally translated as 'Learning in a Regular Classroom' (LRC), refers to 'a kind of carrying out education for students with special needs in general education institutions' (Piao, 2006, p. 55). Furthermore, 'learning in Regular Classrooms can be defined as government-supported arrangements for children with disabilities to be educated in neighborhood schools in classrooms with their peers who do not have disabilities' (Deng and Manset, 2000, p. 125).

There are two phenomena that led to the evolution of the LRC programme in China. One is that many children with disabilities were educated in regular schools in their local rural area. The other is that deaf children, who were previously educated in special schools which isolated them from their hearing peers, made attempts to enter

<sup>&</sup>lt;sup>3</sup> 'sui ban jiu du' in Chinese writing is 随班就读

regular schools (Xu, 2012). The combination of these factors in some areas of China resulted in professionals becoming engaged in developing a way of serving those students with disabilities in the general educational environment.

As mentioned earlier, the roots of the LRC movement can be traced back to two pilot programmes which provided regular education for students with hearing and visual impairments. In 1987, the initial experiment of LRC for deaf children started in Hailun, Heilongjiang province, where 85 deaf students received compulsory education in regular schools (Xiao, 2007). During a similar period, Xu Bailun involved blind children in a project named 'Golden Key Blind Children Education Plan' in Beijing, Shanxi, Jiangsu, Hebei, Heilongjiang and other provinces in China (Xu, 2012). Therefore, these two initial programmes of LRC began a national movement implementing LRC to provide regular education for students with one or more of three disabilities (i.e. visual impairment, hearing impairment and intellectual impairment) throughout China.

In 1989, the Ministry of Education (MOE) and the China Disabled Persons' Federation (CDPF) encouraged LRC approaches for students with visual and intellectual impairments in Beijing, Heibei, Jiangsu, Heilongjiang, Shanxi, Shandong, Liaoning, Zhejiang and other provinces in China (Chen, 2004). After 3 years, the MOE and the CDPF supported additional experiments in LRC approaches for students with hearing and speech impairments in Beijing, Jiangsu, Heilongjiang, Hubei and other provinces in China (Chen, 2004).

In 1994, the Ministry of Education held a conference on National Disabled Children Educated in Learning in Regular Class (LRC) in Yancheng, Jiangsu province. This conference discussed experiences of working within and issues in the implementation of LRC since 1989 (Chen, 2004). Following this conference, the Ministry of Education issued a regulation 'Temporary Measure on Learning in Regular Classrooms for Disabled Children and Adolescents' in 1994 (Chen, 1996; Chen, 2004; Zhao et al, 2011). This regulation viewed LRC as 'a major school-running measure to develop and popularize compulsory education for disabled children in China' (Zhao et al, 2011, p. 219). Therefore, this conference and regulation played an essential role in extensively spreading LRC approaches

throughout the nation.

### 2.1.2 Introduction of inclusion to China

Contemporary conceptualizations of inclusion in developed countries are mainly derived from the Salamanca Declaration. The World Conference on Special Needs Education was held in Salamanca, Spain, in June 1994 by UNESCO. Almost 400 people from 92 countries attended this conference, which announced that many countries in the world would be encouraged to promote inclusive education in their own country (Chen, 2004; Deng 2010). Additionally, the Salamanca Declaration formally addressed the concept of inclusive education and schools, and provided explanation on the context of inclusion. Inclusion was shown here to have absorbed the contexts of mainstreaming and integration in developed countries, such as the 1975 Public Law in the United States and 1978 Warnock Report in the United Kingdom.

The Salamanca Declaration has not only been adopted by a number of developed countries but also in a local context by a number of developing countries, including China. From this perspective, the Salamanca Declaration called on the international agenda for inclusion to advocate the concept of inclusion within special education systems (Armstrong *et al*, 2010). It could also be claimed that the popular terminology changed from 'mainstreaming' or 'integration' to 'inclusion' in the field of special education following the 1990s. For this reason, the new worldwide era of special education embarked on the implementation of inclusion after the 1994 Salamanca Declaration (Huang, 2001).

Before 1994, UNESCO also organized regional seminars to discuss a blueprint for inclusion in some areas of developing countries, including China. In 1993, UNESCO held a seminar on Special Education of Asia and the Pacific in Harbin, Heilongjiang province of China. It proposed the Harbin declaration, forming the initial framework of inclusive education. Also, this conference discussed the implementation of inclusion through the establishment of inclusive schools (Chen, 2004). At this conference, the concept of inclusion was introduced to China, and the English term

'inclusive education' was translated into the Chinese word 'quan na jiao yu'<sup>4</sup>(Piao, 2004). It was worth noting that the concept of inclusion appeared in the Harbin declaration of 1993, a year before the framework of inclusion was formally introduced in 1994 via the Salamanca declaration.

In April 2000, the world conference on Education for All (EFA) was held in Dakar, Senegal. It announced the World Declaration on Education for All, and the Dakar Framework for Action clearly stated that inclusive education was viewed as one of the main approaches to resolve issues of marginalization and exclusion (UNESCO, 2000). On the other hand, the 1990 EFA conference in Jomtien called for international awareness on special education, with the goal of developing an ideal which brings hope for all children and an impetus for transformation in national education systems. Following this, UNESCO produced Education for All Global Monitoring Reports each year from 2002. Particularly notable is the fact that EFA emphasized the word 'all' to cover everyone, rather than solely focusing on the poor and disabled (Armstrong, 2010; UNESCO, 2000). UNESCO (2005, p. 13) further suggested:

'Inclusion is seen as a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities, and reducing exclusion within and from education. It involves changes and modifications in content, approaches, structures and strategies, with a common vision which covers all children of the appropriate age range and a conviction that it is the responsibility of the regular system to educate all children.'

Similarly, the 2009 UNESCO policy guidelines on inclusion in education stressed the importance of inclusive education as a fundamental process for all learners.

A significant systematic framework in international policy was issued in the 21<sup>st</sup> century. This international policy was the United Nations 'Convention on the Rights of Persons with Disabilities' (CRPD), which came into effect on the 3<sup>rd</sup> May 2008. It proposed that the rights of people with disabilities were emphasized in law. Furthermore, it stressed that children with disabilities have the right to receive an education and be included in the general education system (Xu, 2012). China, as a member of United Nations, signed the declaration of CRPD on the 30<sup>th</sup> March 2007

<sup>4 &#</sup>x27;quan na jiao yu' in Chinese writing is 全纳教育

and ratified it on the 1<sup>st</sup> August 2008 (United Nations Human Rights, 2012). China submitted its first report on implementing the convention to the committee of CRPD in August 2010 and regularly submits national reports to the United Nations on the issues related to disabilities (United Nations Human Rights, 2012).

### 2.1.3 The conceptualization of inclusion in China

It is necessary to briefly discuss inclusion in developed countries and the related debates before providing an overview of the development of the conceptualization of the same issue in China.

There is diversity in the definition of inclusion in developed countries and the debate on the subject has been divided into two schools of thought: supporters for full inclusion and opponents of full inclusion (Deng, 2010; Armstrong *et al*, 2010). On the one hand, full inclusionists advocate that all students with disabilities should be involved in all aspects of school life provided by high-quality general education (Armstrong, *et al*, 2010; Deng, 2010). The opponents, on the other hand, do not agree with full inclusion and argue that, all students with disabilities should be educated in diversity-appropriate inclusive schools as far as the type and severity of their disability is concerned (Deng, 2010; Armstrong *et al*, 2010). Additionally, it is suggested that the context of inclusion cannot simply be interpreted as an opposite concept to that of exclusion (Armstrong *et al*, 2010; Armstrong and Barton, 2008). Like two sides of a coin, '*inclusion and exclusion are interrelated processes and their interplay constantly creates new inclusive/exclusive conditions and possibilities*' (Armstrong *et al*, 2010, p. 37).

A great deal of research (Slee, 2001; Ainscow, 1999; Barton and Armstrong, 2003; Barton, 2005; Armstrong, 2003) has discussed issues and challenges in inclusive schooling. In terms of inclusive education for children with disabilities, Barton and Armstrong (2003) suggested that inclusion is related to the wellbeing of all pupils and thus the participation of children with disabilities in mainstream schools should be strengthened. It is further argued that inclusive schooling could be improved by both increasing understanding of the concept of inclusion, and also by listening to the voices of students with disabilities, their parents and their teachers (Slee, 2001;

Ainscow, 1999; Barton, 2005; Armstrong, 2003). Recently, the importance of cultural diversity has been strengthened on the subject of inclusive education (Barton, 2005; Leo and Barton, 2006). Additionally, D'Alessio and Cowan (2013) discussed inclusive and special needs education and proposed that inclusive education can be interpreted differently in different countries or different areas of the same country in order to put the theory of inclusion into practice efficiently.

The term inclusion has not been used widely in China in the past, as it was previously only seen as a narrow concept referring to Learning in Regular Classrooms (LRC). As discussed in the previous section 2.1.2, the concept of inclusion has been broadened alongside development in understanding of practices and research in inclusion over the past two decades (Deng and Poon-McBrayer, 2004). Furthermore, on the one hand, as the concept of inclusion in developed countries has been developing, China has been trying to adopt this concept with a global version. On the other hand, the concept of inclusion in China has been influenced by the developing understanding inclusion within developed countries, such as Education for All (EFA). Therefore, inclusion in China becomes a multifaceted concept that encompasses a broad range of inclusive theory and practice. In addition to the education for children with disabilities (visual, hearing and learning disabilities), China's inclusive education includes other groups of children in mainstream schools, p. 'education in China's impoverished and ethnic minority areas' (Ministry of Education of the P.R. China, 2008, p. 23), 'education for children of migrant workers in China' (Ministry of Education of the P.R. China, 2008, p. 30), 'Education on HIV/AIDS prevention (in China)' (Ministry of Education of the P.R. China, 2008, p. 43) and 'education on disaster risk reduction in China' (Ministry of Education of the P.R. China, 2008, p. 47).

First, the purpose of education in China's impoverished and ethnic minority areas is to ensure the educational rights of people who are from poor and rural areas and/or ethnic groups and to develop the popularization of compulsory education (Ministry of Education of the P.R. China, 2008). Second, it should be acknowledged that education for children of migrant workers in China is mainly divided into two parts, p. one for children relocated along with migrant workers (CRMW) and the other for children left behind (CLB) (Ministry of Education of the P.R. China, 2008). Third, as

far as education on human immunodeficiency virus / acquired immunodeficiency syndrome (HIV/AIDS) is concerned, the Chinese government not only focused on educating children and teenagers to prevent themselves from becoming infected with HIV/AIDS, but also attached great importance to entitling HIV/AIDS patients and their children to education (Ministry of Education of the P.R. China, 2008). Fourth, regarding education on disaster risk reduction, it aims to enhance the students' safety awareness and the ability of self-rescue and mutual rescue, while also protecting students who live in areas of disaster risk and entitling them to education (Ministry of Education of the P.R. China, 2008).

It is an undoubted fact that special education is a central and important part of inclusive education in China. Furthermore, over many years China's special education has developed a systematic framework to provide multi-level educational opportunities for people with disabilities, such as pre-school inclusion and school inclusion (Ministry of Education of the P.R. China, 2008).

Both post-school inclusion and social inclusion are part of the concept of inclusion in China (Ministry of Education of the P.R. China, 2008). Post-school inclusion mainly refers to vocational education and employment skills for people with disabilities, and social inclusion covers the context of social welfare, as well as life skills, provided for people with disabilities. It has been suggested that vocational education can support independent living of students with disabilities and improve their life skills (Deng and Manset, 2000). In response, Beijing has expanded the enrolment rate for students with disabilities in vocation education and reinforced development in secondary vocational and technical education (Ministry of Education of the P.R. China, 2008). Vocational education in special schools is also available, for example 'painting for students with hearing impairment, massage and weaving for students with visual impairments, and sewing for those with mental retardation' (Deng and Manset, 2000, p. 128). However, these vocational education courses are not emphasized in rural areas of China, and such skills are not useful for people who live in these areas (Deng and Manset, 2000). As such, it is suggested that vocational education skills such as farming and handicraft work should be explored in areas where the economy is traditionally agriculturally-based (Deng and Manset, 2000).

### 2.1.4 Chinese and global versions of inclusion

This section 'Chinese and global versions of inclusion' is divided into two main sub-sections: the relationship between LRC and inclusion and the difference between LRC and inclusion.

### The relationship between LRC and inclusion

As discussed in the previous section 2.1.2, before the term of inclusion appeared in China in 1993, 'Learning in Regular Classrooms' (LRC) had been introduced at the end of the 1980s. For this reason, LRC programmes were developing before the worldwide emergence of inclusion.

There have been many different opinions about the relationship between LRC and inclusion. In developed countries, the framework of mainstreaming and integration gave impetus to the formulation of a systematic framework of inclusion. Furthermore, it can be argued that the co-existence of LRC and inclusion has sparked a national debate among Chinese professionals.

Recently, more and more professionals have agreed that the term LRC is similar to the concept of inclusive education. As Piao (1996, p. 43) explained:

'LRC shares some commonalities with the West's mainstreaming in terms of form, but possesses Chinese characteristics in such respects as point of background, guiding principles, and methods of implementation.'

It is necessary to clarify three phrases in the last sentence of the above quote. The first phrase, 'point of background' means that the implementation of LRC became popular providing compulsory education for students with disabilities in rural areas of China at the initial stage of the LRC programme movement (Xu, 2012). The second phrase, 'guiding principles', refers to the core value of collectivism<sup>5</sup> embedded in Communist education (Deng *et al*, 2001). Finally, 'methods of implementation' comply with the 1994 regulation 'Temporary Measures on LRC for

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<sup>&</sup>lt;sup>5</sup> Collectivism refers to when an individual acts in a society through the common identity of the community within a shared culture, the group's goals take precedence over individual goals (Sullivan, 2009; Wang & Liu, 2010).

Disabled Children and Adolescents' (Chen, 2004), which stipulated that LRC target students with any of three types of disabilities and encourages these students to be integrated in a regular class.

Recently, many Chinese professionals have come to agree that LRC is a part of inclusion following gaining a deeper understanding of the concept (Deng and Zhu, 2007; Chen, 2004). From this perspective of the history of inclusion, LRC resembles the mainstreaming/integration components of inclusion in developed countries to some extent. As a result, many Chinese professionals have recognized the difference between LRC and other homogeneous terminologies used in developed countries, such as mainstreaming and integration (Deng and Zhu, 2007).

### The differences between LRC and inclusion

The terminology of LRC is ambiguous to many professionals and has sparked debate when comparing Chinese LRC and inclusion, as explained in the previous section. It is worth noting that the differences between LRC and inclusion are summarized as follows:

Firstly, the terminology is different. The term 'sui ban jiu du' is translated as 'Learning in Regular Classrooms (LRC)' and only used in China, whereas the term 'inclusion' is recognized worldwide.

Secondly, the original idea of the inclusion concept is different. Inclusion emerges from the civil rights movement of the 1950s in the USA, where equality and freedom were formally demonstrated in the 1975 Public Law 92-142 (Reynolds and Fletcher-Janzen, 2002; Deng and Zhu, 2007). To take another example from the United Kingdom, inclusion began to appear in the 1978 Warnock Report following the introduction of disability categories in the 1944 Education Act (Armstrong and Barton, 2008; Armstrong *et al*, 2010). On the other hand, inclusion in China is quite complex, as some scholars argue that the concept has been influenced by the United States and Soviet Union (Deng and Zhu, 2007), while others disagreed, who suggested that the term 'sui ban jiu du' emerged from observing the initial phenomenon of schooling for students with disabilities in rural areas of China (Xu,

2012).

Thirdly, the philosophy of the theory on inclusion is different between China and developed countries. The philosophy of inclusion in developed countries is based on the right to equal opportunity and respect for pluralistic culture (Deng and Zhu, 2007). In contrast, equality has not been widely accepted in China in the past (Deng and Zhu, 2007) where culture was underpinned by 'a hierarchic pyramid of social relationships' because of the remnants of feudal ideology (Deng et al, 2001, p. 291; Deng and Zhu, 2007). Currently, governments in China are dedicated to establishing a harmonious society (Zhu, 2005, cited in Hu and Szente, 2010). In addition, it could be argued that the pilot programmes of the LRC were actually quick and economical ways to solve the problem of providing educational settings for students with visual, hearing and intellectual impairments in the major cities of China.

Fourthly, the attitude towards children with disabilities is different in the two cultures. Educators and professionals in rehabilitation in China often look at the disability instead of looking at the children themselves, making them strongly committed to fixing the disability. In recent years, LRC has gradually changed this connotation and begun to pay attention to the potential of children with disabilities. In developed countries, many professionals who work in the area of special education often look at the special needs of the children and discover their potential.

Fifthly, the theory model on inclusion is based on the different philosophies and attitudes between China and developed countries. It could be argued that LRC in China focuses on a remedial model rather than the educational needs model advocated by developed countries (Deng *et al*, 2001). Also, Communist education emphasized the remediation of students' disability, such as sensory rehabilitation and remedies for defects (Piao, 1988, cited in Deng *et al*, 2001), as influenced by Soviet theories and practices (Deng and Zhu, 2007). In the study of Hu (2010), Chinese teachers were likely to view children with disabilities as problems to be solved instead of special needs requiring attention. On the other hand, students with disabilities who are educated in inclusive education in developed countries have received attention in order to identify their special needs and encourage the abilities that they have (Deng and Zhu, 2007). This is emphasized by the fact that inclusive

schools in developed countries usually accept individual differences and diverse disabilities in order to ensure students with special needs receive an equal learning environment to peers without disabilities (Hu and Roberts, 2011). This is in contrast to China, which is dominated by the views of collectivism.

Sixthly, the goal of inclusion is different. The aim of LRC is to provide an opportunity for normal school life for children with disabilities, whereas inclusion adds the promotion of awareness of the right to receive an equal education.

Seventhly, the theory context of inclusion is different. Inclusion in developed countries contains the Individualized Education Programme (IEP), least restrictive environments, parental involvement and so on (Deng et al, 2001). However, these were not strongly stressed in the origins of the LRC movement. Within the trend of inclusion in China, LRC has started to apply the IEP to instructions for students with disabilities in general classrooms (Deng and Poon-McBrayer, 2004). In addition, the regulation 'Temporary Measure on Learning in Regular Classrooms for Disabled Children and Adolescents' stipulated that IEP should also be applied (Deng and Poon-McBrayer, 2004). Nevertheless, this regulation did not strongly require professionals or teachers who work with children with disabilities in kindergarten to write an IEP, although they expressed their desire for it to be conducted (Hu, 2010). From this perspective, although IEP is becoming a component of LRC programmes, it is not a mandatory responsibility (Ding et al, 2006; Hu, 2010), and there is still a lack of legislation and training on its application (Hu, 2010). Therefore, it is acknowledged that LRC at the initial stage is simpler and less systematic than inclusion in developed countries because of its lesser focus on the principles of IEP, least restrictive environments and so on (Deng et al, 2001).

Eighthly, student recruitment in inclusive education is different. Most types of children with disabilities are welcomed in inclusive education; however, LRC is restricted when recruiting students with disabilities. Only three main types of children with disabilities can engage in LRC: those with visual impairment, hearing impairment and mental retardation (Deng and Zhu, 2007).

Although the conflicting messages between LRC and inclusion exist in China, such

differences diminish with the upward trend towards global inclusion.

### 2.1.5 Inclusion and Learning in Regular Classrooms (LRC) in the 21st Century

Following debates on the two concepts in the 21<sup>st</sup> Century, there is a prevailing view that LRC and inclusion are co-related.

It could be argued that the detail of LRC was not seen as contradictory to the concept of inclusive education after the 1994 announcement of the Salamanca Declaration concerning inclusion (Deng and Zhu, 2007). However some scholars stated that none of the approaches to inclusion used by any one country can be adapted into other countries, especially China because of its social culture and economy (Piao, 1998, cited in Deng and Zhu, 2007). Despite this, LRC has enriched its theory and practice by incorporating the concept of inclusion (Deng and Zhu, 2007). In other words, many professionals have generally realized the issues and the constraints of implementing LRC. As such, it has been summarised that 'LRC falls within the domain of inclusive education' (Deng and Zhu, 2007, p. 26).

### The practices of inclusive education in China

This section provides an overview of the development of inclusive education in China from the perspective of a chronology of child education. From this perspective, education for students with disabilities in China has experienced two types of inclusive education in the past: pre-school inclusion with the provision of early childhood education and rehabilitation services and school inclusion with the provision of LRC.

### **Pre-school inclusion**

Since 2011, it has been claimed that the influence of inclusion has extended to kindergartens in major cities such as Beijing (Hu and Roberts, 2011), yet still lags behind the development of school inclusion which began in the 1990s. For example, the Beijing Municipal Commission of Education (BMCE) recruited 5 top-quality kindergartens as pilot pre-school inclusive schools in 2001, and this number

increased to 18 in 2008 (Hu and Roberts, 2011). This demonstrated that the quality of kindergartens is rated through 'a mandatory process performed by the BMCE on a yearly basis' (Hu and Roberts, 2011, p. 549).

Recently, pre-school inclusion has been initiated and developed through the establishment of early childhood education and rehabilitation institutes, which mainly deliver the service of early childhood care and education to children with disabilities. Generally speaking, rehabilitation and early childhood institutions serve children from 0-6 years old in two groups: nurseries for children aged 0-3 and kindergartens for children aged 3-6 (Ministry of Education of the P.R. China, 2008; Corter et al, 2006). Additionally, services of rehabilitation for people with disabilities vary, including cataract operations to restore eyesight, listening and speech training and limb correction and so on (Ministry of Education of the P.R. China, 2008). Furthermore, most early childhood education and rehabilitation services are often in segregated settings, which may include physical training for children with physical disabilities, listening and speech training for children with hearing disabilities, and behaviour training for children with autism (Liu and Zeng, 2007, cited in Hu, 2010). It was reported in 2008 that over 80% of children with visual, hearing, language and mental disabilities in urban areas had received rehabilitation training during their early childhood years (Ministry of Education of the P.R. China, 2008). Nevertheless, the context of pre-school inclusion is quite new in China and is an on-going process exploring the provision of adequate resources and practical guidelines which will facilitate its development (Hu and Roberts, 2011).

It is suggested that a kindergarten classroom has a lead instructional teacher and a teaching assistant who are qualified with a degree in early childhood education for 3-4 years, for teaching children aged 3-6 (Hu and Roberts, 2011). On average, two teachers and one teaching assistant would have around 35 children in their class, ranging from 20 children aged 2-3, 25 children aged 3-4, 30 children aged 4-5, and 35 children aged 5-6 (Hu and Robert, 2011; Zhu and Wang, 2005). In rural kindergartens, there may be only one teacher who must teach a larger group than their urban equivalents (Corte *et al*, 2006). Furthermore, many children who live in the city usually receive 3 years of pre-school education at kindergarten, while many

children in rural areas attend a one-year kindergarten attached to the village primary school (Zhao and Hu, 2008). In 2001, it was found that approximately 26.41% of children in rural areas and 61.48% of children in urban areas had received early childhood education (Chen, 2003, cited in Liu and Raver, 2011). Therefore, there is a wide disparity in early childhood education between rural and urban areas of China.

### **School inclusion**

Under the influence of inclusion in China, there is no denying the fact that LRC programmes are the main form, and special schools are the foundation of school inclusion in China. It was also clear that:

'the Chinese government has instituted a special education system for disabled persons from kindergartens to senior middle schools, basically setting up a curricular teaching material system for blind and deaf schools, basically setting up a special education pattern with special education schools as the backbone, and special education classes attached to, and attendance of individual disabled students in, ordinary schools as the main body.' (Ministry of Education of the P.R. China, 2008, p. 16)

Recently, the concept of inclusion has been formally implemented in and exerted great influence over the nation, since China signed the CRPD in 2007. The CRPD not only states that children with disabilities should be supported by inclusive education in order to achieve the goal of full inclusion, but also that attention should be paid to the voice of children with disabilities and their choices to access education should be acknowledged (Human Rights Watch, 2013). Therefore, it is important for children with disabilities to have varied choices when in mainstream or special schools.

The Chinese government has entitled children with disabilities to the equal right of inclusive education through implementing a series of relevant laws and regulations (Ministry of Education of the P.R. China, 2008). For instance, the 1994 Regulation on the Education of the Disabled suggested that the relevant disability organizations should not only deliver care and rehabilitation to people with disabilities, but also provide children with disabilities with regular education (Hu, 2010). In response, Temporary Measures on "Learning in Regular Classrooms" for Disabled Children and Adolescents was issued in 1994 and formulated the policy framework of LRC

(Zhao *et al*, 2011). However, this does not mean that all students with disabilities can be educated within inclusive education with the support of LRC programmes, as there is insufficient support for those with complex needs within the main three forms of impairment (hearing, visual and intellectual). It could be argued that there is no explicit standard of recruitment in LRC programmes when children with disabilities start school life. With the development in LRC programmes, the standard in recruiting students with a disability has been changed. For example, in Beijing it is suggested that LRC programmes recruit only lower levels of severe disability (for example, hearing loss from 41 to 60 dB), and this programme has expanded to seven types of disability: visual impairment, hearing impairment, language impairment, physical impairment, intellectual impairment, psychiatric impairment and multiple impairments (Beijing Disabled Persons' Federation, 2013).

On the other hand, the Regulations on the Education of the Disabled have declared that students with disabilities have the ability to receive regular education, and their learning capacity can be offered through an opportunity to attend inclusive schools (Human Rights Watch, 2013). This decision was made by a group of experts who worked in the field of special education and school administrators, including teachers and principals (Human Rights Watch, 2013). However, the judgement of involving students with disabilities in inclusive education must be advocated by the families of children with disabilities (Human Rights Watch, 2013).

The Chinese government has made joint efforts with local governments and all social circles to promote the development of inclusive education (Ministry of Education of the P.R. China, 2008). For example, the Ministry of Education (MOE) and China Disabled Persons' Federation (CDPF) launched a project called 'Helping the disabled to receive education' in Chengdu, Sichuan province, on the 26<sup>th</sup> May 2002 (Ministry of Education of the P.R. China, 2008). This project aimed to offer financial assistance to children with disabilities, especially targeting poor and disabled children, through both an exemption from miscellaneous fees and subsidies for studying and living (Ministry of Education of the P.R. China, 2008). The government also offered financial assistance for 5000 poor and disabled children to receive compulsory education in 16 provinces, including Sichuan, Gansu and Anhui, from 2002 to 2006 (Ministry of Education of the P.R. China, 2008). Also, in the central

and western areas of China, MOE and National Development and Reform Commission (NDRC) carried out 'the 2008-2010 Plan of Special Education School Construction in Central and West China during the 11<sup>th</sup> Five-Year Plan' with joint investment from local governments at various levels and with a wide cross-section of society (Ministry of Education of the P.R. China, 2008). The goal of this project is to promote development in special education with joint investment through building, reconstructing and expanding special education schools (Ministry of Education of the P.R. China, 2008). In addition, many primary and middle schools in China have initiated inclusive education within international trends of inclusion (Hu and Roberts, 2011).

The 12<sup>th</sup> Five Year National Education Programme (2011-2015), issued in July 2010, addressed a clear framework for building more special education institutions. However, it lacked a plan to provide more mainstream schools for students with disabilities (Human Rights Watch, 2013). Recently, some cities and provinces in China, especially coastal regions, committed to inclusive education. For example, Beijing announced that it would allocate resources to mainstream schools and stop building more special schools from November 2012 (An, 2012). It is further suggested that it will hire professional rehabilitation teachers to work in mainstream schools in order to provide professional support to help students with disabilities be integrated into mainstream schools (An, 2012).

In summary, both pre-school inclusion and school inclusion have developed over the past three decades in China. For this reason, significant progress has been made in the area of inclusive education for people with disabilities in the nation.

# The achievements of LRC and inclusion in China

LRC has not only improved public awareness of and positive attitudes towards disability, and at least reduced discrimination against disabilities, but it also changed the traditional education system and provided more placements for students with disabilities in recent years.

There is no denying that LRC has increased social awareness of disabilities and

special education through introducing increased positive images of people with disabilities (Deng and Poon-McBrayer, 2004; Piao, 2006). For instance, many students with disabilities went to regular schools to receive compulsory education with peers without disabilities because of LRC, and this phenomenon makes people more aware of children's disabilities. From this perspective, the implementation of the pilot programmes of LRC have changed people's knowledge of disability, meaning they are more likely to know that some students with disabilities can be educated in a learning environment surrounded by peers without disabilities. Furthermore, the implementation of LRC has changed the public's traditional stereotypes of disabilities because the mixture of students with disabilities and typical development in a regular classroom seldom happened before such programmes. An achievement of LRC programmes has been the elimination of serious discrimination against disabilities to some extent. It is well known in China that the 'National Day of Assisting Disabled Persons' is designated on the third Sunday of May each year. The government and media promote the rights of people with disabilities through publicity slogans and banners regarding knowledge of disabilities on that day (Deng and Poon-McBrayer, 2004). In order to develop public awareness, groups of people with disabilities have an opportunity to show their abilities and skills in the community and public on that day. For instance, students with visual impairments provide free massage services to people, students with hearing impairments perform dances and so forth. Furthermore, more and more Chinese people with disabilities are encouraged to take part in sports, through events such as the Paralympic Games. Also, the China Disabled People's Performing Art Troupe (CDPPAT) has travelled nationwide in China and this team has internationally performed their art activities, such as A Thousand Hands, which is performed by 21 deaf people (CDPPAT, 2008).

The introduction of LRC has changed China's traditional education system (Huang, 2001). Before the introduction of LRC, general education and special education were separated (Huang, 2001) and the only way to develop special education was through running special schools (Deng *et al*, 2001). After establishing LRC programmes, special education systems mainly consists of special schools and regular schools with LRC programmes (Deng *et al*, 2001; Deng and Zhu, 2007; Deng and Poon-McBrayer, 2012; Deng and Pei, 2009). In addition, it was suggested that

regular education should run alongside special education and both should make progress together under the influence of inclusion (Lei and Deng, 2007). For example, regular schools provide the opportunity to access education for students with disabilities and should build a relationship with special schools. On the other hand, special schools should deliver the resources and consultation for the ordinary school's staff and students with disabilities. Therefore, attention should be paid to the partnership between general and special education within the context of inclusive education.

The number of students with disabilities in mainstream schools has increased in recent years. For example, the total number of the students with disabilities who were receiving higher education in mainstream schools was 6,586 in 2009, 6,273 in 2008, 5,234 in 2007 and 4,148 in 2006 (CDPF, 2009). It is further reported that 545,000 students with disabilities received education, and 61.78% were placed in mainstream schools or special classes within a mainstream school in 2009. However, over 211,000 students with disabilities at school age did not have access to education by the end of 2009 (CDPF, 2009). In 2010, the enrolment rate for children with disabilities who received education in the nation was 71.4% (Yu *et al*, 2011). In 2011, 7,674 students with disabilities were educated in mainstream colleges, whereas 1,057 students with disabilities received education in special schools (CDPF, 2011). Therefore, the numbers of students with disabilities in mainstream schools has exceeded that of special schools in 2011 (Xu, 2012). Although there are no official government figures reported for mainstream schools' enrolment rate of deaf children, informal reporting (for example via the media) has indicated an increase since 2012.

The National Plan for Medium and Long Term Education Reform and Development 2010-2020 has demonstrated goals in educational development for people with disabilities. Furthermore, Chapter 10 of this National Plan has emphasised the importance of special education by stating that the Chinese government and its local governments shall speed up the development of special education and put it high on their agenda (Ministry of Education, 2010). This Chapter also suggests that every school shall create positive opportunities for children with disabilities to access compulsory education and expand the provision of LRC or regular schools with special classrooms (Ministry of Education, 2010). Xu (2012, p. 39) further claimed

that 'equal access to education and education quality has become the main concern of development in the next century'. From this perspective, LRC programmes have also faced the challenges of expanding provision for special education within regular classes and increasing access to equal education for children with disabilities (Xu, 2012).

Therefore, there has been a significant shift in the understanding of inclusion in China over a long period, from fixing children's disabilities through rehabilitation institutes to building a learning environment of curriculum and instruction that can accommodate the special needs of children (Hu *et al*, 2011).

# The challenges of inclusive education in the 21st century

Despite the achievements that have been attained over the last 25 years, there are a number of challenges and limits to the implementation of LRC and inclusive education in China.

Firstly, although many students with disabilities have been included in mainstream schools, LRC and inclusive education in China lacks a systematic evaluation framework (Deng and Manset, 2000). For instance, it has paid a great deal of attention to the rate of enrolment in general education and academic performance. However, it is acknowledged that LRC has overlooked the development of social and life skills (Deng and Zhu, 2007). From this perspective, it could be argued that the quality of mainstream schools is much more significant than the quantity of students with hearing impairments at mainstream schools.

Secondly, it is agreed that implementing inclusion is not just about physically including students with disabilities in a general classroom, but it can be extremely challenging to ask students with disabilities to participate in group activities with peers without disabilities (Hu, 2010). It is reported that some students with disabilities have been isolated in mainstream classes, often only sitting in the classroom without being able to follow conversations with their teachers and peers (Deng *et al*, 2001). For this reason, this common phenomenon in LRC practice has been dubbed 'drifting in the regular classroom' (Deng and Manset, 2000, p. 127;

Deng et al, 2001). It is also jokingly called 'sit along with the class' or 'muddle along with the class' (Human Rights Watch, 2013, p. 4), illustrating that many students with disabilities are observed as only being superficially included in class without being able to learn (Human Rights Watch, 2013). As a result, the body of students with disabilities exists in the mainstream classroom, yet their mind is outside of the mainstream class. Therefore, the performance of students with disabilities would be affected and their self-confidence limited (Human Rights Watch, 2013).

Thirdly, there are four main issues relating to special education teachers for students with disabilities: inadequate numbers of teachers in special education, lack of awareness, lack of time and resources, and great pressure from the competition system. It can be argued that the number and quality of special education teachers has been incompatible with the astronomical number of children with disabilities, both in mainstream and special schools (Feng, 2010). Furthermore, among students who graduated with a bachelor degree in special education from the 4 main universities in China (i.e. Beijing Normal University, East China Normal University, Central China Normal University, Southwest China Normal University), very few are available to teach children with disabilities in schools. Also, most teachers who became special education teachers continued to work in special schools or special classes while very few became teachers in mainstream schools or LRCs

#### 2.2 Deafness and education for deaf children in China

The aim of this section is to discuss the different perspectives of deafness with reference to Chinese culture and outline the development of education for deaf children in China. This section will begin with an overview of disability before discussing Chinese perspectives of deafness, including deafhood, deaf culture and deaf identity. Finally, it will explain the education for deaf children in the early years in China.

#### 2.2.1 Legislative movement for people with disabilities in China

In the last three decades, China's special education has undergone tremendous change, including passing some important policies and legislation as shown in Table 2.1.

Table 2.1 Laws and regulations related to disability in People's Republic of China (PRC)

| Laws and regulations name         | The first version             | The amended version                           |
|-----------------------------------|-------------------------------|---|
| Constitution of the People's      | 4 <sup>th</sup> December 1982 | 12 <sup>th</sup> April 1988, 29 <sup>th</sup> |
| Republic of China                 |                               | March 1993, 15 <sup>th</sup>                  |
|                                   |                               | March 1999, 14 <sup>th</sup>                  |
|                                   |                               | March 2004                                    |
| Decisions on Reforming the        | 27 <sup>th</sup> May 1985     |   |
| Education System                  |                               |   |
| The Compulsory Education Law of   | 12 <sup>th</sup> April 1986   | 29 <sup>th</sup> June 2006                    |
| the PRC                           |                               |   |
| The Law of the PRC on the         | 28 <sup>th</sup> December     | 24 <sup>th</sup> April 2008                   |
| Protection of Disabled Persons    | 1990                          |   |
| The Regulations of the PRC on the | 23 <sup>rd</sup> August 1994  |   |
| Education of the Disabled         |                               |   |
| The Education Law of the PRC      | 18 <sup>th</sup> March 1995   | 8 <sup>th</sup> January 2001                  |

The first law to address the provision of special education in China is written in Article 45 of the Constitution of 1982. And, the recent Constitution was amended on the 14<sup>th</sup> March 2004, which declares that 'the State and society help make arrangements for the work, livelihood and education of the blind, deaf-mutes and other handicapped citizens' (National People's Congress, 2004).

In 1985, the Regulation on Decisions on Reforming the Education System proposed a blueprint for compulsory education and the provision of special education. This regulation not only gave impetus to the subsequent laws and regulations, but also had a deep influence on the reform of special education today.

In order to protect citizens' rights to receive an education, the Compulsory Education Law of the People's Republic of China was issued on the 12<sup>th</sup> April, 1986. It stipulated that the government should carry compulsory nine-year education, which consists of 6 years primary and 3 years middle school education. Twenty years later, the government proposed a new amendment to this law on the 29<sup>th</sup> June 2006 (National People's Congress, 2006). According to Article 11 in the Compulsory Education Law, parents or other legal guardians should send their child to a school at the age of six and guarantee their child's completion of compulsory education. If these conditions are not appropriate for some children, the beginning of their schooling may be postponed until the age of seven (National People's Congress, 2006). Furthermore, Article 19 of this law stipulates that mainstream schools should accept students with visual, hearing and intellectual impairments, and offer help in developing their skills in learning and rehabilitation (National People's Congress, 2006). This law also stipulates that special schools should meet the needs of students with disabilities and provide an appropriate environment for learning, rehabilitation and living according to the different disabilities of the students (National People's Congress, 2006).

Another law on disability is 'the Law of the People's Republic of China on the Protection of Disabled Persons' which was promulgated on the 28<sup>th</sup> December 1990. This law was not only considered as a civil rights act, but also as the first law to address the rights of individuals with disabilities (Ellsoworth and Zhang, 2007). After 18 years, this law was amended and passed again on the 24<sup>th</sup> April 2008 (CDPF, 2008). Chapter 1 Article 2 of this law addresses 'a disabled person refers to a person who suffers from the loss or abnormality of a certain organ or function, psychologically or physiologically, or in human structure, and has lost all or in part the ability to perform an activity in the way considered normal' (CDPF, 2008). In addition, Article 48 of this law proposed that the 'National Day of Helping the Disabled Persons' is held on the third Sunday of May every year. The first National Day of Helping the Disabled Persons was 15<sup>th</sup> May, 1991, which increased public awareness of disability while providing a range of information regarding disability (Ministry of Education of the P.R. China, 2008). Over more than 20 years, activities are organized on that special day with different themes each year.

The Regulations of the People's Republic of China on the Education of the Disabled were enforced on the 23<sup>rd</sup> August 1994 by the State Council (State Council, 2011). Furthermore, these regulations were the first to specifically address disabled people's education in order to protect their equal rights to access education for people with disabilities and promote the development of special education in China (State Council, 2011). Also, these regulations included all students with disabilities, even those with more than three kinds of disability as explained in the Compulsory Education Law of 1986. And what is more, these regulations stated that schools must accept children with disabilities and provide assistance to meet their needs as addressed in Article 21. Moreover, Article 14 declared that parents and other legal guardians should enable their children with disabilities to receive compulsory education. In addition, Article 15 stated that children with disabilities should be allowed to enter schools at the same age as their peers, or at a later age if necessary (State Council, 2011).

'The Education Law of the People's Republic of China' was passed on the 18<sup>th</sup> March 1995 (National People's Congress, 1995). This law was amended in accordance with the decision of the State Council on abolishing and amending some administration regulations on 8<sup>th</sup> January 2011 (State Council, 2011). Furthermore, this law stated that education should receive investment and support from financial departments of central and local government (Chai and Cheng, 2011), as addressed in Chapter 7. It was also asserted that new systems of financial investment in education should be written in law through financial support from the government and complementary support through state-owned enterprises, social donations and other educational organizations (Zhang, 2011). In addition, not only parents and other caregivers should provide support for their child and cooperate with schools or educational organizations, but also schools and teachers should provide guidance on home education for parents of their students, according to Article 49.

## 2.2.2 The role of definitions related to disability in organizational changes

The China Disabled Persons' Federation (CDPF) was established on the 11<sup>th</sup> March 1988, and then developed into five different branches: China Association of the Deaf

and Hard of Hearing, China Association of the Blind, China Association of the Physically Handicapped, China Association of Persons with Intellectual Disabilities and their Families, and China Association of Persons with Mental Disabilities and their Families (CDPF, 2014). Chaired by individuals with disabilities, the CDPF not only facilitates many schools for students with disabilities, but also promotes the rights of students with disabilities in poor areas to education (CDPF, 2013).

The China Disabled Persons' Federation (CDPF) organized two surveys in 1987 and 2006 to examine the development of special education and disability services. These surveys offer some interestingly different results, as discussed below.

## Disability categories changes

In 1987, the China National Sampling Survey was conducted for the first time and summarized that 4.90% of people had disabilities in six categories: 16.79% with hearing impairments, 9.65% with intellectual impairments, 7.16% with visual impairments, 1.84% with psychiatric impairments and 6.38% with multiple impairments (CDPF, 2008a). These numbers were slightly changed after the second China National Sampling Survey on People with Disabilities in 2006. It found that 6.34% of people were identified as people with special needs in seven categories: 14.86% with visual impairments, 24.16% with hearing impairments, 6.68% with intellectual impairments, 29.07% with physical impairments, 1.53% with language impairments, 7.40% with psychiatric impairment, and 16.30% with multiple impairments (CDPF, 2008b). Compared with first survey taken in 1987, the number of people with disabilities increased from 51.64 million to 82.96 million due to the changed structure of the population and the social environment (CDPF, 2008b). Meanwhile, one additional category of disability, language impairment, was added in the survey conducted in 2006. Furthermore, the second survey assessed that 63.19% of children with disabilities aged 6-14 were receiving compulsory education, either public or special education (CDPF, 2007). In addition, the number of students with hearing impairments attending mainstream schools has increased from 45% to 85.05% from 1987 to 2006 with the implementation of LRC (CDPF, 2007).

# Hearing loss categories changes

It is worth noting that the standard of classification in hearing impairments has been modified in terms of the first and second China National Sampling Survey on People with Disabilities (see Table 2.2 and Table 2.3).

Table 2.2 Classification in hearing impairments in 1987

| Classification  | Grade of impairments                     | Hearing loss level |
|-----------------|--|--------------------|
| Deaf            | 1 <sup>st</sup> grade of deaf            | >91 dB             |
|                 | 2 <sup>nd</sup> grade of deaf            | 71-90 dB           |
| Hard of hearing | 1 <sup>st</sup> grade of hard of hearing | 56-70 dB           |
|                 | 2 <sup>nd</sup> grade of hard of hearing | 41-55 dB           |

Source: the first China National Sampling Survey on People with Disabilities in 1987

Table 2.3 Classification in hearing impairments in 2006

| Classification | Grade of impairments                         | Hearing loss level |
|----------------|--|--------------------|
| Hearing        | 1 <sup>st</sup> grade of hearing impairments | >91 dB             |
| impairments    | 2 <sup>nd</sup> grade of hearing impairments | 81-90 dB           |
|                | 3 <sup>rd</sup> grade of hearing impairments | 61-80 dB           |
|                | 4 <sup>th</sup> grade of hearing impairments | 41-60 dB           |

Source: the second China National Sampling Survey on People with Disabilities in 2006

From the above tables, it is clear that terms related to hearing loss have been changed from 'deaf' and 'hard of hearing' to 'hearing impairments'. According to the second survey taken in 2006, the term of hearing impairments is defined as 'referring to different levels of permanent hearing loss caused by various reasons, leading to the fact that people with hearing loss cannot hear clearly the sound of language and surrounding environment, affecting their engagement in daily routine and social activities' (CDPF, 2006). Furthermore, it is noted that the grade of impairments has been slightly modified and relevant hearing loss levels have been revised. For example, the hearing loss level within the 2<sup>nd</sup> grade of hearing impairments has risen

from 71dB to 81dB, and the hearing loss level within the 4<sup>th</sup> grade of hearing impairments has increased by 5dB. From this perspective, the level of hearing loss has been raised by the more scientific stipulations.

# 2.2.3 Chinese perspectives of deafness

The section 'Chinese perspectives of deafness' is mainly divided into two sub-sections: the understanding of deafness<sup>6</sup> and the models of deafness.

## The understanding of deafness

In English, deafness is mainly categorized by two types of appearance in writing, one is deaf (lower-case) and the other is Deaf (upper-case). The former often describes the majority of people who have different levels of hearing loss and views deafness as a hearing impairment (Corker, 1998). And the latter refers to another group of people who recognize themselves as members of the Deaf community, which has a unique deaf culture (Corker, 1998; Ladd, 2003). This unique culture of the Deaf community views sign language as the first or mother language and then views English as the second language.

Furthermore, Padden and Humphries (1988) suggest that the boundaries between deaf and Deaf are not rigid. On the one hand, deafness includes the Deaf group, and deaf people may become Deaf when they learn the knowledge and beliefs of Deaf culture (Padden and Humphries, 1988). On the other hand, Deaf people are part of both the Deaf and deaf groups, and all share the condition of not hearing (Padden and Humphries, 1988; Corker, 1998). In order to remove such confusions, it has been suggested that the twinning of "d/Deaf" might deal with the distinctions between big D and little d 'deafness'. Therefore, d/Deaf refers to all deaf people, oral language users, sign language users or users of both (Brueggemann, 2008).

<sup>-</sup>

<sup>&</sup>lt;sup>6</sup> The term deaf with a small d and the other term Deaf with the big D can be used interchangeably in this PhD thesis according to Chinese cultural background. The Deaf with the big D lays emphasis on the group of deaf people who are part of a Deaf culture with sign language and are involved in the Deaf community.

In 2010, a new term, 'DeaF', attempts to distinguish between 'deaf' and 'Deaf'. The term 'DeaF' is defined as 'a linguistic marker of a fluid nature of the bicultural deaf person's identity that is situated between both the Deaf and the hearing worlds, hence the emphasis of the F in DeaF' (Mcilroy and Storbeck, 2011, p. 510).

However, the capital D of Deaf in developed countries is not likely to be understood by deaf communities and cultures in developing countries (Ladd and Lane, 2013). To take the example of China, deafness is not case-sensitive in the orthographic structure of the Chinese character '聋', which is totally different from the English writing of deafness in both lower-case and upper-case appearances. The Chinese character '聋' could be translated into English as 'deafness' or 'deaf'.

It is well known that an estimated 80% to 90% of Chinese characters are semantic-phonetic characters (Shu *et al*, 2003), including the Chinese character '聋' as shown in Figure 2.2. Furthermore, 聋 (long2, deaf/deafness) is a semantic-phonetic character with 龙 (long2, dragon) at the top as the phonetic component, which provides the pronunciation of the character, and 耳 (er3, ear) at the bottom as the semantic component, which provides the meaning of the character. As a result, 聋 (deaf/deafness) shares pronunciation with 龙 (dragon) as the top component and gives information related to 耳 (ear) as the bottom component.

Figure 2.2 Chinese character of deaf/deafness<sup>7</sup>

聋 (long2, deaf/deafness) =龙 (long2, dragon) +耳 (er3, ear)

From this perspective, it is clear that deafness in Chinese characters means "dragon cannot hear" or 'the dragon ear' depending on the interpretation' (Yang, 2011, p. 342). However, it could be argued that this interpretation could reflect her way of viewing deafness in Chinese characters which only relates to a dragon as an animal, not related to human beings. Consequently, when deafness in Chinese characters is

 $<sup>^7</sup>$  Note: Chinese Mandarin has four tones:  $1^{st}$  tone is high-level tone,  $2^{nd}$  tone is rising tone,  $3^{rd}$  tone is low or dipping tone,  $4^{th}$  tone is falling tone. (https://en.wikipedia.org/wiki/Standard\_Chinese\_phonology)

related to a human being's hearing, it can be seen as a person is so deaf that he/she cannot hear loud sounds, such as the roars of a dragon.

In order to promote public awareness on hearing loss and hearing impairment, National Ear Care Day occurs on the 3<sup>rd</sup> of March every year. Public awareness of deafness has increased since the first National Ear Care Day in 2000 which featured the theme 'Preventing deafness caused by ototoxic drugs'. Furthermore, the date of the 3<sup>rd</sup> of March demonstrates the meaning of people with hearing impairments, as it is symbolized by double ears in the shape of two number threes written in normal and reverse directions (WHO, 2013). Additionally, China's considerable efforts to increase public awareness in preventing hearing loss have gained the recognition of the World Health Organization (WHO). In response, the First International Conference on Prevention and Rehabilitation of Hearing Impairment was held in Beijing in 2007, and jointly hosted by the China Rehabilitation Research Centre for Deaf Children (CRRCDC), the CDPF and the WHO. It proposed the 'Beijing Declaration', which addressed that International Ear Care Day should occur globally on the 3<sup>rd</sup> of March to promote public awareness of preventing hearing loss and enhancing hearing health (WHO, 2013).

## The models of deafness

There are two main models of deafness in developed countries, medical and cultural-linguistic models (Knight and Swanwick, 1999; Young, 1999). The former defines deafness as a deficit and deviation compared to the normal sensory/physiological condition (Young, 1999; Knight, 1998). The latter focuses on language use and cultural identity instead of impairment (Young, 1999). Ladd (2003) further explained that the cultural-linguistic model of deafness tends to be the predominant approach in developed countries after the social model of disability emerged in the disability movement of the 1980s. According to a social model of deafness, deafness and relevant problems related to deafness can be seen as being caused by the social environment and/or social factors.

It is further evident that the medical model of deafness laid heaviest emphasis not only on the cure to deafness and use of audiology aids, but also on deaf children's language development and skills (Knight and Swanwick, 1999). As Knight (1998, p. 217) said, 'this medical scenario is the first experience of deafness for most parents'. On the other hand, it has been argued that the medical model of deafness creates difficulties for deaf children to learn spoken language and discourages them from functioning like hearing children (Knight and Swanwick, 1999). Leigh (2009) further explained that deaf people can function like everyone following intensive auditory and speech training and access to sound though the use of hearing aids or cochlear implants. Compared to the medical model of deafness, the cultural-linguistic model of deafness not only enables deaf children to have choice on their own preferred language and encourages them to build up their own identity within Deaf culture, but also promotes the good relationship between deaf children, parents and future educational plans (Young, 1999; Knight and Swanwick, 1999).

However, the situation in China is quite different, where social attitudes towards deafness have been universally negative in the past. The way of perceiving deaf children as disabled did not originate from the medical model of disability, but largely affected by the ideology of feudal society in China, in which the deaf and dumb were seen as being possessed by devils and a heavy burden on society and family (Shen, 2010). Between the 1950s and 1980s, Chinese deaf education was mainly influenced by defective psychology from the Soviet Union (Shen, 2010). The medical model of deafness was not introduced in Chinese deaf education until the middle of the 1980s (Shen, 2010). From this perspective, the public perceived deafness as a handicap in China and this led to the commitment of Chinese parents and professionals to the treatment of deafness (Zeng, 1995).

In light of the development of the medical model of deafness in China, Shen (2010) used a dichotomous approach to evaluate both its advantages and disadvantages. Within the advantages, the introduction of theory within the medical model facilitated the movement of early intervention and rehabilitation education for deaf children. As a result, a large number of doctors and audiologists promoted the approach to rehabilitation in listening and speech and, subsequently, many listening and speech training centres were established in the nation (Shen, 2010). From this perspective, the traditional oral approach was elevated in the field of deaf education with the wider application of the medical model of deafness in China (Shen, 2010).

The trend for the medical model of deafness also promoted development in the technology of hearing aids and cochlear implants (Shen, 2010). However, Shen (2010) argued that the medical model of deafness lacked awareness of the comprehensive development of deaf children in education on physics, intelligence, morals and arts, and was restricted instead to rehabilitation education in listening and speech. Shen (2010) pointed out that the deaf children's skills in written and oral language were universally poor, and sign language did not develop with age. Many teachers of the deaf were not able to sign in class and this led to barriers of communication between hearing teachers and deaf students (Shen, 2010). From this perspective, Shen (2010) further maintained that the medical model of deafness placed restrictions on the quality of teaching and learning in the field of Chinese deaf education. Therefore, it was concluded that the medical model of deafness could promote development in audio technology and speech therapy, however, it overlooked the importance of sign language and deaf culture.

## 2.2.4 Chinese deaf culture

Deaf culture is constructed by Deaf people to reinforce a sense of belonging in the Deaf community (Leigh, 2009). The concept of a Deaf culture was first popularized in academic literature, such as *Deaf in American: Vocies from a Culture* (Padden and Humphries, 1988). Padden and Humphries (1988) emphasized that deaf culture is not about the hearing impairment, but about the Deaf community and its shared sign language. Furthermore, Ladd (2003, p. xvii) defines Deaf culture as 'the belief that Deaf communities contained their own ways of life mediated through their sign language'.

In China, Shen (2010) suggested that deaf culture should be made up of various contexts, such as sign language, deaf identity, deaf arts, deaf history, deaf community, deaf role models, deaf rights and technology aids for deaf people. According to the sociolinguistic/cultural model of deafness, which could promote the position of deaf culture and sign language, Shen (2010) argued that deaf culture could contribute to the manifold viewpoints of deafness and also counteract negative effects, such as the tragic view of deaf children as disabled. Shen (2010) further explained that deaf culture can take the diversity of deaf individuals into account and promote the

development of teaching deaf children within deaf education.

# Chinese Sign Language (CSL)

It has been argued that deaf culture did not appear to be strong in China in the past, in spite of the fact that deaf people and deaf students shared a sense of deaf culture and communicated by sign language (Zeng, 1995; Callaway, 2000). Furthermore, Zeng (1995) concluded that there were three reasons why the sense of deaf culture was not strong in the past in China. Firstly, deaf people mainly live in a hearing community. Secondly, they have to depend largely on their families in their lives and receive financial help from the government and their families. Thirdly, the signs used by Chinese deaf people were not fully developed as a systematic set of Chinese Sign Language, and also not uniformly recognized as a language, in contrast to American Sign Language.

Spoken language has acted as the main communication mode for deaf children at school and in the family in the past, and this often neglects the cognitive development of deaf children (Johnson *et al*, 2009). For this reason, listening and speech rehabilitation and the techniques of oralism have been the top priority of national policy, despite the fact that more and more deaf people are using sign language (Johnson *et al*, 2009). From the perspective of deaf culture and sign language, the medical model of deafness has been prevalent in deaf education in the past decades (Shen, 2010).

In the last decade in China, a sense of deaf culture attracted public attention through the popularization of Chinese Sign Language. More and more Chinese people have appreciated the beauty of Chinese Sign Language after its popularization via dance performance in the mass media, such as 'qian shou guan yin' [Bodhisattva with a Thousand Hands] and 'xing xing ni hao' [Hello Stars].

A sense of deaf culture has become stronger for deaf people after increasing public awareness that has been influenced by the wider use of Chinese Sign Language

<sup>&</sup>lt;sup>8</sup> 'qian shou guan yin' in Chinese writing is 千手观音

<sup>&</sup>lt;sup>9</sup> 'xing xing ni hao' in Chinese writing is 星星你好

among hearing people. Furthermore, Chinese Sign Language interpreters play an important role in creating a barrier-free environment of communication between deaf and hearing people. For example, the Beijing Olympic and Paralympic Games in 2008 recruited many interpreters in Chinese Sign Language to serve deaf people. Also, the Chinese government signed a declaration of the CRPD in March 2007, confirming that 'persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture' (CRPD, 2006, p. 24). Following this, the Chinese government has begun to advocate deaf culture and sign language for deaf people after signing the CRPD in 2007 (Zhang, 2010). This view is also supported by Shen (2010), who explained that this action of government would promote viewpoints of deaf culture for deaf children, and also promote the development of research on deaf education from a new angle of deaf culture, with reference to international theories and practice.

## Chinese deaf role models and deaf community

Deaf adults as role models can promote parents' understanding of their children's deafness (Young, 1999) and contribute to deaf identity development (Leigh, 2009). Similarly, Chinese deaf role models play an essential role in encouraging deaf children to develop a positive attitude towards deaf identity and in developing a sense of belonging in society (Shen, 2010; Callaway, 2000). From this perspective, Chinese deaf role models, either oral-language or sign-language users, can contribute to deaf lives. They also enhance deaf pride by walking through the two cultures of deaf and hearing people.

It is acknowledged that there is a false belief that deaf people are unable to become teachers of the deaf because they cannot use oral language to teach (Johnson *et al*, 2009). On the other hand, it is asserted that deaf people are capable of teaching sign language if they are teachers of the deaf (Biggs, 2004). Furthermore, the presence of teachers who are deaf in education can facilitate the increased confidence and better self-esteem in deaf children, and also represents positive life experiences for deaf people in a hearing society (Callaway, 2000). It is also agreed that teachers who are deaf can use sign language to remove communication barriers between themselves

and deaf students in order to improve the quality of teaching and learning (Shen, 2010). Deaf students have shown more trust in teachers who are deaf than their hearing equivalents and this promotes deaf teachers' good relationships with their deaf students (Shen, 2010). In comparison with deaf teachers, hearing teachers are likely to lack understanding of deaf students' needs and misinterpret their intentions and this causes deaf students' difficulties in working with hearing teachers (Li and Prevatt, 2010).

In the past, the mass media has highlighted famous people with disabilities, for example Deng Pufang and Zhang Haidi <sup>10</sup>, but also reported the successful achievements of deaf persons who are oral users, for example Yang Junhui and Zhou Tingting. Furthermore, Yang Junhui was the first deaf student to attend regular education in 1986 (Johnson *et al*, 2009). Zhou Tingting was the youngest deaf student to attend university at 16 years old. Therefore, deaf role models, who are oral language users, could attract the attention of hearing parents and this could influence their decision on using oral language.

The dominant position of the medical model of deafness has become less pervasive with the popularization of Chinese Sign Language and deaf culture in China in the last decade. Furthermore, deaf role models who are sign-language users have appeared on TV shows, for example deaf dancer Tai Lihua and deaf presenter Jiang Xintain. Therefore, deaf role models, who are sign-language users, can reduce prejudice against sign language and increase public appreciation of the value of sign language.

Additionally, deaf communities are often described as separate linguistic and cultural groups or linguistic minority groups in developed countries, especially in the USA (Lane *et al*, 2011). Deaf people, as a linguistic minority group, share sign language, Deaf identity and Deaf culture (Leigh, 2009). As such, it may be acceptable to perceive deaf people as a linguistic minority group in China. Some Chinese professionals and Chinese teachers of the deaf agree that deaf people can be defined

China Disabled Persons' Federation (CDPF) from 1988 to 2008. And the current president of CDPF is Zhang Haidi

Deng Pufang and Zhang Haidi are wheelchair users. Deng Pufang is the previous president of the

as a group akin to 'a linguistically and culturally distinct group' (Callaway, 2000, p.91).

The understanding of deafness in China is progressing from a small d to a big D as the position of Chinese Sign Language has improved in recent years. The recognition of deaf culture can contribute to the diversity of deaf identity and promote positive attitudes towards deafness. Therefore, this appears to represent a shift from the medical model of deafness to a cultural-linguistic model with subsequent changing attitudes towards deafness in China.

#### 2.2.5 Deafhood

Paddy Ladd (2003) coined the new term 'deafhood' in the 1990s, and this is defined as a group of people with hearing impairments existing in an ethnic community, named the deaf community, with its own unique deaf culture. Furthermore, Ladd (2003, p. xviii) explained:

'Deafhood is not seen as a finite state but as a process by which Deaf individuals come to actualize their Deaf identity, positing that those individuals construct that identity around several differently ordered sets of priorities and principles, which are affected by various factors such as nation, era and class.'

As a result, deafhood aims to widen the population of deaf people, rather than limit it to Deaf people. For example, a number of hard-of-hearing people might not meet the criteria of Deaf culture, and they still have deaf identity. This group of deaf people could have a sense of deafhood.

On the subject of deaf ethnicity, deafhood is a more encompassing term which embraces collective language, identity culture, history and arts within different countries (Ladd and Lane, 2013). It is further explained that deaf people who are from different countries might have a similar deafhood, in spite of a different background in the context of their deaf ethnicity (Ladd and Lane, 2013). For example, deaf children can develop a sense of deafhood, and they cannot develop an ethnic identity until they meet deaf adults and/or engage in the deaf community (Ladd and Lane, 2013).

#### 2.2.6 Deaf identity

The deaf identity is generally classified into two types: a global version of deaf identity and a Chinese deaf identity.

## Global version of deaf identity

Neil Glickman proposed the first theory of Deaf identity in 1993 (Scheetz, 2003). Glickman (1996) subsequently developed a theory of Deaf identity development via four stages: culturally hearing, culturally marginal, immersion in the deaf world and bicultural. The first, culturally hearing assumes that deaf people would like to be involved in a hearing world and try to define themselves as normal. Consequently, these deaf people would view their hearing loss as a deficit model and focus on their hearing impairments. The second, culturally marginal claims that deaf people could not fit into a deaf or a hearing world. The third, immersion in the deaf world states that deaf people's life is centred to Deaf culture and the Deaf community. Therefore, these deaf people have pride in their deafness and are proud of being deaf. They also view deaf culture and sign language as positive, and do not accept hearing culture. The fourth, bicultural demonstrates that deaf people not only immerse themselves in deaf culture, but also embrace hearing culture. Additionally, Glickman (1996) suggested that it is not necessary for deaf people to fit into any one particular stage of deaf identity development. Instead, it was suggested that deaf people can start at any stage of deaf identity development, even moving forwards and backwards, skipping one or two stages if needed (Glickman, 1996).

Aside from Glickman's theory, Ohna (2004) proposed a theory of deaf identity development in Norway, again categorized into four phases: taken for granted, alienation, affiliation, and deaf in my own way. Firstly, the phase of 'taken for granted' indicates that deaf people know they are deaf but do not understand what deafness means. Secondly, the phase of 'alienation' means that deaf people understand that they are different from hearing persons. Thirdly, the phase of 'affiliation' refers to deaf people knowing they are deaf. Fourthly, the phase of 'deaf in my own way' explains that deaf people must negotiate their own position among deaf and hearing persons (Ohna, 2004). From this perspective, the stage of 'deaf in

my own way' represents a way of holding deaf and hearing identities (Ohna, 2004), which is similar to the stage of bicultural defined by Glickman (1996).

On the other hand, Maxwell-McCaw and Zea (2011) applied acculturation concepts to deaf identity and developed the Deaf Acculturation Scale (DAS). According to the DAS, people with hearing losses could again be categorized into four types: hearing acculturated, marginal, deaf acculturated and bicultural (Maxwell-McCaw and Zea, 2011). Hearing acculturated refers to high scores in hearing acculturation and low scores in deaf acculturation. Marginal refers to low scores in both hearing and deaf acculturation. Deaf acculturated refers to high scores in deaf acculturation and low scores in hearing acculturation. Bicultural refers to high scores in both hearing and deaf acculturation (Maxwell-McCaw and Zea, 2011). From this perspective, the bicultural concept of DAS is also similar to the stage of bicultural in Glickman's theory of deaf identity development.

In alignment with the bicultural stage of Glickman's theory, the term 'DeaF' attempts to reflect this bicultural/bilingual identity (Mcilroy and Storbeck, 2011). It is further explained that:

'The capital F in DeaF highlights the deaf person's fluid postmodern interactions and engagement and dialogue across the conventional dividing line between Deaf and culturally hearing identities and communities as an authentic bicultural DeaF person' (Mcilroy and Storbeck, 2011, p. 497).

From this perspective, deaf people on the journey of forming deaf identity can stand within and between positions of deaf and hearing identities (Leigh, 2009). Therefore, it is important for deaf people to bridge the cultural divide between the two opposing worlds of hearing and deaf in order to develop their own self-identity (Mcilroy and Storbeck, 2011; Leigh, 2009).

According to the deaf identity developmental model used by Glickman (1996), the stage of immersion and bicultural can contribute to a healthy identity for deaf children within the perspective of deaf culture. Glickman (1996) further explained that the stage of culturally hearing and culturally marginal can create negative emotions, such as depression and confusion. Furthermore, Weinberg and Sterritt (1986) suggested that deaf people with dual identification are more likely to have

better academic achievement and social development than those with either deaf or hearing identification.

However, in contrast, several studies have argued that monocultural identity, such as the stage of culturally hearing or culturally marginal in Glickman's theory, could develop healthy identity formation in deaf children (Bat-Chava, 2000; Hintermair, 2008). Hintermair (2008) further claimed that deaf people who identify themselves as marginal may lead a better life and may have more flexibilities in entering into the hearing and deaf worlds.

# Chinese deaf identity

The theory of deaf identity development written by Glickman has been prevalent in China (Zhang, 2010; Yang, 2010; Lin, 2009). As such, Chinese deaf identity development is seen as reinforcing the four stages of Glickman's theory of deaf identity development. However, it is evident that, to date, not one Chinese scholar has developed a separate theory of Chinese deaf identity according to the specific social-cultural background in China.

The Chinese character '龙' [dragon] is the symbol of power in authority, and was particularly related to emperors in the age of feudal society. Furthermore, the '龙' [dragon] is considered a totem of power in Chinese culture that is deeply rooted in the vitality, creativity and cohesion of China during the period of imperial power. Consequently, '龙' [dragon] has become the symbol of the Chinese nation in modern times. From this perspective, every Chinese person is considered as a descendant of the dragon. However, a dragon is often considered as evil in developed countries. In order to avoid misunderstanding of the dragon in different cultures, it could be argued that '龙人' [dragon people] is better translated as 'loong people' or 'LOONG people'. As such, 'loong' [龙] can be interpreted as a Chinese dragon and 'seraphim' in developed countries.

Within Chinese characters, Yang (2010) suggested that the character '聋' [deafness] does not have a top component '龙' or bottom component '耳', as illustrated in

Figure 2.2, and none of them means illness. Consequently, the Chinese character '聋' [deafness] suggests that deafness is not a disease (Yang, 2010). Furthermore, Yang (2011) stated that some Chinese deaf people regard themselves as '龙人' [dragon people] instead of '聋人' [deaf people] in order to show their deaf pride. It is further explained that '聋人' [deaf people] sounds the same as '龙人' [dragon people] because '龙人' [dragon people] appears to be a commendatory term, as dragons are celebrated in ancient Chinese legends. From this perspective, Chinese deaf people can be seen to have a sense of deaf identity and positive attitude towards their deafness when they view themselves as '龙人' [loong people]. In this way, Chinese deaf people feel honored to be so empowered, and do not think of themselves as disabled.

However, it is hard for Chinese hearing parents to revere the Chinese character '聋' (deaf/deafness), linked with deaf community or deaf culture, if they do not perceive '聋人' (deaf people) as '龙人' (loong people). It is not easy for the majority of Chinese hearing parents to understand the knowledge of big D 'Deaf', as distinguished from little d 'deaf', as this different appearance in English writing does not work for Chinese characters. In this case, a large number of Chinese hearing parents have been more concerned with the medical model of deafness (Callaway, 2000) and, consequently, this has resulted in hearing parents training their deaf child in speech skills (Callaway, 2000). This reinforces the belief that deaf people including deaf children can function like everyone else when they receive intensive auditory and speech training and access sound though the use of hearing aids or cochlear implants (Leigh, 2009).

In summary, the emerging Chinese deaf culture can contribute to theory and practice with regard to the development of deaf identity in China, although this is restricted by the remaining prevalence of the medical model of deafness in the nation.

# 2.2.7 Education for children with hearing impairments in the early years in China

Early intervention for deaf children in China

It is well known that 'three early' theory has been popularized in China from the late 1980s onwards. Furthermore, the core concept of 'three early' theory focuses on the word 'early' in three dimensions: early discovery, early diagnosis and early treatment. The 'three early' theory inspires Chinese parents of children with disabilities to know the importance of children's development during the 'early' period of childhood.

Undoubtedly, there are urban-rural differences in delivering available information and establishing regional early intervention institutions. For example, Chinese parents who lives in big cities like Beijing and Shanghai are likely to be given information about 'three early' theory and early intervention services, compared to others who live in rural areas and/or poor areas. Additionally, although the knowledge of the importance of early intervention has grown in recent years, there is still a lack of resources to support deaf children in rural areas as the numbers of early intervention services in cities are far beyond that of villages.

When it comes to deaf children, Shen (2012) claimed that early childhood education requires the strategies of early intervention to be applied to language development. Furthermore, the critical period of language learning for deaf children is around the first 2-3 years, and language acquisition after 3 years old is not natural (Marschark and Hauser, 2012). Similarly, if Chinese hearing parents miss the critical period of language development, their deaf children may find it difficult to learn language after 6 years old. In contrast, deaf parents of deaf children can know whether their infants are deaf in the first months through observation and visual communication (Marschark, 2007). Regarding this matter, Sheridan (2008) suggested that the poor vocalizations of children with hearing impairments should be given more attention after 8 or 9 months and parents should be aware that normal infants usually respond to sudden noise. The critical period in the child's early milestone developments should be noted, such as spoken language development in the period of 1-3 years old, language learning in the period of 2-5 years old, and intelligence and behaviour development in the period of 3-4 years old (Sheridan, 2008). In other words, deaf children are likely to make simple sounds like 'a-a-a' or 'a-ya-a-ya', and their speech skill should develop little by little, even where some find it difficult to make a sentence, compared to hearing children who are able to make simple sentences with two or three words at the age of 2 and can ask questions beginning with 'what', 'who' and 'where' at the age of 3 (Sheridan, 2008).

In developed countries, children with hearing impairments are referred to early intervention services and early childhood education after their diagnosis of deafness is confirmed (Harr, 2000). China has not developed a cooperative system integrating special education, health care and social welfare in the last three decades (Hu and Yang, 2013). However, this situation has changed in recent years with advanced technology to help to remove the barriers caused by little integration between hospital and educational services on the subject of early childhood education and intervention for children with disabilities. Recently, most Chinese parents of children with disabilities are likely to be referred to educational support services for early intervention by doctors and/or other professionals. Therefore, the core concept of the 'three early' theory in early intervention should be included in the context of the theory of early childhood education for children with hearing impairments.

As Densham (1995, p. 2) suggested, 'the time of diagnosis is perhaps the most critical period, when decisions are made which can have far-reaching consequences for the rest of a child's life'. McCracken and Sutherland (1991) further stated that an excellent start for deaf children could be led by three important factors: early diagnosis, good parental guidance and responsive parents.

It is acknowledged that universal newborn hearing screening (UNHS) was introduced in China in 1999, and then was widely applied since the China Disabled Persons Federation (CDPF) issued 'The National Plan of Hearing Impairment Rehabilitation 2007-2015' in 2007 (Liu and Raver, 2011). This new technology was firstly implemented in big cities like Beijing and Shanghai and then widely used in city hospitals throughout China in 2007 and after (Liu and Raver, 2011).

Possible explanations for this might be the cost of individual implants (40,000 Yuan) and their operation, and also the price of follow-up audiology services (Liu and Raver, 2011). Another possible explanation for this is that donations of free cochlear implants were only available to to 0-3 year old deaf children with severe-to-profound hearing loss who pass a test for adaptability to cochlear implants, speech and

listening ability assessment and intelligence assessment, meaning not every child is eligible to access them (Liu and Raver, 2011). The Taiwanese entrepreneur, Mr. Wang Yongqing, donated 14,750 cochlear implants to the China Disabled Persons Welfare Funds between 2005 and 2013 (Liu and Raver, 2011). The government has planned to spend 400 million Yuan on cochlear implants and 1,500 children were offered free cochlear implants and associated services from 2009 to 2011 (Liu and Raver, 2011).

# Hearing and Speech Training Centres in China

There are two main institutions which provide hearing and speech training in Beijing, one is the national institution and the other is the local institution. The first hearing and speech centre in Beijing was established in 1983 and called the 'China Rehabilitation Research Centre for Deaf Children' (CRRCDC) (CRRCDC, 2015a). This national centre was identified as a pioneer in the field of hearing and speech rehabilitation therapy. CRRCDC not only offers audiology and speech support to children with hearing impairment throughout China, but it also carries out research regarding hearing impairment and deaf education (CRRCDC, 2015a). In other words, CRRCDC intervention programmes mainly consist of language and auditory training (Yang, 2003, cited in Hu and Yang, 2013).

After the establishment of the national rehabilitation institution for deaf children in 1991, the number of local language development training centres has increased and developed over three decades. Furthermore, the number of hearing and speech training centres is increasing each year. These training centres are widely distributed throughout 4 municipality cities (i.e. Beijing, Shanghai, Chongqing, Tianjin) and 27 provinces (e.g. Hebei, Zhejiang, Anhui, etc.) (CRRCDC, 2015b). There has been a few listening and speech training centres under the provincial-level available in rural and/or poor areas in the past. For this reason, parents of deaf children had to leave their jobs in their hometown and move closer to the available rehabilitation centres due to the wide disparity in services between urban and rural areas of China (Liu and Raver, 2011). Hu (2010) further found that Chinese families of children with disabilities had to overcome difficulties caused by long-distance travel and the expensive cost of school and/or a rehabilitation service centre.

In order to remove the barriers to regional variation in services, the grassroots-level language development training centres have been created and established in different cities and provinces from late 1990s onwards. For example, the numbers of grassroots-level centres had reached 961 by the end of 2015 (CDPF, 2016). These training centres not only deliver services in speech and listening skills to children with hearing impairments and their families, but also provide audiological technology services (Liu and Raver, 2011). Also, these training centres provide activities regarding listening skills and speech therapy, such as perception and comprehension of sound through identifying natural sounds and distinguishing between different sounds (Liu and Raver, 2011).

Using the Beijing Hearing and Speech Training Centre as an example, it mainly recruits children with hearing impairments aged approximately 3 to 6 or 7 years old. If children live in Beijing they can go home every day and be with their parents. If children live outside Beijing, some are offered a place to live in this institution and others are not because of the limited space provided.

The Hearing and Speech Training Centre in Beijing is a local government-based organization. Furthermore, this institution is sponsored by the Beijing Disabled Persons' Federation, which places heavy emphasis on the promotion of oral-only development as the main principle of inclusion in deaf education. Additionally, this training centre is not viewed as a form of mainstream school or special school. Instead, it acts a progression towards schooling education and inclusive education at mainstream schools.

In the Beijing training centre, most deaf people are children aged from 3 to 6 or 7. They are placed in the training centre to practise language skills and develop a solid foundation for communication skills. If some of these children are trained well in the skills of language, they may have a potential opportunity to develop their skills in communicating with hearing people and understanding what they are saying. Consequently, these children could be possibly enrolled in mainstream schools if they develop their language skills well enough.

The Beijing Institution mainly aims to help children improve skills of hearing and speech. Furthermore, children learn language and develop their skills of listening and speech from teachers who work at this institution, either through one-to-one or group classes. The one-to-one classes focus on individual training in hearing and speech and intensive interaction between a single teacher and student according to the language development of the individual. The group classes focus on students' general training in speech and listening, and add interaction between deaf children and their deaf peers in a class.

Additionally, this centre also holds at least one or two short-term training programmes for parents each year, aiming to help them better understand deafness knowledge and the training skills in speech and listening. Aside from this, the institution holds induction meetings at the beginning of each term, aiming to help new parents get to know what the speech and listening training centre is and further develop their knowledge of deafness. Occasionally, the institution invites some children who have successfully learned oral language skills to attend to develop confidence in parents.

## Mainstream schools for deaf children in China

In China, children with hearing impairments who were born in the 1980s and 1990s did not find it easy to receive an education at mainstream schools, compared to other children who were born in 2000s. Therefore, many parents experienced difficulties in helping children be involved in mainstream education in the 1980s and 1990s.

The numbers of mainstream schools including children with hearing impairments have developed at a fast rate from the 1990s onwards. Some schools which accepted children with a disability started to share experiences with other organisations which had never met children with disabilities previously. Furthermore, the Ministry of Education set up three different teams of people to work with and support LRC in different areas of China in 1996, including working with children with hearing impairments, visual impairments or intellectual impairments. In 1998, professionals and teachers who worked within LRC established a conversation meeting in Beijing to share experiences in educating children with disability in mainstream schools.

After that meeting, the progress of mainstream schools for educating children with disability developed quickly.

The reasons why parents advocate their deaf children attend a mainstream school are, firstly, the first series of laws relating to disability had been issued gradually since 1986, for example the 1986 Compulsory Education Law of the People's Republic of China and the 1990 Law of the People's Republic of China on The Protection of Persons with Disability. Secondly, most teachers and staff who worked at mainstream schools had little experience to educate children with disability in the twentieth century. Furthermore, many mainstream school teachers and staff in the 1980s and 1990s lacked knowledge related to disability and deaf awareness, but also lacked understanding about disability issues. Also, it was an undoubted fact that many mainstream school teachers felt incapable of educating children with disability, although they may have desired to accept such children at the time. They also felt unable to teach children with a disability because they could not judge and evaluate the issues relating to the learning ability of children with a disability or their own teaching abilities.

## The development of deaf schools and curriculum

Generally speaking, changes in special education have significantly influenced the education of deaf children. Before 1949, deaf education had developed very slowly, particularly over 20 years of war in China. During this period, the main form of special education was to set up deaf and blind schools. After 1949, there was a revolution in special education after China set up a new country to end the civil war. Then special education was formally incorporated into the national education system.

Between 1949 and 1979, China experienced economic change and political turbulence, and special education was also affected by these national changes. Almost all deaf and blind schools were forced to close down. Then China began to open its door to the world in 1979 and this influenced special education. The development in deaf schools and curriculum has rapidly improved since then.

In 1993, the Ministry of Education formally issued regulations on the Curriculum

Framework for Full-Time Deaf Schools, which were influenced by the two laws of Compulsory Education Law and the Protection of the Person with Disability Law. These regulations stipulated that deaf students should register at a deaf school at the same age as normal students, including students aged below 10 years old when they may face particular situations (Zhang, 2002). Furthermore, some deaf children could start studying at deaf schools in rural areas during their teenage years (Callaway, 2000).

Compared to Learning in Regular Classrooms, curricula in deaf schools are lower in academic standards than those of mainstream schools (Zhang, 2002; Callaway, 2000). It is further reported that students with disabilities became happier and more confident when they were transferred from mainstream to special schools, in which teachers who work there provide better help and more individual support (Human Rights Watch, 2013).

In November 2000, the conference on China Deaf Education Reform and Development of the 21<sup>st</sup> Century was held in Nanjing, Jiangsu province (Zhang, 2002; Biggs, 2004). This conference welcomed nearly 400 people and discussed trends in Chinese deaf education and a blueprint for deaf education (Zhang, 2002). As far as the issues for deaf people's communication are concerned, this conference summarized:

'The competence of listening and speaking is vital for the deaf to get involved in society, continue learning and lifelong developing. The attention should be paid to the goal of developing the deaf students' listening and speaking as far as the issues of national deaf education are concerned. This goal is also be part of the special context of implementing general education by deaf school. All is the shared responsibility of teachers of the deaf and parents of the deaf to achieve this goal through education activities in school and deaf students' regular life. Schools should carry out the relative regulations and assessment to ensure the implement of those regulations.' (Zhang, 2002, p. 271)

Furthermore, this conference discussed the trend of multi-communication modes and encouraged educators to consider the approach to 'bilingual education' for deaf students (Zhang, 2002).

It is acknowledged that the bilingual and bicultural approach in China is available in four places in the 2000s: Nanjing, Kunming, Hefei and Tianjin (Mudgett-DeCaro and

# 2.3 Parental involvement for children with hearing impairments in China

The aim of this section is to provide an overview of parental involvement with reference to Chinese culture and inclusive education for children with hearing impairments.

#### 2.3.1 Parental involvement in inclusive education in China

Despite research on teachers' perspectives suggesting inclusive practices have made positive strides, only a very small number of studies mention the importance of parental involvement in inclusive education.

It is well known that parents are the first teachers of their children when they come into the world as babies according to the traditional viewpoint held from the late 1960s to the mid/late 1980s (Gargiulo, 2012; Turnbull *et al*, 2010). In this way, all the parents are the same, no matter whether they have, children with disabilities or children with typical development. Similarly, in China, it is agreed that parents are viewed as the teachers of their children with disabilities across their life span. Additionally, Gargiulo (2012) suggested that parental involvement in inclusive education is a crucial factor which facilitates success in educational experience and all-round development of children with disabilities. In comparison to teachers and professionals, parents appear to have a greater investment in their child's education and know more about their child's personality and characteristics (Gargiulo, 2012).

The traditional viewpoint of parents as teachers has evolved from the 1970s into a current expectation for parents to act in a range of diverse roles (Gargiulo, 2012). As Turnbull *et al* (2010) suggested, parents have range of functions in raising their children with disabilities while acting as political advocates, educational decision-makers and collaborators. Furthermore, Turnbull *et al* (2010) explained that parents not only advocate for their disabled child in different places, such as legislature, courts and executive agencies, but they also make collaborative efforts to

resolve educational decisions and judgements on the choice of educational settings with other members within the family. Also, Hepburn (2004) identified two different parental roles in children's education: parents as educators and parents as leaders. On the one hand, the former role focuses on the family relationship that influences children's growth and development and begins with parent-and-child attachments that stimulate children's desire to learn and explore the world (Hepburn, 2004). The latter role emphasises that parents are true experts who both know their children and act as decision-makers for their children to support their readiness for school and community activities (Hepburn, 2004).

Hu and Yang (2013) point out that families did not place importance on involvement in the early intervention system in China in the 1990s, based on the fact that special schools provided intervention training for parents, whereas parent-to-parent groups and community-based early intervention services had only recently emerged in the 2000s after the concept of family support was introduced into China. From this perspective, the core value of parental involvement can be seen as having shifted from a school-centred definition to a family-focused outlook (Hepburn, 2004).

Families play an important role in advocating and supporting their disabled child's rights to education, social services and health care from early childhood to adulthood (Hu, 2011, cited in Hu and Yang, 2013). Therefore, parents are regarded as primary partners in their disabled child's development and schooling (Hepburn, 2004).

In China, most parents are aware that they play an important role in providing the best education for their child within the influences of Chinese cultural values (Hu and Yang, 2013). Furthermore, McCabe (2008) suggests that Chinese parents have a desire to offer the best for their child in spite of feeling embarrassed if they have a disabled child. As far as the families of children with disabilities are concerned, Chinese parents not only take on a large amount of duties in raising a child with a disability to help them to be integrated into their local school and community, but they also spend an astronomical amount of time and money seeking inclusive education available for children with disabilities. As a result, parents have two arduous tasks to support their disabled child's life, both rehabilitation and education. For this reason, it can be claimed that parents of children with disabilities must spend

more time and money than families of children without disabilities.

In addition, a large amount of literature has demonstrated that parental involvement can increase parents' confidence in childrearing and contribute to children's active learning (Corter *et al*, 2006; Moeller, 2000; Hu, 2010; Fan and Chen, 2001; Desforges and Abouchaar, 2003; Pomerantz *et al*, 2007; Powers, 2003; Wilder, 2014). Parents of a disabled child not only need to look after their disabled child in the community to prevent them from harm caused by disabilities, but they also need to devote increased effort to help their disabled child break the barriers of inclusive education that they face. It is further suggested that 'parental encouragement and home support beyond the normal school day can be used as vital resource in the child's integration in school' (Harr, 2000, p. 12). Therefore, it is acknowledged that the quality of general education received by children with disabilities is dependent on the priority of the quality of home education provided (Lei and Deng, 2007).

The reasons why Chinese families emphasise their child's education are that: firstly, China's cultural values ask Chinese parents to take primary responsibility to provide the best education for their only child (Hu and Yang, 2013); and secondly, there are economic and regional disparities in providing children with an early education in China, so parent education can help fill the gap caused by such inequalities (Corter *et al*, 2006). Furthermore, parents of children with disabilities often expect their children to receive an education when they are of school age and then be integrated into competitive society when they are grown up. Parents also have great concern about their disabled child's future, especially after their own deaths (McCabe, 2008; Wang and Michaels, 2009). From this perspective, the involvement of parents plays an important role in engaging with consultations, decision-making, and monitoring processes of implementing inclusive education (Human Rights Watch, 2013).

However, it could still be claimed that parents are offered the opportunity to share their duties with teachers who work in inclusive education, rather than traditionally taking sole responsibility for raising their child with disability (Hu, 2010). In the study of Hu (2010, p. 22), which explored teachers' perspectives on pre-school inclusion, she cited an interviewee stating that 'teacher preparation is the key focus while parent relationships are the key challenges' in order to express the importance

of teachers' working with parents. Furthermore, Hu (2010) suggested that parents who are highly involved in their child's early childhood inclusive education programme are supportive and cooperative in terms of the partnership between schools and the family. Hu (2010) also reported that parents who are sceptical could affect the process of partnership between teachers and parents, for example, teachers would become stressed and develop low self-esteem. Therefore, Hu (2010) highlighted the importance of positive parental involvement, although her study focused on the views of teachers on pre-school inclusive education.

The parental role of promoting inclusion faces challenges in China (Hu, 2010; Zhang et al, 2009; Pang and Richey, 2006; Corter et al, 2006). Chinese families not only meet difficulties in early childhood education and rehabilitation when their children with disabilities are growing up, but they also face obstacles in providing their children with inclusive education.

Firstly, parents of children with disabilities overcome difficulties caused by transport limitations when attempting to locate services of early childhood education and rehabilitation (Hu, 2010). For example, there is a lack of early childhood education and rehabilitation in villages and parents often have to travel from rural areas to big cities, such as Beijing and Shanghai, to find pre-school inclusive services (Hu, 2010). Also, Chinese parents are often overwhelmed when seeking high-quality early childhood care and rehabilitation, and may have to keep detailed records of visits to doctors and assessments to aid this process (Zhang *et al*, 2009). Meanwhile, many parents have to leave their employment to accompany their young child to a pre-school inclusive education programme in the city (Hu, 2010), and children also feel isolated from their local peers and need to be with their parents in order to feel a sense of security and adjustment.

Secondly, parents of children with disabilities experience a mixture of feelings about this situation, including fear, distrust, and worry and so on, as social stigma towards disability and a social hierarchy still exists in contemporary China. Furthermore, the ideology of Confucianism lays heaviest emphasis on respect for elders and filial piety (Pang and Richey, 2006; Holroyd, 2003). Families regard professionals and educators as the authorities, so it is not easy to develop an equal relationship between

parents and teachers (Pang and Richey, 2006). In this way, some families are afraid to tell teachers their concerns and family needs (Pang and Richey, 2006). Some parents are also reluctant to argue against the opinions of teachers who work in the field of inclusive education because of their deep respect for professionals and educators (Pang and Richey, 2006).

Thirdly, Chinese families face a financial burden when they raise their child with a disability (Hu, 2010). The reasons why Chinese parents have to pay high fees for services of inclusive education and early childhood care are that: firstly, the national economy underpinned by the socialist market asks parents to pay fees for quality pre-school inclusive education and care when they can afford it (Corter *et al*, 2006) and, secondly, the increasing level of provision of pre-school inclusive education encourages families to demand considerable investment in their disabled child's education and rehabilitation (Corter *et al*, 2006).

The Chinese government has implemented financial assistance for children with disabilities to facilitate their access to inclusive education (Human Rights Watch, 2013). For example, the policy of 'two exemptions and one subsidy' aims to reduce miscellaneous fees and provide a small amount of financial support to students with disabilities (Zhang, 2011; Human Rights Watch, 2013). However, this is not enough for families of children with disabilities, and many are still unable to pay for their child's education. Furthermore, the fees of pre-school inclusive education and early childhood care at private agencies are often higher than the parents' salaries (Hu and Yang, 2013). The tuition of privately-run inclusive education is much more costly than that of public-based programmes, based on the fact that the services at private institutions can provide comprehensive and one-to-one training (Hu and Yang, 2013), even though fees for pre-school inclusion at public institutions are usually not free. For this reason, the fees for private institutions are often required to balance out the salaries of teachers and staff who work at private agencies (Hu and Yang, 2013).

Despite the challenges and issues of parental involvement in inclusion, more and more parents have a positive attitude towards disability due to the trend in increased social awareness of inclusive education. In the past, parents had little ability to protect their child with a disability from the hurt caused by exclusion in regular early

childhood education (Liu, 2007; cited in Hu and Yang, 2013). With the international and national trend in inclusion, many parents have advocated the rights of inclusive education for their disabled child. For example, in recent years many Chinese parents tended to accept their child's disability when they came to understand the conditions through screening and assessment services (Hu and Yang, 2013). In addition to the change in parents' perspectives on their child's disability, a tiny number of Non-Governmental Organizations (NGOs) run by parents of the children with disabilities are currently appearing. For example, the Beijing Stars and Rain Centre, established in 1993, is the first non-governmental organisation run by parents of children with autism. The aim of this private institution is to provide a comprehensive service in early childhood education and care, and one-to-one training (Beijing Stars and Rain, 2007).

Therefore, it could be argued that Chinese parents play a primary role in caring for and educating children with disabilities (Hu, 2010; McCabe, 2008).

# 2.3.2 Impact of deafness on parental involvement

It is well known that having a disabled child can disable the whole family (Gargiulo, 2012). Similarly, the diagnosis of deafness is a disaster and a traumatic experience for hearing parents of deaf children (Meadow, 1980; Young, 1999). Furthermore, most parents found the diagnosis of deafness to symbolise a loss of their dream and devastated their image of a perfect child (Schirmer, 2001; Moses, 1985, cited in Densham, 1995). Although the diagnosis of deafness is less serious than that of dying or life-illness, hearing parents had similar reactions (e.g. shock, grief, etc.) to their child's deafness as if they had lost their child (Densham, 1995; Beazley and Moore, 1995). As Adams (1997, p. 6) described, 'the diagnosis of a condition in a child generally brings forth reactions that are similar to those experienced by persons who have lost something of value'. Therefore, it is common that hearing parents find it difficult to accept their child's deafness and learn the relevant knowledge about deafness (Adams, 1997; Knight and Swanwick, 1999).

A hearing family can be affected and/or changed by the introduction of a deaf baby/child (Marschark and Hauser, 2012). As Henderson and Hendershott (1991,

p.325) described, 'because the deaf child is a component of the family system, the deafness belongs not just to the child but to the entire family'. From this perspective, it is not easy for hearing parents to recognize the position of their deaf baby and themselves in the family. It is suggested that hearing parents should come to understand their position as parents of a deaf baby and their family as the family of a (Bodner-Johnson, 2003). This significant recognition deaf person acknowledgement lays a foundation for hearing parents to become aware of their deaf baby's needs and understand what deafness is (Bodner-Johnson, 2003). However, this is not agreed by Moores (1996) who stated that the birth of any baby could fundamentally change the pervious family routine and nature of family life, including either hearing or deaf children. It is further suggested that hearing parents should learn and appreciate that their deaf child is different, rather than helping them to integrate into their family life as usual (Moores, 1996; Knight and Swanwick, 1999). From this perspective, once a child is diagnosed as deaf, their family is no longer a family anymore and but has become deaf and hearing (Moores, 1996; Adams, 1997). Therefore, in order to create an environment that makes a deaf child grow into a successful deaf adult, hearing parents can make adjustments to having a deaf child in their hearing family and put an end to the expectation of having a hearing child in their life plan (Knight and Swanwick, 1999).

When a deaf child unexpectedly arrives in a hearing family, it is a great challenge for hearing parents to adjust to the new situation after a period of joy with the arrival of a new baby. They can struggle to slowly accept this deafness. In a summary of the literature (Young,1999; Knight and Swanwick, 1999), the reasons why hearing families and/or hearing parents have negative emotions when having a deaf baby were given as: firstly, most hearing families have a normal hearing life, so they have little exposure to deafness (Young, 1999); secondly, most hearing parents never plan to have a deaf baby in their normal family and people around them are usually hearing, including extended family members; thirdly, most hearing parents have seldom met a deaf person (Knight and Swanwick, 1999) and/or have little knowledge about deafness; fourthly, most hearing parents are not interested in learning sign language as a way of communicating. Therefore, most hearing parents experience emotional changes after having a deaf baby, and only a few become accustomed to this change in their family life after a period of time.

In contrast to hearing families and/or hearing parents, deaf parents and/or deaf families may not experience emotional changes when they have a deaf baby and may actually feel much pride in being deaf (Marschark, 2007; Ladd, 2003). Furthermore, deaf families have different expectations from hearing families when they have deaf children (Webster, 1994). For example, deaf parents not only accept their children's deafness (Meadow, 2005; Ladd, 2003), but also have their own deaf culture and sign language to support interactive communication with their deaf babies (Webster, 1994; Ladd, 2003). As a result, they may not need to cope with many of the barriers derived from accessing the hearing world their culture. Compared with deaf parents, hearing parents have little exposure to deaf culture and deaf adults in their normal lives, so they may need to adjust to the problems of the deafness. From this perspective, such different expectations from two different groups of families can have great influence on shaping deaf children's identity in different cultures (i.e. hearing or deaf) and languages (i.e. sign language or oral language).

A large number of studies has shown that hearing parents often have similar reactions to a child with a hearing impairment, such as shock, doubt, grief, stress and so on (Kampfe, 2004; Feher-Prout, 2004; Vernon and Wallrabenstein, 2004; Marschark, 2007; Beazley and Moore, 1995). There are three main stages in parental reaction to disability: the primary stage (i.e. 'shock, denial, grief and depression'), the secondary stage (i.e. 'ambivalence, guilt, anger, shame and embarrassment') and the tertiary stage (i.e. 'bargaining, adaptation and reorganization, acceptance and adjustment') (Gargiulo, 2012, p. 122). Furthermore, parents experience a great sense of loss of their baby's normal hearing and seem to wallow in this situation (Webster, 1994, cited in Beazley and Moore, 1995). Consequently, these emotional stages are quite similar to the process of bereavement (Webster, 1994, cited in Beazley and Moore, 1995). In short, Beazley and Moore (1995, p. 11) summarized that 'there is a confusing expectation that parents need to respond to the news that their child is deaf in a similar way to if they had actually discovered that their child was dead' (original emphasis).

Although a diagnosis of deafness is much less serious than a diagnosis of dying or life-illness, hearing parents had similar reactions (e.g. shock, grief, etc.) to their

child's deafness compared with those who experienced a child who dies (Densham, 1995; Beazley and Moore, 1995). As Adams (1997, p. 6) described, 'the diagnosis of a condition in a child generally brings forth reactions that are similar to those experienced by persons who have lost something of value'. For hearing parents, the diagnosis of deafness is a disaster and a traumatic experience (Meadow, 1980; Young, 1999). Furthermore, most parents find the diagnosis of deafness symbolises a loss of their dream and devastates their image of a perfect child (Schirmer, 2001; Moses, 1985, cited in Densham, 1995). Therefore, it is common that hearing parents find it difficult to accept their child's deafness at the beginning and then learn the relevant knowledge about deafness (Adams, 1997; Knight and Swanwick, 1999).

There is nothing more important than parents' coping with stress and processing negative emotions. Kampfe (2004, p. 24) provided an insight into parental reaction to a child's a hearing impairment through a model of transition, including five main factors: 'conducive to stress, perception of event, responses, outcomes and conditioning variables'. This model of transition helps parents cope with emotional changes in having a deaf baby and facilitates parental adaptation to a child's deafness (Kampfe, 2004).

The unchangeable truth of a child who is deaf can have a harsh impact on four domains of family life: family interactions, family resources, parenting and support services (Jackson and Turnbull, 2004). In other words, hearing families of deaf children face uncharted challenges and potential obstacles that affect multiple and diverse aspects of family life, such as communication, time demands, social networks, decision-making, emotional well-being, family interaction and so on (Jackson *et al*, 2008; Jackson *et al*, 2010). During the period of raising a deaf child in the early years, parents have to take great responsibility in making many decisions on the choices between two different cultures (i.e. deaf or hearing), two different languages (i.e. sign language or spoken language), two different school settings (i.e. special schools or mainstream schools) and so on (Jackson and Turnbull, 2004; Marschark, 2007; Beazley and Moore, 1995). In this way, family life can be affected by the parents' struggle with decisions on these choices when their deaf child begins school life. Also, it is quite difficult for parents to make a sound judgement on such different choices (Webster, 1994). As Calderon and Greenberg (2000, p. 168)

asserted, 'parents question their ability to evaluate and to determine the best plan of action to help their child develop necessary life skills and realize their academic potential'. As a result, it is challenging for parents to discover their deaf child's potential (Calderon and Greenberg, 2000). However, Jackson and Turnbull (2004) suggest that parents of deaf children could develop the skills of problem-solving after they experienced all areas of emotional adjustment and physical actions in terms of their reaction to the news of having a deaf baby. In developed countries, hearing parents might decide to design a life-span plan for their deaf child, for example, the choices of spoken language and mainstream schools might be taken as a priority (Webster, 1994; Jackson et al, 2008).

As discussed in the last section, parental involvement can contribute to academic performance for children with disabilities (Corter *et al*, 2006). Similarly, parental involvement and support can facilitate the educational development, as well as academic performance, of deaf children (Harr, 2000; Marschark and Hauser, 2012). From this perspective, it is agreed that deaf children are likely to be successful in school if their parents have a desire to engage in their child's daily life and help their child be involved in family activities (Schirmer, 2001). It is further argued that parental communication skills are the most significant factor to facilitate deaf children's positive language and academic development, so parental involvement can also contribute to deaf children's early reading and social-emotional development (Calderon, 2000). Meanwhile, the relationship between hearing parents and their deaf children can be further developed by the former's involvement in the latter's communication and interaction. However, Calderon and Greenberg (2000) pointed out that deafness might have an adverse effect on both family interaction and the child's academic and socio-emotional development.

In addition, there are few differences with regard to the importance of parental involvement for deaf children and hearing children. Parents of deaf children are more likely to observe, whereas parents of hearing children tend to interact (Powers and Saskiewicz, 1998).

#### 2.3.3 Hearing parents' perceptions on deaf children

Hearing parents should quickly go through the stages of grieving and accept the truth of their child's deafness. Furthermore, hearing parents should recognize their deaf child as a member of their hearing family and be aware of their own position as parents of a deaf child (Henderson and Hendershott, 1991; Bodner-Johnson, 2003) and/or as parents of both deaf and hearing children (Moores, 1996; Adams, 1997). In addition, Knight and Swanwick (1999) suggested that parents of deaf children maintain the responsibility of being parents and carrying out natural parenting.

As discussed in the previous section 2.3.2, it is well known that parents usually have a wide range of feelings following diagnosis, such as sadness, confusion, grief and so on (McCracken and Sutherland, 1991; Adams, 1997; Knight and Swanwick, 1999). Although these feelings are normal, their emotions still affect the attachment relationship between parents and deaf children (Adams, 1997). As Densham (1995, p.3) argued, 'parents go through a process of grieving the loss of a 'perfect' child in order to be able to accept a 'new' child with a disability'. Therefore, Knight and Swanwick (1999) suggest that families with deaf children should be given time to adjust a new situation and be provided with the appropriate support to help their deaf children.

Hearing parents should be informed of the two main models of deafness and encouraged to find a balance between them (Knight and Swanwick, 1999; Young, 1999). The medical model of deafness lays heavy emphasis not only on the cure to deafness and the use of audiology aids, but also on skills in the development of listening and speech (Knight and Swanwick, 1999). This is because 'this medical scenario is the first experience of deafness for most parents' (Knight, 1998, p.217). For parents, it is agreed that the medical model of deafness can create difficulty for deaf children to learn spoken language and discourages function compared to hearing children (Knight and Swanwick, 1999). In this way, deafness is often referred to as a medical condition, emphasizing the need for a cure (Knight and Swanwick, 1999). However, it was warned by Knight and Swanwick (1999) that some types of deafness are not curable and it might be difficult for some deaf children to learn and acquire spoken language if they are not given an opportunity to access sign language as a first language. By comparison, the cultural-linguistic model of deafness not only enables deaf children to have choices in their own preferred language and to build up

their own identity within Deaf culture, but also promotes a good relationship between deaf children and their parents which can in turn aid the development of future educational plans (Young, 1999; Knight and Swanwick, 1999).

Regardless of the debate over the two models of deafness, Young (1999) suggests that the fundamental approach should encourage hearing parents to firstly accept their deaf child as a child (i.e. childness) and secondly accommodate the child's special needs (i.e. deafness). However, parents find it difficult to distinguish between the two, although they are aware that their deaf children are unlike their hearing counterparts and their previous expectations of having their own children (Young, 1999). As Young (1999, p.168) explained:

'Parents benefited from being able to grasp their deaf child's world, and experienced a sense of not understanding that child. Simultaneously, parents could experience the negative comparisons between deaf and hearing children, and recognize the positive difference of being deaf.'

In addition, Shen (2010) suggested that deaf children should be perceived as a child with visual advantage and/or sign language users rather than as a disabled child. As a result, it is suggested that deaf children follow the same growth and development as all children, except that they cannot hear, as their intelligence and cognition function are the same as a hearing child (McCracken and Sutherland, 1991; Moores, 1996; Knight and Swanwick, 1999).

In order to help parents avoid confusion about their child's deafness, Marschark (2007, p. 185) claimed that 'deaf children can be different from hearing children without being "deficient". Marschark (2007) further explained that deaf children are just as capable as their hearing peers and, while they might vary in their access to cognition, language and knowledge learning, such differences should not be judged in a good or bad way. This was echoed by Freeman et al (1981, p. 10) who stated that 'people who are deaf lead lives that are in some ways different, but not inferior to the lives of people with normal hearing'. From this perspective, it is not sensible to think that having a deaf child will change every part of family life and require parents' varied and demanding coping skills to adapt to new situations and feelings (Freeman et al, 1981). In other words, if parents with deaf children could accept deafness as a difference instead of a defect they would feel more confident in raising their deaf

children (Freeman et al. 1981; Marschark, 2007; Adams, 1997).

On the subject of deafness and disability, people who have a Deaf identity often do not perceive themselves as disabled (Lane, 2008; Ladd, 2003; Leigh, 2009). However, deaf people are often labelled as people with a hearing impairment or hearing loss. Furthermore, the definition of disability is 'an evolving concept' and suggests that:

'Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.' (CRPD, 2006, p. 1).

The definition of impairment in an early document of the World Health Organization (WHO) was identified as 'any loss or abnormality of psychological, physiological, or anatomical structure or function' (WHO, 1980, p. 48). Later, in 2001, the WHO added environmental factors in causing disability to the previous definition of impairment. Recently, the WHO (2007, p.9) stated that 'impairments are problems in body function or structure such as a significant deviation or loss'.

According to these two above definitions of impairment, it is explained that a disability in hearing is a disability from the perspective of a functional deficiency in the ear (Leigh, 2009). Additionally, deaf people may face a struggle for rights to education and language if their deafness is classified within the definition of disability (Lane, 2008). Therefore, it is important for deaf people to have a sense of cultural deafness because Deaf identity can help them find a way of belonging and develop values of being deaf (Lane, 2008; Leigh, 2009). The effect of labels related to deafness can affect the way parents think of their deaf children (Leigh, 2009).

From this perspective, the labels of 'hearing impairment' and 'deaf' could convey meanings of hearing difference and these labels demonstrate the perspective of the medical model of deafness (Leigh, 1999; Leigh, 2009). However, the meanings of labels can change over time and some can be revised based on new information (Leigh, 2009). For example, the label of 'hard of hearing' can cover a range of the hearing difference which could blur the boundaries between hearing-centred identity and deaf-centred identity (Leigh, 2010). Deaf people who wear cochlear implants are often called 'cochlear implant users' (CI users). This label of CI users does not

provide a clear indicator of identity development for deaf children. On the one hand, the identity of CI users, as discussed previously, can be regarded as an artificial hearing identity, as cochlear implants cannot recreate the way in which hearing people hear sounds (Ladd, 2007). On the other hand, the identity of CI users could be perceived as a hearing-centred identity, as cochlear implants can promote deaf children's skills in language development, granting them to have access to both deaf and hearing worlds (Wheeler *et al*, 2007; Leigh, 2010).

In summary, Knight and Swanwick (1999, p. 49) suggested that parents who have a deaf child should be 'parents' and their role should be to deliver 'natural parenting' to develop their deaf child's skills in language, social activities and cognition.

#### 2.4 The gap between policy and practice

Generally speaking, most research has discussed the importance of the role of schools and family in educating deaf children (Powers, 2001; Lynas *et al*, 1997; Angelides and Aravi, 2007; Stinson and Antia, 1999). Furthermore, it is an undoubted fact that currently teachers and parents of deaf children place a great deal of emphasis on the relationship between language and social skills (Watson and Parsons, 1998).

As D'Alessio and Cowan (2013) suggested, many countries have shared agreements within policy and practice on inclusion at an international level, and maintained their national culture, history and policy. This includes China. It could be argued that China has developed its national educational systems based on its own cultural and political situations, including inclusive and special education.

In China, Learning in Regular Classrooms (LRC), as the main pattern of inclusion, not only overlooks the social and life skills of students with disabilities (Deng and Zhu, 2007), but it also lacks awareness in meeting these students' needs with respect to the school environment (Human Rights Watch, 2013). Also, teachers and staff find it difficult to meet the individual special education needs of every deaf child, particularly as a result of the large student-teacher ratio in China (Yu *et al*, 2011, Xu,

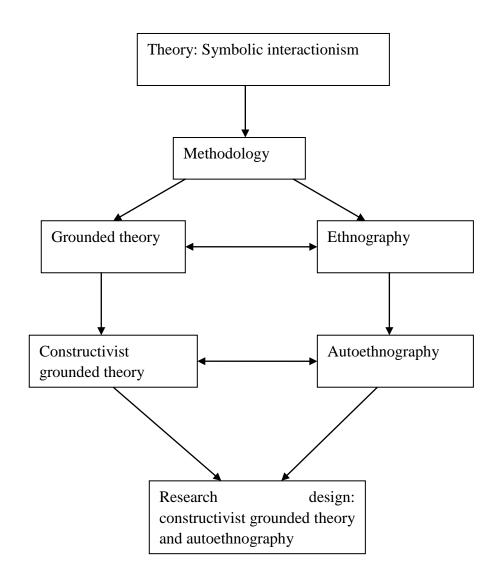
2012). Furthermore, there are currently very few parent support groups for families with children with hearing impairments in China. In addition, there is limited access in mainstream schools to well-established support services, such as note-takers and interpreters, or well-trained teachers of the deaf for deaf students (Lytle *et al*, 2005/2006).

Parental involvement is more likely to positively contribute to language and academic performance in regards to educating deaf children (Calderon, 2000; Eriks-Brophy *et al*, 2006). From this perspective, improving education for Chinese deaf children could involve increasing parental involvement, as waiting for educators and policy-makers to make the relevant changes in the near future may be unrealistic, despite the positive steps currently in evidence. However, studies on Chinese families of children with hearing impairments are limited, although there is an increase in research on parental involvement and engagement in developed countries. Particularly, there is little literature about home coaching strategies for Chinese hearing parents to support their children with hearing impairments during the school period, although there is a great deal of material about deaf children's speech and listening skills and language development in China. Consequently, to address these issues it is essential to explore how a small group of Chinese hearing parents support their deaf children to be integrated into mainstream schools in Beijing, China.

# **Chapter 3 Methodology**

This PhD study used the qualitative methodologies of constructivist grounded theory and autoethnography in the research design as shown in Figure 3.1 below.

Figure 3.1 An overview of this research design



The methodology chapter is divided into five sections. The first gives a brief overview of symbolic interactionism and its philosophical paradigms, as this underpins both methodologies. The second section sheds light on the concepts of the two methodologies used in this study, namely constructivist grounded theory and autoethnography. The third section discusses the relationship between constructivist grounded theory and autoethnography, followed by the relationship between grounded theory and ethnography. Following this, the focus of the fourth section is to examine the relationship between symbolic interactionism as a theory and the two methodologies of constructivist grounded theory and autoethnography. Finally, the ethical considerations of this methodological approach are discussed to conclude this chapter.

#### 3.1 Symbolic interactionism

Symbolic interactionism is an empirical perspective of sociological and social psychology on the study of human life and human beings.

Williams (2008, p. 849) explained that the term symbolic interactionism is divided into two concepts of 'symbol' and 'interaction':

'Symbol refers to any social object (e.g., physical object, a gesture, or a word) that stands in place of or represents something else', and 'interaction highlights the significance of interpersonal communication in transmitting the meaning of symbols.'

Symbol refers to the object, language, action and interaction. Interaction arises from social action with others, and internal action with the self. Based on these two concepts, human beings can use symbols to communicate with the self and interact with others. Moreover, individuals create action, human action creates social interaction, and social interaction forms culture and society. In turn, social interaction influences human action and the individual mind. From this perspective, social interaction is dynamic and creative.

Symbolic interactionism can offer a theoretical perspective to interpret the meaning created by human beings in individual actions and social interactions. This framework

can help researchers learn about people and their actions, and understand the meanings created by social interaction. Meaning is complex, in that the individual is different in a society with a shared culture, and their social interaction changes over time.

According to Mead (1934), symbolic interactionists treat social interaction as dynamic and view human life as process and change. In Mead's (1934) view, the self and mind develop simultaneously in the process of forming social interaction and developing meaning in society. In turn, social interaction and ongoing meaning can influence the self and mind.

Herbert Blumer first coined the term 'symbolic interactionsim' based on Mead's work in 1937 (Williams, 2008; Charmaz, 2014). According to Blumer (1969, p. 2), there are three key premises that underpin symbolic interactionism. Firstly, 'human beings act towards things on the basis of the meanings that things have for them'. Secondly, 'the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellow'. Thirdly, 'these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters'. Based on these three key premises, it could be argued that the meaning created by human beings is a symbolic and dynamic process developed through interacting with individuals and others in society.

In addition to Blumer's three key premises, symbolic interactionists have introduced another two key principles. First, 'all social life is intersubjective' and 'human experiences are inextricably social in nature' (Williams, 2008, p. 851). Williams (2008) further demonstrated that symbolic interactionists focus on studying how meaning creates conversations with the human mind and develops out of life. Second, symbolic interactionism 'highlights the centrality of emotions to social life' (Williams, 2008, p. 851). Williams (2008) further explained that symbolic interactionists do not interpret people's emotions solely from the biological perspective, rather they define emotions in the psychological process they are shaped by and, in turn, shape social action.

Charon (2007, p. 30) suggested that the perspective of symbolic interactionism has five central ideas to understand human actions, including 'social interaction, human thinking, definition of the situation, the present, and the active nature of the human being'. Firstly, symbolic interactionists focus on social interaction, which is central to what human beings do, instead of exploring individual personality characteristics and the purpose of human behaviours. Secondly, human beings as thinking animals create interaction and make conversations with themselves. Thirdly, the humans' definition of the situation is the outcome of social interaction and human thinking at any a time and place in a process. Fourthly, the present definition of the present situation, which humans are in, will be influenced by factors in both the past experience of human beings and the present social interaction with present thinking. Fifthly, symbolic interactionists consider human beings as active persons who are able to overcome difficulties and barriers they face in an environment, instead of being passive in responding to an environment. Therefore, in summary, human beings are not only active persons with a thinking mind derived from conversing with the individual, but they are also social persons through interacting with the present environment based on their acquired knowledge and present definition of the situation they are in (Charon, 2007).

With respect to cultural studies, symbolic interactionists point out that society is created by social interaction, which shapes identities and develops culture through 'a shared perspective' and 'a generalized other' (Charon, 2007; Mead, 1934). Furthermore, Charon (2007, p. 164) explained that culture is constructed by 'a shared perspective through which individuals in interaction define reality' and 'a generalized other through which individuals in interaction take on rules that control their own acts'.

In turn, culture maintains society over time (Charon, 2007; Mead, 1934). On the one hand, culture builds on the cooperative values that emerge from individual knowledge and understanding within a shared language (Charon, 2007). Following this, culture becomes the agreement in social rules which guide human beings to manage and control their actions (Charon, 2007). On the other hand, human beings have the ability to reflect on themselves and their actions and to understand and modify meanings given by culture, which in turn shape the culture (Becker, 1963). In

short, culture is the social product of common language and social process with shared meanings (Charon, 2007; Prus, 1996).

On the subject of emotions, Williams (2008) emphasized that the emotions of human beings are central to everyday life. Charon (2007) argued that emotions are social objects based on the fact that human beings deal with emotions in situations and feel internal emotional responses. Prus (1996, p. 173) further claimed that emotional experience is viewed as 'a generic social process', because human beings can learn to use cultural perspectives to define emotions and develop their skills in expressing and managing their own emotions in their own situations.

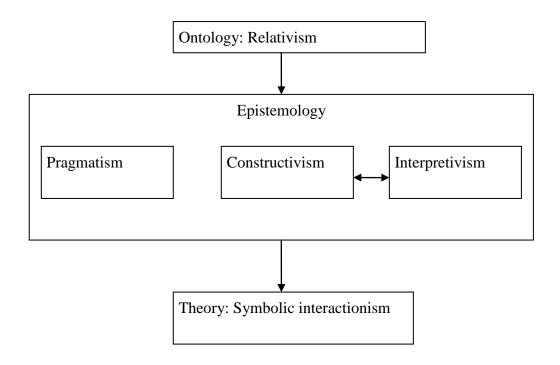
The work of Williams (2008) and Charon (2007) stems from the original ideas of Mead (1934) and Blumer (1969). For example, Williams (2008) and Charon (2007) emphasize that meaning arises from social interaction through human life and the human mind, and this statement can also be found in the work of Mead (1934) and Blumer (1969).

When it comes to discussing differences in their work, Williams (2008) mentions the role of emotion in social interaction while Charon (2007) focuses on the role of human beings as social and active persons played in social interaction. From this perspective, symbolic interactionism not only studies human action and social interaction, but also learns about human beings' emotions and their culture that they are present in a society.

### 3.1.1 Symbolic interactionism and its philosophical paradigms

As shown in Figure 3.2 below, the philosophical epistemologies of pragmatism, constructivism and/or interpretivism are influenced by the ontology of relativism (Lincoln *et al*, 2011).

Figure 3.2 An overview of philosophical paradigms in this qualitative research design



Relativism supports the idea that 'reality is produced, constituted or constructed through language' and acknowledges multiple realities (Hughes and Sharrock, 1997, p. 145, original emphasis). Crotty (1998) further explained that the same phenomena are interpreted differently according to historical and cross-cultural contexts within different times and different places. Moreover, relativists claim that 'what may be true in one reality is independent of and different from what is true in another' (Hughes and Sharrock, 1997, p. 145). From this perspective, realities are constructed and co-constructed through multiple meanings given by individual understanding and the relevant social contexts (Lincoln et al, 2011).

Aside from ontology's attempts to define what is the nature of reality, epistemology discusses the relationship between the researcher and the researched by asking how we know what we know (Creswell, 2013; Lincoln *et al*, 2011; Crotty, 1998). Within this context, it could be argued that symbolic interactionism, as a theoretical perspective, has philosophical roots in pragmatism, constructivism and/or interpretivism (Creswell, 2014; Crotty, 1998; Hughes and Sharrock, 1997).

In terms of pragmatism, Creswell (2014) explained that researchers focus on the research problem through exploring the questions of what and how. 'In pragmatist philosophy, meanings emerge through practical actions to solve problems, and

through actions people come to know the world' (Charmaz, 2014, p. 344). From this perspective, 'pragmatists see facts and values as linked rather than separate and truth as relativistic and provisional' (Charmaz, 2014, p. 344). As a result, pragmatists use different methods and different assumptions to understand a pluralistic reality, which is often based on how researchers work in solving problems (Creswell, 2014).

It is noted that American pragmatism was an influence on social psychologist George Herbert Mead, who laid the foundations of symbolic interactionism in the early 1930s. And Mead's approach to symbolic interactionism focuses on human action rather than personality or society (Charon, 2007). Charon (2007) further explained that pragmatism believes that humans often interpret their environment and define symbolic meaning that they have to act towards objects.

It is suggested that constructivism and social constructivism are interchangeable, and these two terms are often combined with interpretivism (Creswell, 2014; Lincoln *et al*, 2011).

According to Crotty (1998), constructivism argues that human beings construct meanings through interaction with their world and interpret meanings based on their individual historical and social perspectives. Creswell (2014) further explained that the meaning of social constructivism is varied and multiple based on the fact that different individuals are from different historical and cultural backgrounds. From this perspective, researchers with a constructivist worldview try to use their personal, cultural and historical experience to interpret the participants' meaning, which is constructed by their social interaction in a cultural setting, including the participants' interpretation of their activities and actions (Creswell, 2014; Crotty, 1998).

Within the subject of interpretivism, knowledge of the world is gained through human understanding of the studied phenomenon from the perspectives of participants and researchers. According to Hughes and Sharrock (1997, p. 104), participants in the studied phenomena 'give meanings to themselves, to others and to the social environments in which they live' by explaining the reasons for their actions and declaring their motives for their decision-making. Blaikie (2010, p. 99) further explained that 'social reality is regarded as the product of its inhabitants' within

interpretivism. From this perspective, the world of the participants is interpreted by the meanings that are produced from their interaction with their everyday activities (Blaikie, 2010).

Therefore, constructivism focuses on the interaction process and specific context in which people act, and interpretivism places emphasis on human understanding of the social world based on their knowledge and experience.

### 3.2 Constructivist grounded theory

Charmaz (2014, p. 342) stated that 'constructivist grounded theorists aim for abstract understanding of studied life and view their analyses as located in time, place, and the situation of inquiry'. Unlike objectivist grounded theory, which is underpinned by positivism, constructivist grounded theory takes interpretivism into account (Charmaz, 2014). Compared to objectivist grounded theorists who view data analysis as an objective process, constructivist grounded theory acknowledges the researchers' view and the importance of engaging in reflexivity throughout the research process (Charmaz, 2014).

In terms of a constructivist approach, Creswell (2007, p.238) explained that:

'The constructivism approach incorporates the researcher's views; uncovers experiences with embedded, hidden networks, situations, and relationships; and makes visible hierarchies of power, communication, and opportunity'.

As Charmaz (2014, p. 240) summarized, 'a constructivist approach means being alert to the conditions under which such differences and distinctions arise and are maintained'.

There are two main reasons why constructivist grounded theory (Charmaz, 2006; Charmaz, 2014) was used in this PhD study.

Firstly, Charmaz's stance on grounded theory is closely related to social constructivism and symbolic interactionism (Charmaz, 2014; Charmaz, 2006; Charmaz, 2005). Charmaz (2014, p. 344) further explained that social constructivism 'assumes that people create social reality or realities through individual and

collective actions' and 'symbolic interactionism is a constructionist perspective because it assumes that meanings and obdurate realities are the product of collective processes'. Therefore, constructivist grounded theory is a useful approach in this study, as it aims to explore the participants' meanings and experiences within their social world of being a hearing parent with a deaf child.

Secondly, constructivist grounded theory can integrate subjective experiences with the studied phenomenon (Charmaz, 2005). For example, this study includes the author's subjective experience as a deaf person growing up in a hearing family. It is further explained that the constructivist approach allows researchers to interpret research work by locating the participants' meanings and actions in a social process (Charmaz, 2014). Their meanings and actions could reflect the participants' values and the researchers' perspective, because 'the realities are multiple in the constructivist view' (Charmaz, 2014, p. 240). As Charmaz (2000, p. 525) suggested, 'constructing constructivism means seeking meanings – both respondents' meaning and researchers' meaning'.

Thirdly, the main advantage of grounded theory is to allow data collection and data analysis to be intertwined, such as theoretical sampling and memo-writing.

Therefore, the constructivist approach can lead grounded theorists to look at and beyond how the participants view their actions in various situations (Charmaz, 2014; Charmaz, 2006; Charmaz, 2005).

#### 3.3 Autoethnography

'Autoethnography is an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the culture' (Ellis and Bochner, 2000, p. 739). It is further explained that:

'Back and forth autoethnographers gaze, first through an ethnographic wide-angle lens, focusing outward on social and cultural aspects of their personal experience; then, they look inward, exposing a vulnerable self that is moved by and may move through, refract, and resist cultural interpretations. As they zoom backward and forward, inward and outward, distinctions between the personal and cultural become blurred, sometimes beyond distinct recognition.' (Ellis and Bochner, 2000, p. 739)

It is argued that autoethnography combines the two approaches of autobiography and ethnography (Ellis, 2004; Ellis *et al*, 2011).

Generally speaking, scholars have slightly different understandings of the term 'autoethnography'. According to Reed-Danahay (1997), the word 'autoethnography' can be seen as auto (self) - ethno (culture) - graphy (research process). Meanwhile, Chang (2009) argued that the term 'autoethnography' consists of three dimensions: autobiography (content), culture (interpretive orientation) and ethnography (methodology). Moreover, Ellis *et al* (2011) claimed that autoethnography is a method of writing personal experience (auto) with a systematical analysis (graphy) in order to understand the culture (ethno). From this perspective, autoethnography has characteristics combining ethnography and autobiography (Ellis, 2004; Ellis *et al*, 2011). To summarise, it is best accepted that autoethnography is viewed as 'part <u>auto</u> or self and part ethno or culture' (Ellis, 2004, p. 31, original emphasis).

It can be argued that autoethnography is a family member of ethnography. And 'autoethnography is an ethnographic inquiry that utilizes the autobiographical materials of the researcher as the primary data' from the perspective of methods (Chang, 2008). When researchers conduct ethnography, they are likely to be a participant observer, collecting data through field notes and/or interviews that are conducted in a field study (Ellis et al, 2011). Ethnography also offers a perspective of cultural practice which helps insiders (cultural members) and outsiders (cultural strangers) to better understand the culture (Maso, 2001).

Similar to ethnography, autoethnography refers to the process of doing a study and the written product produced from the process (Ellis, 2004). In comparison with ethnography, autoethnographers collect data through personal experience and/or interviewing to demonstrate the experience of cultural characteristics that are familiar to both insiders and outsiders (Ellis *et al*, 2011). As Chang (2007, p. 207) asserted, 'autoethnography emphasizes cultural analysis and interpretation of the researcher's behaviors, thoughts, and experiences in relation to others in society'.

Autoethnography helps the researcher connect the self with others in the studied

world by learning other people's stories and understanding their culture. As Wall (2006, p.146) stated, 'the intent of autoethnography is to acknowledge the inextricable link between the personal and the cultural and to make room for nontraditional forms of inquiry and expression'. And what is more, autoethnography acknowledges the researchers' personal and cultural beliefs and their reflexive mind in response to the collected data. According to Alvesson and Sköldberg (2000, p. 245),

'Reflection means thinking about the conditions for what one is doing, investigating the way in which the theoretical, cultural and political context of individual and intellectual involvement affects interaction with whatever is being researched, often in ways difficult to become conscious of.'

From this perspective, reflection in autoethnography plays a significant role in thinking of multiple layers of the studied phenomena in personal, social and cultural ways.

# 3.4 The relationship between constructivist grounded theory and autoethnography

Both constructivist grounded theory and autoethnography are applied in this PhD study.

Autoethnography can be combined with the approach of grounded theory in a qualitative design (Ellis and Bochner, 2000). Ellis and Bochner (2000, p. 757) stated that researchers who use autoethnography 'could do a straight grounded theory analysis'. They further explained that researchers who apply grounded theory with autoethnography not only compare and analyse the data, but also 'write in an authoritative voice about the patterns' that the researchers observe (Ellis and Bohner, 2000, p. 758).

Ellis (2009, p. 99) further explained that 'constructionsits are willing to examine emotion as a private as well as social experience, but they move quickly to the social part of emotion, playing down its private essence as belonging to psychology'. Charmaz (2014, p. 239) argued 'the theory depends on the researcher's view', which is in line with the techniques of introspection derived from autoethnography (Ellis,

2009). Therefore, Ellis and Bohner (2000, p. 758) recommend that researchers should follow the guidelines of Charmaz when choosing which version of grounded theory that is applied to autoethnography.

#### 3.4.1 Grounded theory and ethnography

The methodologies of grounded theory and ethnography belong to qualitative research, and both share the same philosophical orientation, symbolic interactionism (Charmaz, 2014; Glaser, 2002; Corbin and Strauss, 2008; Charmaz and Mitchell, 2001; Aldiabat and Le Navenec, 2011). It is argued that both grounded theory and ethnography have a similar goal of understanding the cultural meanings constructed by events and experiences (Aldiabat and Le Navenec, 2011).

It is argued that grounded theory and ethnography do have different viewpoints. The former emphasizes studying 'the basic social process' and 'social psychological processes' that construct the reality in which human beings live (Charmaz, 2014, p. 34), paying no attention to cultural background (Aldiabat and Le Navenec, 2011). The latter provides the focus on a wide description of cultural meanings constructed by human beings living in a specific culture (Charmaz and Mitchell, 2001). In short, Charmaz and Mitchell (2001) claim that ethnography concerns only one aspect of reality within a cultural study, whereas grounded theory is open to the reality of the whole context.

However, Pettigrew (2000, p. 256) suggested that grounded theory and ethnography represent a 'happy marriage'. Pettigrew (2000) also claimed that both grounded theory and ethnography can act in a compatible way on the grounds that ethnography can provide rich descriptions for the data analysis of grounded theory. Furthermore, 'ethnographers can make connections between events by using grounded theory to study process' (Charmaz, 2014, p. 41). Aldiabat and Le Navenec (2011) also argued that grounded theory leads the data to theoretical abstraction, whereas ethnography focuses on the rich descriptions of cultural studies.

In light of the data analysis strategies of constructivist grounded theory, Charmaz (2014, p. 41) explained:

'A grounded theory emphasis on comparative methods leads ethnographers 1) to compare data with data systematically from the <u>beginning</u> of the research, not after all the data are collected, 2) to compare data with emerging categories, and 3) to demonstrate relations between concepts and categories.' (original emphasis).

From this perspective, grounded theory can guide ethnographers to gain a systematic insight into the study's settings by using the strategies of comparative methods (Charmaz, 2014). To take this current PhD study as an example, comparative methods analyse different parents' behaviour during the same events (e.g. the diagnosis of deafness, teaching deaf children to speak, home coaching, etc.) and the same parents' attitudes toward deafness during the period of childhood.

In conclusion, Charmaz and Mitchell (2001, p. 160) point out that grounded theory and ethnography can interplay in a complementary way:

'Using grounded theory methods can streamline fieldwork and move ethnographic research towards theoretical interpretation. Attending to ethnographic methods can prevent grounded theory studies from dissolving into quick and dirty qualitative research.'

#### 3.4.2 Constructivist grounded theory and autoethnography

In order to clearly interpret the studied phenomena, autoethnography can help the grounded theorist deeply understand experience by living with the data, not simply talking about it. It is argued that 'we are part of the world we study, the data we collect, and the analyses we produce. We construct our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices' (Charmaz, 2014, p. 17, original emphasis). Also, autoethnography can provide a platform of reflection on the researchers' analysis alongside the wide descriptions provided by the approach to ethnography. As Pace (2012) further explained, 'autoethnographers reflexively explore their personal experience and their interactions with others as a way of achieving wider cultural, political or social understanding'. Constructivist grounded theory and autoethnography can help the researcher gain deep insight into the data and reflect the data analysis forward and backward by connecting their personal stories to the culture of the study. Consequently, constructivist grounded theory can make sense of the narratives of autoethnography and interpret personal experience.

The aim of this PhD study was to explore how Chinese hearing parents provide support for their deaf children to prepare them for education in mainstream schools in Beijing. The reasons why both constructivist grounded theory and autoethnography are applied within this study are that:

On the one hand, constructivist grounded theory mainly offered flexible guidelines for data collection and analysis, and this enabled the author to uncover a theory grounded from the data through multiple levels of coding and constant comparison. According to Charmaz (2006), constructivist grounded theory can allow the researcher to focus on the views, beliefs, feelings and experiences of the Chinese hearing parents who engaged in this PhD study. This constructivist approach can also allow the author to reflect on the participants' interpretations, and such interpretations can then be influenced by the author's personal experience as a deaf adult who grew up in a hearing family and attended mainstream schools in Beijing.

On the other hand, autoethnography can allow the author's personal journey to be reflected in and integrated with the 10 Chinese hearing parents' experiences of raising their deaf children (Ellis, 2009). Furthermore, the author played an important role in being an insider to connect personal experiences of being deaf to the interviewed data. Additionally, autoethnographic reflection captured how the process of parental involvement in raising deaf children was influenced by the possible factors within the personal, familial, societal and cultural contexts.

Therefore, autoethnography embraced the full involvement of the author in the world of parenting deaf children, and constructivist grounded theory enabled the author to build a theory based on the typical phenomenon found in the world being studied on the topic of hearing parents supporting their deaf children to attend a mainstream school.

# 3.5 The relationships among symbolic interactionism, constructivist grounded theory and autoethnography

Within this PhD study, symbolic interactionism, which underpins both constructivist

grounded theory and autoethnography, aids the researcher to understand the dynamic social actions that Chinese hearing parents took part in. The use of symbolic interactionism enables the researcher to be sensitive to the meanings given by the participants and their actions in various situations (Williams, 2008). In order to deeply understand the meanings that are constructed by Chinese hearing parents, autoethnography aids the author to develop an understanding of the participants' emotions and actions in a process and how this changes over time. Moreover, autoethnography allows the researcher to use introspection to access personal narratives as private experiences and produce various interpretations from the perspectives of the participants and the author self (Ellis, 2009). In terms of symbolic interactionsim, the researcher's personal experiences can offer the perspective of a Chinese deaf adult who grew up and was educated at mainstream schools in Beijing, thus encouraging her to learn about Chinese hearing parents' actions, meanings, troubles and emotions in a process of raising their deaf children (Charmaz, 2014), but also aiding her to understand emotional studies (Ellis, 2009), for example, Chinese hearing parents' response to deafness and language and their emotional change over time.

#### 3.6 Ethical considerations

Ethical issues play an important role in limiting the occurrence of badly designed or harmful research. Consideration of ethics not only ensures that respondents know about their rights but also protects the researcher's position (Bell, 2005). The purpose of the ethical dimensions of research work is to ensure not only that all the participants are volunteers who were protected from any harm, but also that they have the right to refuse participation at any stage without giving any explanations.

In short, although this study was carried out in China where ethical issues are not a high priority, a good place to start is to understand and consider some of the ethical issues involved in achieving transparency and openness in the design of research work (Burgess *et al*, 2006). Therefore, it is essential to consider the ethical issues through all phases of the research process, from research questions to data collection and analysis.

#### 3.6.1 Informed consent

In order to gain support from participants, ethical consideration places responsibility on the staff who will support the research and researchers to explain to respondents as fully as possible what the research is about, why the questions have been chosen and what information will need to be obtained (Bell, 2005; Creswell, 2007). Ongoing debate, reflection and statements about ethical issues can help researchers to get useful background information and deal with any tricky issues arising from the participants (Silverman, 2004; Silverman, 2013). Therefore, Creswell (2007, p.142) claimed that 'although in most instances this information is deleted from analysis by the researcher, the issue becomes problematic when the information, if reported, harms individuals'.

Firstly, I contacted staff who were working in the training centre in Beijing or hearing aid and cochlear implant companies in Beijing, and showed them the invitation letter (see Appendix 1) with my research aims, Secondly, according to the information provided by staff, I contacted and met potential hearing parents of deaf children to confirm their engagement in my research through the information sheet (see Appendix 2) and consent form (see Appendix 3).

All the participants were provided with an information sheet for participants (see Appendix 2) which included details about their involvement prior to research participation. For those who agreed to take part in this research study, they were provided with and asked to sign a consent form (see Appendix 3) in accordance with the regulations before starting the interviews. Therefore, participants were made aware of their right to refuse participation at any stage, without needing to provide an explanation, or to withdraw information before this PhD research project's completion.

#### 3.6.2 Participants' protection

In most circumstances, there are possible factors which may affect the rights of both the researchers and the participants, such as social bias and disability discrimination. The key to solving these problems is based on a good relationship, established through a sense of rapport with feelings of trust and confidence between the researchers and the participants (Cohen *et al*, 2007). Consequently, the issue of ethics is primarily concerned with the attitudes and engagements of the participants.

Those who would consent to participate were given the choice of remaining anonymous and allowed to choose a pseudonym in order to protect their identity. These participants also knew they had the right to withdraw from this research at any time without prejudice. All the data, both transcripts and materials related to information on the participants, would be destroyed on completion of this research. From this perspective, the risks for participants who engaged in this research were minimal.

Although participants are entitled to full confidentiality, the researcher needs to inform the participants about the requirement to contact the appropriate authorities if any an issue of children's protection is raised. Therefore, it is necessary for the researcher to take responsibility to protect participants from any harm caused by the research project and explain clearly the purpose of the research, but also inform parents of children's protection policy and procedures as appropriate.

#### 3.6.3 Data storage

This PhD research project was carried out in Beijing, China, following ethical approval from ethics committees of Northumbria University in 2009. Once I finished data collection, I brought all the relevant data and materials to Northumbria University and carried out the stage of data analysis. All the interview data are labelled confidentially with the same code as the field notes. Furthermore, copies of research diaries were not only safely kept in a locked box file but were also scanned into my laptop. All the data are copied twice on two different memory sticks. Data were printed and copied and then the printed papers were safely kept in the locked box files. In addition, the memory sticks and all printed papers and materials were locked in my locker in the PhD student office at Northumbria University and only accessed by myself.

All the data were privately saved and protected on my laptop which was only

accessed via a confidential password. Furthermore, all the data were only used in my PhD research project. Finally all the data were completely destroyed once my PhD thesis was completed and submitted to Northumbria University.

In short, all the data were stored safely in the locked box files and a secure locker in the PhD student office at Northumbria University. All the data were copied at least twice on my laptop and backed up on two different memory sticks.

#### 3.6.4 Outputs of research data

All the data were kept safely and privately by the researcher, Xirong He. Participants' names and details were kept confidentially by me and will not appear in any printed materials.

It is suggested that the researcher should not share participants' experiences with other participants in the process of constructing the research (Creswell, 2007). However, useful results can be shared at conferences or be published in peer reviewed journals, and provided with guidance toolkits for organizations (Creswell, 2007), for example, some of the themes emerged from this PhD research are developed into a theoretical model of parental involvement. Furthermore, this research included some examples of what participants told me, but their names are be anonymised and confidential, so that parents can learn from this research project to help their children improve their abilities in studying at mainstream schools, without knowing the identity of the participants.

### 3.6.5 The ethical issues within autoethnography

There is a debate over ethics in the methodology of autoethnography. Ellis (2007, p. 26) claims that 'not only are there ethical questions about doing autoethnography but also that autoethnography itself is an ethical practice'.

Following Ellis's guideline (2009, p. 308), relational ethics requires autoethnographers to 'act from our hearts and minds, to acknowledge our interpersonal bounds to others, and to initiate and maintain conversations'. It is

further explained that relational ethics should be 'true to one's character and responsible for one's actions and their consequences on others' (Slattery and Rapp, 2003, p. 55). From this perspective, relational ethics can establish a mutual respect and good rapport between the autoethnographers and the study itself, and between the researchers and participants (Ellis, 2009).

Ellis (2007, p. 17) suggests that it is the autoethnographers' responsibility to 'resolve how and what to tell intimate others about how they have been included in our stories'. In terms of relationships between autoethnographers and research participants, Ellis (2007) argues that these relationships may change over time regardless of consent forms signed by participants, or these relationships may go deeper or become more complicated depending on people's changing perspectives in the process. In this case, it is suggested autoethnographers should not only inform participants what they wrote about and let participants read their work, but also use pseudonyms to protect participants' privacy (Ellis, 2007; Ellis et al, 2011).

#### 3.6.6 The researcher's role in the research

It is very important to critically identify and develop my role in this research, as both insider and outsider. On the one hand, I am an insider because I am a pre-lingual profoundly deaf person, as explained before, and I know the various difficulties that deaf people experienced. However, the view from myself as an insider would affect the quality of my research to large extent. For this reason, I would like to step outside my perspective and empathize with participants. On the other hand, I am an outsider and it would help me to understand how and why participants acted in certain ways in certain situations. Bell (2005, p. 162) also suggested that 'the researcher becomes less of an interviewer, more of a moderator or facilitator'.

# **Chapter 4 Methods**

The previous chapter described the overview of the philosophical paradigm of symbolic interactionism and its underpinning methodologies of constructivist grounded theory and autoethnography. In this chapter, both the implementation of the research design and considerations of qualitative validity and reliability are presented.

#### 4.1 Initial sampling and recruitment

As Charmaz (2014, p. 197) suggests, 'initial sampling in grounded theory gets you started; theoretical sampling guides where you go'. According to constructivist grounded theory, the initial sampling guides the researcher to recruit the participants by establishing a sampling criteria, but also allows the researcher to plan how to enter the field (Charmaz, 2006; Charmaz, 2014). The tool of theoretical sampling in the stage between data collection and analysis will be discussed later in this chapter.

For the purpose of this PhD study, the inclusion and exclusion sampling criteria for recruiting parents (see Table 4.1) was designed to aid the researcher focus on the participants who should be included in this study.

Table 4.1 Inclusion and exclusion sampling criteria for recruiting participants

| Inclusion sampling criteria | Exclusion sampling criteria |
|-----------------------------|-----------------------------|
|                             |                             |

- 1 Participants are hearing parents
- 2 Children of hearing parents are pre-lingual hearing impaired 11
- 3 Participants are living in Beijing, China
- 4 Participants have experiences of educating their deaf children at mainstream schools
- 1 Participants are deaf parents
- 2 Children of hearing parents are post-lingual hearing impaired <sup>12</sup>
- 3 Participants are living outside Beijing, China
- 4 Participants have never educated their deaf children at mainstream schools

In terms of sampling for grounded theory, Morse (2007, p. 235) suggests four main sampling methods: 'convenience sampling', 'purposeful sampling', 'theoretical sampling' and 'theoretical group interviews'. Furthermore, Morse (2007, p. 236) argued that 'snowball or nominated sampling' may be applied after the use of 'a preliminary convenience sample'.

At the beginning of data collection, three main sampling methods (convenience sampling, purposeful sampling, snowball or nominated sampling) were used to recruit Chinese hearing parents in this PhD study. First, convenience sampling was to 'obtain an overview of the overall process', and 'to determine the dimensions and boundaries, as well as the trajectory of the project' (Morse, 2007, p. 235). Second, snowball or nominated sampling means that the researcher could invite the initial participants' acquaintances to engage in the research (Morse, 2007). Third, purposeful sampling refers to the confirmation of the scope of the phenomena and trajectory (Morse, 2007).

For example, I visited hearing and speech training centres and hearing aid and cochlear implant companies in Beijing. These visits increased my opportunities to meet various parents by asking staff who work at these organizations to spread information to parents and give them the invitation letter (see Appendix 1). Also,

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<sup>&</sup>lt;sup>11</sup> Children with pre-lingual hearing impairment refers to the children who became deaf before 3 years old and these deaf children did not form a language base at that time.

<sup>&</sup>lt;sup>12</sup> In contrast with children with pre-lingual hearing impairment, children with post-lingual impairment means that children became deaf after 3 years old and they usually have a basic language foundation.

information sheets and consent forms (see Appendix 2 and 3) were delivered to hearing parents if they had expressed their interest in taking part, in order to raise their awareness of this PhD study's aims. According to the sampling criteria in Table 4.1, I recruited Chinese hearing parents of deaf children in three different places in Beijing and then carefully selected a small number of hearing parents who met the criteria in this PhD study. Furthermore, 10 hearing parents took part in this PhD study, including 8 individual hearing parents representing their family as a whole and 1 couple of hearing parents. Also, the details of participants and their deaf children are illustrated in Appendix 11. Additionally, I contacted representatives of Chinese hearing parents and asked them to invite their friends by giving them the information sheet (see Appendix 2).

#### 4.2 Data collection

Symbolic interactionism places a great deal of emphasis on the dynamic interaction between the researchers and participants. Both autoethnography and constructivist grounded theory place me in the position of the author who tells a self story and the relevant stories about others (Ellis, 2009; Charmaz, 2014; Denzin, 2014; Denzin, 2001). Consequently, data were collected through self stories and intensive interviews.

## 4.2.1 Autoethnography self story

I wrote my story, as a deaf person with oral language, growing up in Beijing from birth to school age (See Appendix 10). I also used this to briefly introduce myself to the hearing parents when I met them. During the stage of data collection, the role of the self story was to help me quickly to enter into the field and build a relationship with Chinese hearing parents.

#### **4.2.2** Intensive interviews

Charmaz (2014, p. 58) explained that 'intensive interviews focus on research participants' statements about their experience, how they portray this experience, and what it means to them, as they indicate during the interview'. Furthermore, intensive interviewing fits constructivist grounded theory 'because it facilitates conducting an open-ended, in-depth exploration of an area in which the interviewee has substantial experience' (Charmaz, 2014, p. 85).

Following Charmaz's interview guide (2006), this PhD study used two main rounds of interview questions (See Appendix 4 and 5). To take an example of this PhD study, the first-round interview questions mainly consisted of two parts: one is about Chinese hearing parents' views about deafness and the other is about Chinese hearing parents' views about educating their deaf children at mainstream schools. Furthermore, the second-round interviews included the first-round interview questions with several additions. For example, the new questions mainly included what Chinese hearing parents' views of their deaf child are, why hearing parents choose mainstream schools, how their deaf child enters into a mainstream school, what hearing parents' experience of supporting their deaf child at the mainstream school is and so on.

Also, back-up interview questions were added (See Appendix 6). It could be argued that the advantage of the back-up interviews was to check the interview data with the participants to ensure that important questions had not been missed and also to check whether data saturation was reached or not. In this way, these questions allowed the researcher to go forwards and backwards in a flexible way (Charmaz, 2006; Charmaz, 2014).

All Chinese hearing parents were interviewed twice. There were a total of 18 interviews with 10 hearing parents after the first-round and second-round interviews. Furthermore, the major interviews were mainly conducted in a meeting room of training centres and companies, and each interview lasted 1.5-2 hours. Moreover, there were 4 interviews with 2 Chinese hearing parents (i.e. Parent Li and Parent Liu) located in the participants' homes, and each interview lasted approximately half a day. All the interviews were audio-recorded using a digital voice recorder in the Chinese language, as all the hearing parents can only speak Chinese. The digital voice

recorder helped the researcher to concentrate on the hearing parents' stories and maintained eye contact during the interview, and then get access to the detailed data after the interview (Charmaz, 2006; Charmaz, 2014; Charmaz and Mitchell, 2001).

#### 4.3 Data transcription and translation

After collecting interview data, it was important to transcribe the audio-recording data in Chinese first and then translate it into English. For example, at the first stage of transcribing the interviews, two assistants transcribed the first two interviews verbatim in Chinese, and then I compared the two transcriptions and selected the most similar words (up to 80%) and defined these words as the original language obtained from interviews. Following this, I took these transcriptions back to the participants to ensure that the data were accurate in the language used and check if any missed information. If there were any inconsistencies or errors, the transcribed materials were altered to reflect and then checked. At this stage, the data had only been accessed by the researcher and two assistants. Also, the data had been made anonymous and labelled with a pseudonym for this PhD research.

After transcribing the interview data in Chinese, it was important to translate data from the mother tongue of Chinese into the foreign language of English. It is suggested that translations in cross-cultural research should be conducted by at least one translator, who is bilingual, via back-translation (Chen and Boore, 2009). Back-translation refers to 'translating from the source to the target language' and 'blindly translating back from the target to the source', before comparing these versions to ensure they are equivalent (Brislin, 1970, p. 186).

In order to ensure the Chinese transcriptions were correctly translated into English, two translators were used in this PhD study. One of the two translators is the author, myself, who is able to speak and write Chinese and English equally well and specializes in the field of deaf education. The other translator is a bilingual person who is able to master Chinese and English equally well and has experience in education. In the early stages of data collection, I and a bilingual person both independently translated these data verbatim into English. Following this, both

translators took this English version and blindly translated from English to Chinese. After this stage, both translators discussed the similarities and differences in the translations and selected the most appropriate and relevant English words before reaching an agreement on the final English version.

In addition, data that had been made anonymous was encrypted and confidentially transferred by email to my supervisors whenever problems arose for requiring a further discussion.

#### 4.4 Data analysis

In constructivist grounded theory, the coding and comparative methods were simultaneously used in the stage of data analysis.

#### 4.4.1 Coding and its phases

'Grounded theory coding is the process of defining what data are about' (Charmaz, 2014, p. 111). 'Coding means categorizing segments of data with a short name that simultaneously summarizes and accounts for each piece of data' (Charmaz, 2014, p. 111). It is argued that coding shows the researcher's analytical development through selecting and sorting the data (Charmaz, 2014). Moreover, 'the coding process is interactive' as it studies the participants' views and actions as well as examining the use of language from the perspectives of participants and researchers (Charmaz, 2014, p. 115). Consequently, Charmaz (2014, p. 113) claimed that coding is the first analytic step to study the fields that participants take part in, offering 'the pivotal link between collecting data and developing an emergent theory to explain these data'.

In constructivist grounded theory, it is suggested that coding should consist of at least two main phases: initial coding and focused coding (Charmaz, 2006; Charmaz, 2014). As Charmaz (2014, p. 143) emphasized, 'consistent with the logic of grounded theory, both initial and focused coding are emergent processes'.

#### The first phase: initial coding

Initial coding refers to 'naming each word, line, or segment of the data' at the beginning of coding analysis (Charmaz, 2006, p. 46). It is suggested that initial coding should 'code data <u>as</u> actions' rather than coding people or topics and themes (Charmaz, 2014, p. 116, original emphasis). In other words, coding data as actions refers to the data that demonstrates what is happening. Charmaz (2014) argued that coding for actions with gerunds can help researchers stay close to the data that may demonstrate what participants do in a time and space.

Unlike word-by-word coding, which might be helpful in the analysis of 'documents or certain types of ephemera, such as Internet data', line-by-line coding fits analysis with 'detailed data about fundamental empirical problems or processes', which is collected by 'interviews, observations, documents, or ethnographies and autobiographies' (Charmaz, 2006, p. 50). Charmaz (2014) further explained that line-by-line coding can encourage the researcher to learn about the participants' views and sparks new ideas about the data through interacting with the data and the coding. In light of the interview data, line-by-line coding helps researchers gain a close insight into the meanings that participants constructed at a particular time, and the changed meanings over time, while identifying 'implicit concerns' and 'explicit statements' (Charmaz, 2006, p. 50).

In this PhD study, the method of 'line-by-line coding' was applied at the stage of initial coding (Charmaz, 2006; Charmaz, 2014). When I started initial coding, I read the first paragraph of the first interview for the first time to get a general meaning of this paragraph. Later, I re-read this paragraph and began to code line-by-line to identify potentially useful codes. At the same time, I used a coloured highlighter pen to highlight each line and create a code label. Following this, I moved to another paragraph of the same interview to carry out further line-by-line coding. The highlighted words were named as codes and written in the margin of the interview transcription, as shown in Table 4.2.

**Table 4.2 Initial coding example** 

| Quotes  | Initial Coding           |
|---|--------------------------|
| It is really hard to describe the mixed feeling     | Having mixed feeling     |
| about that sudden news. At first, I can't believe   | Not accepting            |
| that she became deaf and I feel very shocked. At    | Feeling shocked          |
| the same time, I am very afraid of bad things. I    | Feeling afraid           |
| got used to the news until her deafness was         | Confirming deafness      |
| confirmed by three famous hospitals in Beijing.     |                          |
| And then I was so so disappointed and painful       | Not accepting            |
| that I cried into my arms and burst into tears. It  | Feeling disappointed and |
|   | painful                  |
| was like a thunderbolt out of a clear sky. I really | Crying                   |
| did not know why why deafness happened on           | Shocking                 |
| my little daughter, and she was only up to 1 year   | Why                      |
| old. Why bad luck also happened on my daughter.     | Bad luck                 |
| I was still in confusion and my mind was blank.     | Feeling confused         |
|   | Feeling lost             |

### The second phase: focused coding

Focused coding is 'to sort, synthesize, integrate, and organize large amounts of data' by using 'the most significant or frequent initial codes' (Charmaz, 2006, p. 46). It is suggested that focused coding can lead to theoretical analysis by synthesizing and conceptualizing the initial codes (Charmaz, 2014). Moreover, Charmaz (2014) argued that focused coding not only requires the researchers to make decisions about which initial codes represent a large body of the data, but it also increases their confidence in developing their analysis to a conceptual level. An example of how focused coding can work with the categories within two participants' interview data is presented in Table 4.3.

Table 4.3 Focused coding example

| Quotes   | Initial Codes            | Focused     |
|--|--------------------------|-------------|
|  |                          | codes       |
| It is really hard to describe the mixed        | Having mixed feeling     | Feeling     |
| feeling about that sudden news. At first, I    | Not accepting            | about the   |
| can't believe that she became deaf and I       | Feeling shocked          | deafness    |
| feel very shocked. At the same time, I am      | Feeling afraid           | diagnosis   |
| very afraid of bad things. I got used to the   | Confirming deafness      |             |
| news until her deafness was confirmed by       |                          |             |
| three famous hospitals in Beijing. And then    |                          | NT .        |
| I was so so disappointed and painful that I    | Not accepting            | Not         |
| cried into my arms and burst into tears. It    | Feeling disappointed and | accepting   |
| was like a thunderbolt out of a clear sky. I   | painful                  | deafness    |
| really did not know why why why                | Crying                   |             |
| deafness happened on my little daughter,       | Shocking                 |             |
| and she was only up to 1 year old. Why         | Blaming                  |             |
| bad luck also happened on my daughter. I       | Bad luck                 |             |
| was still in confusion and my mind was         | Feeling confused         |             |
|  | Feeling lost             |             |
| blank.   |                          | 77 11       |
| I think it is quite hard for me to step out of | Feeling hard and painful | Feeling     |
| the tight spot and I still feel very sorry for | Feeling sorry,           | about the   |
| my little son. I also could not afford to      | Feeling incapable        | deafness    |
| educate him in any hearing and speech          | language training centre | diagnosis   |
| centre and mainstream school as well.          | school setting           | Educational |
| Only if my son is happy, I could be            |                          | settings    |
| content. YeahI don't mind what kind of         | Feeling content          | Expectation |
| person he will be.                             | Hope for the deaf child  |             |

#### 4.4.2 Comparative methods

Comparative methods can be used throughout data analysis in at least two stages, initial coding and focused coding. It is argued that comparative methods help researchers 'find the similarities and differences' among data and coding (Charmaz, 2006, p. 54).

In this PhD study, on the one hand, I compared statements and actions within the same participant data, through earlier and later interviews, such as emotional reactions before and after diagnosis of deafness, views about deafness and language over time, etc. On the other hand, I compared the same events at different times and places for the same or different participants, such as diagnosis of deafness at home and at hospital, coaching deaf children before or after the age of mainstream schools, etc.

# 4.5 The strategies used in the data collection and analysis

There are four main strategies that were applied in the interactive process of data collection and analysis, including theoretical sampling, theoretical saturation, memo-writing, and theoretical sorting.

# 4.5.1 Theoretical sampling and theoretical saturation

It is suggested that theoretical sampling in constructivist grounded theory helps guide the direction of data collection and analysis until theoretical saturation is reached (Charmaz, 2006; Charmaz, 2014).

The method of theoretical sampling was used to ensure that the data were constructed in a conceptual and theoretical way during the period of data collection and analysis (Charmaz, 2006; Charmaz, 2014). Furthermore, theoretical sampling not only encourages the researcher to 'define gaps among categories' (Charmaz, 2014, p. 206, original emphasis) and 'fill out the properties of a category' (Charmaz, 2014, p. 205) in the early stage of data analysis, but also helps researchers to 'demonstrate links'

among categories' in the later stage of data analysis (Charmaz, 2014, p. 205). In short, theoretical sampling helps the researcher to develop data analysis by focusing on the theoretical categories and helping to distinguish between these categories (Charmaz, 2014).

Theoretical saturation can help researchers to know when to stop collecting data (Charmaz, 2006; Charmaz, 2014). Charmaz (2006, p. 189) further explained that 'theoretical saturation refers to the point at which gathering more data about a theoretical category reveals no new properties nor yields any further theoretical insights about the emerging grounded theory'.

In this PhD study, I mainly conducted two rounds of interviews within the stage of data collection and data analysis, plus a small-round of back-up interviews. The process of data collection and data analysis with the strategies of theoretical sampling and theoretical saturation is presented in Appendix 9.

First-round interviews were conducted with 5 hearing parents (Parent Li, Wang, Zhang, Chen, Liu), 3 mothers and 2 fathers. After collecting the first 2 hearing parents (Parent Li and Parent Wang), I started to analyse the data from the first 2 interviews. Following this, I collected another 3 hearing parents (Parent Zhang, Parent Chen, Parent Liu) and analysed their interview data. After finishing the data analysis of the 5 interviews, I found that a cluster of data relating to parents' views of deafness had almost reached theoretical saturation, while other data relating to parents' views of education was still underdeveloped. Later, I decided to conduct second-round interviews with new parents as well as the 5 previous parents. For the previous 5 hearing parents, I not only checked the transcriptions with them, but also asked them new questions.

The second-round interviews were conducted with 3 new parents (Parent Mei, Zhao, Song), 2 mothers and 1 father, plus 1 couple of hearing parents (Parent Xue), alongside the previous 5 participants. After interviewing 1 new mother (Parent Mei) and 1 couple of parents (Parent Xue), I started to analyse these two sets of data. When I finished the analysis of the interview data with Parent Mei and Parent Xue, I found the data related to parents' emotional reaction to deafness had reached the

level of theoretical saturation. As a result, I removed questions about the parents' reaction to deafness, and instead asked more questions about the parents' experience in educating their deaf child. Thus, when I started to interview another 2 new parents (Parent Zhao and Parent Song), 1 father and 1 mother, I mainly asked questions about their views of educating their deaf child at a mainstream school.

After collecting 10 hearing parents' interview data, I analysed these data again. I also conducted a round of back-up interviews and checked the transcriptions with the parents. For example, in the second-round interviews, I did not ask the last 2 parents (Parent Zhao and Parent Song) questions about their views of deafness. After finishing the interviews with them, I found their emotional reaction to deafness was similar to the other 8 hearing parents. Thus, the data relating to parents' reactions to deafness had reached theoretical saturation.

## 4.5.2 Memo-writing with autoethnography

Within grounded theory it is suggested that 'memo-writing is the methodological link, the distillation process, through which the researcher transforms data into theory' (Lempert, 2007, p. 245). Charmaz (2006, p. 94) defined memo as 'a record of your research and of your analytic progress'. From this perspective, Charmaz (2006) pointed out that memo-writing is an essential step between data collection and data analysis in the process of developing and constructing a theory. Moreover, it is explained that through memo-writing researchers can use constant comparative methods to help them define and develop the coding analysis to conceptual categories (Charmaz, 2006; Charmaz, 2014). As Charmaz (2006, p. 91) described, 'memo-writing relies on treating some codes as conceptual categories to analyze'. In other words, memo-writing can encourage researchers to move from descriptive data to codes' definitions (Charmaz, 2006; Charmaz, 2014).

According to constructivist grounded theory, memo-writing can prompt new ideas in researchers about the data by increasing interaction between themselves and the act of writing (Charmaz, 2006; Charmaz, 2014). Lempert (2007, p. 245) pointed out that memo-writing is the 'fundamental process of researcher/data engagement' as it keeps the data grounded in the study. Ellis (2009, p. 101) explained that introspection

is 'a social process' which enables researchers to connect their own experience with the lived experience of others. From this perspective, it could be argued that memo-writing can help apply autoethnography within constructivist grounded theory.

In terms of autoethnography, introspection is viewed as 'a source of interpretive materials' which can enable sociologists to engage their own dialogue with others' lived, emotional experiences (Ellis, 2009, p. 102). Introspection can be illustrated in a written form, such as field notes, narrative text, free writing and so on (Ellis, 2009). According to constructivist grounded theory, memo-writing can be carried out in personal and informal language to keep researchers involved in the data and codes, and to engage in reflexivity for the purpose of increasing the level of analysis (Charmaz, 2014).

From this perspective, introspection can be explained through memo-writing by studying the emotions and lived experiences of the participants. Consequently, introspection in memo-writing helps reflect on data and inspire researchers to explore the difference and similarities of experiences between participants and their own culture by engaging with their feelings and thoughts (Ellis, 2009; Charmaz, 2014).

In this PhD study, memo-writing connected the author's self story to the other stories of families who have a deaf child in order to develop the author's understanding of the data to a conceptual level. In the terms of autoethnography, my personal story not only provides a new approach to interpret the interview data of the participants, but also allows me to use introspection to examine other stories of hearing parents. Consequently, both memo-writing and introspection not only helped the author to gradually gain more understanding of the data, but also allowed the data of the self and more general ideas to dynamically interact.

In conclusion, memo-writing with introspection can evoke relevant life memories in the researcher, either good or bad, and also help prompt the researcher's insights into data by making comparisons and connections between self stories and those stories of the participants.

## 4.5.3 Theoretical sorting

In grounded theory, theoretical sorting plays an important role in developing 'emerging theory' (Charmaz, 2006, p. 115). Charmaz (2006, p. 115) suggested that theoretical sorting can help researchers to develop 'a way of creating and refining theoretical links', and also encourages researchers to 'compare categories at an abstract level'. In order to develop the relationships among categories and concepts, such diagrams 'provide a visual representation of categories and their relationships' (Charmaz, 2006, p. 117).

In this PhD study, I made use of the software tool named MindGenius to inspire my analytical development. MindGenius is a type of diagram that enables researchers to explore the relationships between coding and categories through the visual images and links among them. Appendix 10 has illustrated the final version of the conceptual map after connecting coding and categories backwards and forwards many times.

## 4.6 Qualitative validity and reliability

Qualitative validity is to check for accuracy within the research findings, while qualitative reliability is to investigate the consistency of the researcher's approach (Creswell, 2014, Gibb, 2007).

In order to ensure that all data and findings are valid, Creswell (2014) suggests that more than one validity strategy enhances the accuracy of findings, and convinces readers of this accuracy. Furthermore, terms such as authenticity, trustworthiness and credibility are used to address and evaluate qualitative validity (Creswell and Miller, 2000). Lincoln (1990) argued that authenticity is viewed as trustworthiness (Lincoln, 1990), which refers to 'judging the processes and outcomes of naturalistic or constructivist inquiry' (Guba and Lincoln, 2005, p. 207, original emphasis). Lincoln (1990, p. 72) further explained that the main core context of authenticity criteria is the 'states of being'. In other words, trustworthiness is to investigate whether the findings of the qualitative research are accurate and representative of the views expressed by participants (Lichtman, 2011; Creswell and Miller, 2000). In

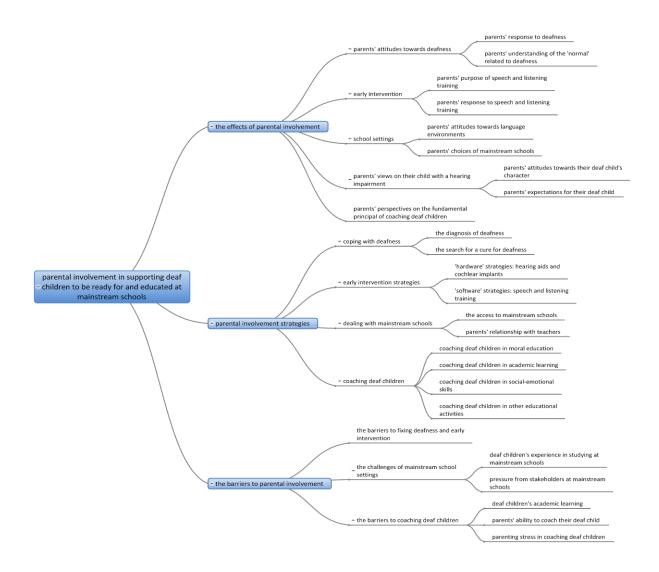
this PhD study, the different data collected from the author's self story, prolonged time in the field and intensive interviews were used to enhance the dynamic interaction between the author and the Chinese hearing parents as research participants. During the process of the intensive interviews, the strategy of back-up interviews was used as a form of member checking. This strategy enables the author to bring the transcriptions back to participants and provides the opportunity for participants to comment on the data and themes emerging from the interview. Also, memo-writing in constructivist grounded theory and introspection in the autoethnography were applied to examine the diverse voices of the hearing parents and the author's self, in order to deeply interpret multiple insights and form a theory emerging from the data.

In terms of qualitative reliability, both transcriptions and codes were cross-checked to assess whether the researcher's approach was consistent or stable (Creswell, 2014; Gibb, 2007). In this PhD study, the approaches of second-round interviews and back-up interviews were to check whether the participants felt that all transcriptions were accurate and that there were no obvious mistakes transcribed in the interview data. During the process of coding, the strategy of theoretical sampling and memo-writing was used to check the process of coding and to determine whether focused coding was developing into conceptual coding. Also, discussions with supervisors were used as part of this coding cross-checking to ensure data collection and analysis was proceeding in a logical fashion.

# **Chapter 5 Findings**

As discussed in the methodology and methods chapters, interviews were conducted with 10 Chinese hearing parents in Beijing, China. After the data analysis, the Findings Chapter explores the topic of parental involvement in supporting deaf children to be ready for and educated at mainstream schools in Beijing, which identifies the three themes as: the effects of parental involvement, parental involvement strategies and the barriers to parental involvement, as shown in Figure 5.1.

Figure 5.1 Three key themes of Findings Chapter



#### **5.1** The effects of parental involvement

Chinese hearing parents talked about the key aspects of the effects of their involvement, as illustrated in Figure 5.2.

the first transition: grieving parents' response to deafness the second transition: coping with grief - parents' attitudes toward deafness through blaming and taking action parents' understanding of the 'normal' related to deafness language development \_ parents' purpose of speech and listening mainstream school preparation arents' response to speech and listening training - the effects on parental involvement parents' attitudes towards language - school settings parents' choices of mainstream schools parents' attitudes towards their deaf child's characters parents' views on their child with a hearing impairment social function - parents' expectations for their deaf child social 'usefulness' role future happiness parents' perspectives on the fundamental principal of coaching deaf children

Figure 5.2 The effects of parental involvement

#### 5.1.1 Parents' attitudes towards deafness

In terms of parents' attitudes towards deafness, the majority of Chinese hearing parents in this study mainly discussed their response to deafness and their understanding of the 'normal' related to deafness.

#### 5.1.1a Parents' response to deafness

When their child is diagnosed as being deaf, Chinese hearing parents in this study talked about feelings of grief in the first instance. These took the form of various different emotional responses, for example shock, frustration, fear, anger, guilt and so on. This grief can last for months, or even longer. After a period of difficulty, some Chinese hearing parents can adjust their attitude to their child's deafness and become

strong. However, some other Chinese hearing parents cannot face the truth of their child's deafness for a period and become passive.

Generally speaking, parents' response to deafness can have two main stages: the first transition and second transition of grieving. In brief, the majority of Chinese hearing parents experience grief in the first transition and then learn to cope with grieving in the second transition.

# The first transition: grieving

Most Chinese hearing parents experience grieving through emotional and/or physical responses to the diagnosis of deafness during the first stages of the parents' response.

Grieving: emotional response to deafness

For example, in the following data (1), parents felt shocked when the staff in the nursery told them that their child might have a problem with hearing. Furthermore, parents felt helpless and their minds became blank at that moment. They were very sad and worried.

In addition, parents were in disbelief over their child's lack of hearing and tested their baby's hearing themselves. Parents often believed that their baby could hear. However, they were forced to accept the facts when their baby's deafness was confirmed.

# (1) Parent Li [line 16-23]

"When she was around 1 year old, I did not realize she had a problem with hearing, and I always thought she developed language skills slowly. When the staff in nursery told me that she might have a slight problem, my mind suddenly blanked out. And then I felt like I was freezing in the hot weather and my heart was blooding. Also, I still could not believe the words from staff and I wish I did not hear this news through my ears. And then I tried to call my daughter behind her to test her hearing until I realized that she had a problem with her hearing. So I feel painful and have to face the truth at last."

In the above data (1), Parent Li expressed her grief via different responses, for example shock, sadness, disbelief and pain. In the following data (2), Parent Wang was afraid to learn what happened to his child following an unusual phone call from his partner. His partner cried because she knew of her child's deafness and felt pain. He began to cry because he did not expect their child's deafness. Later, he pretended to be strong and comforted his partner saying that nothing was wrong with their daughter. Actually he was not clear about this himself and felt afraid and unhappy.

# (2) Parent Wang [line 5-10]

"Well, I remembered I got a telephone call from my wife at a very early morning time. I felt unusual and hesitated to answer her phone. And then I became silent to hear my wife's crying and I only felt everything was frozen. I kept trying to comfort her. After fifteen or twenty minutes, my wife felt better and stopped crying. Later, my wife suddenly cried again by saying 'no hearing'. I also started to cry. After a long time, I calmed down and comforted my wife. However, my mind was not clear and I did not know what I said to her."

*Grieving: physical response to deafness* 

In the following data (3), parents were unable to deny the deafness of their child and had to accept the truth. They could not control their feelings and bodies when experiencing such grief.

#### (3) Parent Wang [line 10-11]

"I only felt my hand was shaking to hold the phone."

Similar to the previous example (data 3), the following parent avoided the truth of their child's deafness by drinking alcohol instead of confronting the news. This parent felt frustrated to accept the truth and tried to be alone.

#### (4) Parent Wang [line 14-15]

"I can't remember how many amount of alcohol I have drunk at midnight. I can remember I cried a lot and I hided my face in the dark corridor at midnight. I felt

much sorrow."

The second transition: coping with grief through blaming and taking action

After accepting grief over time, hearing parents started to cope with grief through

blaming and taking action during the second stages of their response to diagnosis.

Coping with grief: blaming

Blaming themselves

Using the data (5) below as an example, Parent Mei felt guilty and angry about his

daughter's deafness and did not understand why she was deaf. Furthermore, she felt

guilty because they believed they caused their child's deafness.

(5) Parent Mei [line 5-7]

"I feel sorry for my little daughter about her deafness...Her deafness had

resulted from me. I don't know why it happened to her and not me? I have been

trying to give her what she wants and to meet her needs."

In the following data (6), other parents (e.g. Parent Xue) felt depressed and guilty

because they were unable to do anything to alleviate the effects of deafness in their

child. Furthermore, they faced financial strain to educate their child. When parents

were aware of their inability to change the situation, they became passive and felt

helpless. This forced them to make the decision that they were willing to let the child

do anything they wanted.

(6) Parent Xue [line 5-8]

"I think it is quite hard for me to step out of the tight spot and I still feel very

sorry for my little son. I also could not afford to educate him in any a hearing

and speech centre and a mainstream school. Only if my son is happy, I would be

content. Yeah...I don't mind what kind of person he will be."

Blaming doctors

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In the following data (7), Parent Liu felt shocked when they compared the previous 'normal' hearing state of her son to his 'deafness' following receiving injections. She never thought an injection would change the life of her son and her family. She only thought the injection could cure her child's illness, rather than kill a sense organ in her baby. Furthermore, she felt frustrated when having to negotiate with the doctor about her son's deafness. However, the doctors denied their responsibility by wrongly blaming the weak immunity of the child. Therefore, the parent did not believe her child became deaf because of an injection and kept hoping her child's hearing to get better. Finally, she felt helpless to accept the truth and went on to develop unrealistic expectations.

#### (7) Parent Liu [line 10-16]

"When I consulted the doctor about his deafness, the doctor negotiated that 'it is not a problem of medicine but the weak constitution of your child'. I was worried and then I put my faith in luck to think that an injection cannot cause deafness. So, I clung to the hope that my son would get better in hearing, even he could make the slightest improvement in hearing. Last, everything can't be changed until the proof of diagnosis was unfolded in the front of my eyes."

At first, the child's parents, when feeling something was wrong but wanting confirmation, asked doctors about treatment for their child. However, the doctors did not understand the parents' feelings. They did their job as usual rather than communicating with patients. When parents insisted on knowing what kind of injection was given to their child, the doctors had sympathy for and told them the details. Furthermore, hearing parents learned that medicine could affect their baby's hearing cells and frequently consulted with doctors on this subject. However, nothing could not stop the treatment happening and hearing parents felt helpless to stop its effects.

In the example below (data 8), the mother was unable to prevent the doctor giving her son an injection named 'streptomycin'. When she was aware that the medicine could affect human hearing cells, she negotiated with the doctor about the issues of the injection. The doctor seemed reasonable and explained the low risk of deafness

after receiving such an injection. Finally, the doctor comforted her and she reluctantly accepted the doctor's reassurance and expected her child would be fine.

# (8) Parent Zhang [line 7-16]

"I remembered I asked the doctor 'what kind of injections you gave my son?'. The doctor responded 'you would not believe in doctors, would you?'. So I stopped to ask more. When the doctor saw I looked much worried, he told me the details. However, my brain bombed when I heard the word 'streptomycin' told by the doctor. I could not believe my ears and asked the doctor the same question again, 'What? Did you take streptomycin? It would cause deafness.'. And then, the doctor comforted me 'It is not possible. Many people look the same as before and after they got injection of streptomycin. Who get deafness?'. I put off my doubts on his deafness when I heard the doctor said 'who get deafness?'. So I thought deafness would not happen on my little son."

#### Blaming 'luck'

Other parents had mixed feelings, alongside those of fear, anger and disappointment, when they learned their children became deaf. For example, one parent named Parent Li questioned that deafness happened to her daughter by repeating the same word, 'why', three times. Also, she did not understand deafness and was frustrated trying to work out who caused her child's deafness and why her daughter had such bad luck. Therefore, this illustrated her belief that the deafness was caused by nothing except bad luck.

#### (9) Parent Li [line 5-12]

"It is really hard to describe the mixed feeling about that sudden news. At first, I can't believe that she became deaf and I feel very shocked. At the same time, I am very afraid of bad things. I got used to the news until her deafness was confirmed by three famous hospitals in Beijing. And then I was so so disappointed and painful that I cried into my arms bursting into tears. It was like a thunderbolt out of a clear sky. I really did not know why why why deafness happened on my little daughter, and she was only up to 1 year old. Why bad luck happened on my daughter. I was still in confusion, and my mind was empty."

Coping with grief: doing efforts to help the child

Some Chinese hearing parents talked about helping their child with hearing impairments in order to alleviate their grief and compensate for their guilt.

For example, one parent named Parent Zhao below (data 10) invested in cochlear implants for his deaf daughter and thought this showed responsibility for his daughter. He could compensate for their guilt by providing their child with a cochlear implant. From this perspective, cochlear implants helped the hearing parents and seemed to reduce their guilt. Perhaps, the advanced technology could compensate for hearing parents' guilt.

#### (10) Parent Zhao [line 6]

"She is wearing a cochlear implant. I think I did efforts for my little daughter."

# 5.1.1b Parents' understanding of the 'normal' related to deafness

Most Chinese hearing parents talked about 'normal' issues in relation to the deafness of their children, either directly or indirectly. They highlighted the stigma associated with having a child who is deaf. Furthermore, these parents did not expect and were unprepared for a diagnosis of deafness in their child. From this perspective, hearing parents who have a deaf child viewed deafness as stigma for their family, especially when only one child was deaf in a hearing family. These hearing parents also thought deafness was not 'normal' and this reflected their negative attitude towards deafness. Therefore, they had great difficulty in facing a new life with a deaf child. This new life can be seen as one which they considered as being different to the 'normal' path.

The 'normal' related to deafness can be classified in two ways. One is that the 'normal' child has disappeared, and the other is that the 'normal' hearing identity nearly 'appears'.

#### The 'normal' child disappears

Most Chinese hearing parents initially had a hearing baby who became deaf because specific situations occurred. In this way, these hearing parents believed that they have a normal child except for the deafness, although some of them were reluctant to accept this truth. These parents also might admit their child is deaf, but still wished their child's hearing could be normal.

According to the comments from parents (data 11 and 12), the 'normal' child refers to their parents' hope that a child is a hearing person. However, nothing can change the truth of a deaf child, and the 'normal' child may not fit in their family life.

# (11) Parent Zhang [line 21-22]

"The local hospital gave me the response 'Your child looks normal and he would be able to speak until he is older.""

#### (12) Parent Liu [line 9-10]

"It was out of surprising. I couldn't imagine my son was good and normal before getting injections, however, he changed into a stark contrast against the normal."

#### The 'normal' hearing nearly 'appears'

Most hearing parents wish that their deaf child is normal, and hope their child's hearing becomes normal again, although they know there is no cure for deafness, for example sensorineural deafness. However, they misunderstand the function of hearing aids and cochlear implants. Furthermore, it can be argued that hearing parents think that their deaf child's hearing nearly 'appears' when they provide them with hearing aids and/or cochlear implants.

Unlike the previous examples (data 11 and 12), the comments from data 13 and 14 illustrated that Chinese hearing parents hoped their child's hearing could improve and, at least, their child could hear a normal voice to some extent. In this instance, 'a natural voice' or 'the sound of nature' can be interpreted as 'normal' sounds from the perspectives of hearing parents. Also, these parents believed that it would be possible for their deaf children to access 'normal' sounds through hearing aids and cochlear implants.

# (13) Parent Wang [line 41-42]

"It is such a great opportunity for children with hearing impairments to find an accessible approach to hear nature voices."

#### (14) Parent Chen [line 34]

"It was said that a cochlear implant can hear the sound of nature."

# 5.1.2 Parents' attitudes towards early intervention

With regard to parents' attitudes towards early intervention, Chinese hearing parents mainly talked about the purpose of speech and listening training and their responses to oral language training.

## 5.1.2a Parents' purpose of speech and listening training

Most Chinese hearing parents in this study supported the idea that their deaf children should receive training in speech and listening skills. They also thought this could both help their children to develop language skills and help their children to prepare for mainstream schools.

#### Language development

Most Chinese hearing parents in this study encouraged their children to receive training in speech and listening because they thought this could help their children develop these skills. In this study, the majority of Chinese hearing parents acknowledged the importance of 'early intervention' and were aware of the key period of language development in their deaf child's early years. For example, Parent Li interpreted 'early intervention' in two ways by explaining that deafness can be cured and language can be taught as early as possible.

#### (15) Parent Li [line 38-39]

"Early intervention means deaf children could be earlier cured if possible and could be earlier educated in language."

To take another example from data 16, Parent Li made a decision to support her deaf daughter in speech and listening training through buying hearing aids after their many attempts to cure the deafness had failed. Parent Li also wanted her daughter to become a deaf person who can engage in conversation with hearing people, and she emphasised that her daughter should be educated as a person who can speak Chinese as a first language. These hopes, for deaf children to achieve the goals of social function in a hearing world, appear to be highly demanding.

# (16) Parent Li [line 42-45]

"I made a strong decision to support her to be involved into hearing people and could speak fluent Chinese. When she was 5 years old, there seemed little hope for her to cure her deafness. In order to help her to learn language, I realized I need to buy hearing aid for her as soon as possible."

In the following example (data 17), some parents like Parent Li mentioned the words 'responsibility' and 'duty' to express their strong desire to raise their deaf children to be integrated into the hearing world. Parent Li did not have the heart to give up her choice of teaching her deaf daughter to speak, although she struggled with this for a long time. After she accepted her child's deafness, she became aware of the importance of early education and early intervention. Following this, she praised her daughter's hard work, although her own efforts should be credited.

# (17) Parent Li [line 30-32] [line 301]

"When I saw her little cute and foolish face I realized I must take the responsibility for her. I made a decision to teach her to open her mouth and to pronounce sounds, although I admitted her deafness very late. So it drew my attention to importance of early intervention." "It is my duty and she really does well."

#### Mainstream school preparation

The majority of Chinese hearing parents viewed mainstream schools as normal schools, in that they would be particularly proud of their deaf child's achievements

there. Furthermore, they thought that training in speech and listening was the foundation for their children to be prepared for and to be educated at mainstream schools.

In the following example (data 18), Parent Chen decided to support his deaf daughter to receive speech and listening training after having a family meeting about education options. The word 'education' can be interpreted as 'inclusive education', according to Parent Chen' comments. Therefore, they thought the path to inclusive education would increase their hopes for their deaf child's future.

# (18) Parent Chen [line 28-30]

"We had a family meeting to discuss my daughter's education. We decided to help her to get the rehabilitation training in hearing and speech. Perhaps it would bring hope for her."

Similar to the previous example (data 18), Parent Song (data 19) below trained her deaf son in speech and listening, so that her son could be educated at a mainstream school. Therefore, Parent Song spent a great deal of time at home training her child's pronunciation after a day of studying at the speech and hearing training centre.

#### (19) Parent Song [line 10-11]

"In order to send him to a mainstream school early, I spent a large amount of time teaching him in pronunciation practice after the training centre."

Unlike the example of data 18, Parent Zhang below (data 20) built a normal language environment for her deaf son, and she did not merely use the speech and listening training centre in order to enable her son to be involved in the social functions of the hearing world.

# (20) Parent Zhang [line 139-140]

"I hope I can create a usual language environment for him, in order to lay a good foundation for going to mainstream society in the future."

Similar to the previous examples (data 20), Parent Zhang below (data 21) did not

want their deaf child to 'live in a silent world'. The phrase 'a silent world' can be interpreted as 'a deaf community' or 'a deaf world', according to Parent Zhang' comments. Parents often took their child to a mainstream school after finishing one-day classes at the training centre in order to foster their child's interest in mainstream schools.

## (21) Parent Zhang [line 80-83]

"I was reluctant to see my son remain in a silent world. I made attempts to take my son to any mainstream school to observe after one day in a hearing and speech centre to see whether my son was interested in a mainstream school."

## 5.1.2b Parents' response to speech and listening training

In this study, there were many different parental responses to speech and listening training, for example happiness, anxiety, difficulty and so on. Some parents were proud of their deaf children when they were able to pronounce a word, no matter how clear. Some parents also talked about their feelings when they saw their children's negative emotions of learning language.

In the following example (data 22), Parent Zhang was very happy when her deaf son was identified as a deaf person instead of deaf and dumb.

#### (22) Parent Zhang [line 58-59]

"I was very happy to hug my son and I danced with him. My son can speak now and he will not be a dumb anymore."

Unlike data 22, Parent Liu (data 23) was anxious over her deaf son's two contradictory levels of speech performance: he could not speak well outside whereas he could speak well at home.

## (23) Parent Liu [line 58-59]

"It is ok [with his pronunciation]. Sometimes he would speak well at home and sometimes he would not speak well outside."

Similar to the previous example (data 23), some parents like Parent Zhao (data 24) had no idea how to cope with his deaf child's crying during training in speech and listening. Parent Zhao also tried to understand what his deaf daughter wanted to express, but this was often painful for his daughter to use finger language to express her needs. Furthermore, Parent Zhao did not consider sign language to be appropriate and finger language was only viewed as a last resort when all other attempts to oral language training had failed. Moreover, his daughter was often too exhausted to express herself in an oral language. Therefore, some parents like Parent Zhao found it difficult to understand their deaf child's needs through different types of expressions, such as crying and finger languages.

## (24) Parent Zhao [line 11-13]

"Sometimes I compromised with my litter daughter. When I saw my daughter crying, I had no idea how to comfort her. I think she wanted to say something using finger languages, and she was too frustrated to express in an oral way."

In the following example (data 25), some parents (e.g. Parent Song) were anxious that their approach to training within the children's spare time was difficult for their child at such a young age, however they still hoped their child would appreciate their efforts. They also worried about their child's future and seemed less confident of their son's language development in spite of them training well in oral language.

#### (25) Parent Song [line 11-14]

"I feel very sorry to use his spare time for studying in order to receive the good results. Hope he could understand my real heart one day and would appreciate what I have done for him. However, I was still a bit worried about my little son although he was well trained in speaking."

#### 5.1.3 Parents' attitudes towards school settings

Most Chinese hearing parents in this study chose mainstream schools for their deaf children, instead of deaf schools, because they thought mainstream schools could provide their children with a spoken language environment and a diversity of education activities. Furthermore, some Chinese hearing parents indicated that it might not be worth learning sign language in a hearing family.

# 5.1.3a Parents' attitudes towards language environments

The majority of Chinese hearing parents in this study encouraged their deaf child to use oral language instead of sign language, due to the spoken language environments in mainstream schools that would be provided for children with hearing impairments.

Most hearing parents in this study emphasised the importance of oral language and encouraged their child with a hearing impairment to learn oral language. These parents also emphasised that the convenience of oral language plays an important role in creating the interaction between hearing people and deaf children, although they were still aware of their child's difficulty in learning oral language.

# (26) Parent Li [line 248-249]

"In order to communicate easily and conveniently, I encouraged her to learn oral language although it was more difficult for her to learn at her young age."

In data 27 below, some parents (e.g. Parent Li) described that the challenge for their deaf daughter was to communicate with hearing people through oral language. However, oral language is not visual for children with hearing impairments and consists of many abstract meanings that deaf children cannot master. For this reason, their child with a hearing impairment depended on visual language to communicate with the outside world. Furthermore, she explained that oral language was much more useful than sign language because information is mainly received by hearing and listening. In addition, she was worried that her deaf child could not survive in society, where a large number of people use spoken language, if her child was not able to speak. Therefore, these reasons were an important factor for hearing parents to think about within language choices for their children with hearing impairments, as they wanted them to be involved in society in the future.

#### (27) Parent Li [line 260-267]

"Oral language is a bit abstract for her to explain its meaning to her. You know she lost hearing and she have to receive information by her visual sense. Oh, I remembered that a theory but I forgot who said this famous theory. It is described that 'information is received by 70% hearing, 20% seeing and 10% other sense'. This statement could illustrate that visual language is far less useful than verbal language. Additionally, most people use oral language to communicate in a hearing society, not sign language. This is very important to think and teach how my daughter could live in the life of most people."

Some hearing parents in this study were reluctant to learn sign language because they are hearing themselves and had no chance to learn a new language. Furthermore, in their interviews, some hearing parents talked about how proud they would be when their deaf child was educated at mainstream schools. From this perspective, parents preferred to encourage their child to learn oral language, although they still had a positive attitude towards sign language.

In the following example (data 28), some parents (e.g. Parent Li) explained their views of sign language, and they agreed that sign language is the first language for deaf people. Furthermore, they suggested that sign language was easy for deaf children to learn and understand because it featured visual expression. In addition, it was apparent that parents did not make an effort to learn sign language although they appreciated the advantage of sign language offered for their child.

#### (28) Parent Li [line 252-255]

"I think sign language for deaf people is their mother language. Sign language is very visual to understand the meaning of words. So sign language is easier for her to learn than oral language. ....he he...I am not professional and it is only my experience."

In the following example (data 29), some parents (e.g. Parent Li) compared oral language with sign language because of its popularity and application, and explained why they don't like their child to use sign language. They felt oral language was the language tool of wider application in life.

#### (29) Parent Li [line 241-247]

"It is really hard to explain this question clearly. Firstly, the deaf people are a

really small group in society [compared to hearing people], like the blind people, the wheelchair people and so on. Secondly, the law related to special education is not well-systematical before and has come into effect since 1980's. Thirdly, in the long run, sign language could limit her development and future, and I had no experience to educate her to use sign language. Fourthly, if she learns sign language, the members of my family need to learn a new language sign language to communicate with her."

Some parents (data 30) paid great attention to teaching their child to speak instead of using sign language. They had little awareness of sign language, so their deaf child had little opportunity to access sign language.

#### (30) Parent Zhang [line 144-145]

"I did not have a thought to ask him to learn sign language. Instead, I focused on teaching him speaking. So he had little chance to access sign language."

Some parents (data 31) had strong views against sign language, as they saw no benefit in its application and use in the future.

#### (31) Parent Liu [line 172-174]

"No, [I would not oppose sign language]. Actually I approved of his learning sign language. And, when I concerned if he learnt sign language, how would his future be? How would he chat with hearing people? Right?"

#### 5.1.3b Parents' choices of mainstream schools

Some Chinese hearing parents in this study had positive attitudes towards their choices of mainstream schools and chose them because of the provision of oral language. In contrast, others had negative attitudes towards their support for their child to study in mainstream schools. Furthermore, the majority of Chinese hearing parents in this study had concerns about the inclusive educational environment provided for their deaf child, although they still made a decision to choose mainstream schools.

Parents developed a positive attitude towards their child's deafness after struggling with choices and decisions about their child's future. Furthermore, they gave serious consideration to the educational options for their deaf children after learning a great deal of information related to deafness. For example, Parent Wang (data 32) talked about how he looked for the best educational path provided for his deaf daughter.

# (32) Parent Wang [line 26-29]

"When I saw her sparkling eyes, I realized that she is too young to know what had happened. Hmm...And I would like to take a more optimistic view about her future in spite of her deafness. So I started to learn about deafness from different resources and to explore which option of education plan was the best for her in the future."

In the following example (data 33), some parents (e.g. Parent Li) thought their child with a hearing impairment could benefit from mainstream schools. Furthermore, they thought mainstream schools could stimulate deaf children's potential in spoken language through education activities which might be unavailable in deaf schools. The phrase 'good language environments' refers to spoken language as a useful channel of communication between deaf children and hearing people, such as teachers and peers.

#### (33) Parent Li [line 108-110]

"First of all, a deaf school might not inspire her to oral language and I don't like her to use sign language at young age. Secondly, a mainstream school could encourage her to do lots of activities and provide her with good language environments."

In the following example (data 34), some parents (e.g. Parent Li) expressed that they did not want their deaf child to be educated in special schools including deaf schools. Furthermore, they believed their deaf child could use spoke language to communicate.

#### (34) Parent Li [line 236-238]

"First of all, I did not have a chance to learn sign language; secondly, I don't like

her to go to a special school; thirdly, I want her to be an excellent person and I believe she could speak Chinese."

In the following excerpt (data 35), some parents like Parent Liu thought deaf schools only taught their deaf child sign language instead of oral language, and also expressed their reluctance to send their child to deaf schools.

## (35) Parent Liu [line 167-169]

"I would not like him to be educated in a deaf school. If he would be educated at a deaf school, he could not speak Chinese. He could only use sign language to learn and communicate."

The majority of Chinese hearing parents in this study preferred a mainstream school for their children with hearing impairments because of its many benefits. For example, Parent Wang (data 36) was eager for their child to be educated at mainstream schools.

#### (36) Parent Wang [line 32]

"I encouraged my daughter to go to mainstream schools one day."

Some parents like Parent Zhang (data 37) did not persuade their deaf children to be educated in mainstream schools and left this aside after considering their children's personality. These parents also respected their children's ideas and accommodated their needs, although their children could not express their ideas through speech. Thus, these parents' choices and decisions for mainstream schools would be influenced by their children's likes and dislikes.

### (37) Parent Zhang [line 71-72]

"I think he should be educated at mainstream schools. And the key point was to see whether my child was likely to go to mainstream schools or not."

Some parents like Parent Zhang (data 38) were worried about their child's ability to study at mainstream schools, although they still decided to teach their child to speak Chinese and learn songs everyday. However, these parents were confused because

they did not know how to decide on an appropriate educational placement for their deaf children.

# (38) Parent Zhang [line 65-68]

"I decided to teach him to speak Chinese and I am sure he can be. I taught him children's songs every day and I played with him while I was teaching him. When he reached the age of schooling, I became worried about his educational placement. I wondered whether he could be educated at mainstream schools."

Some parents like Parent Song (data 39) had a strong belief that a mainstream school with a good spoken language environment could develop language skills and improve communication skills. However, these parents were anxious that their child's progress would lag behind their hearing peers, although they hoped that their deaf children could communicate with their peers in a class.

#### (39) Parent Song [line 26-29]

"I think a mainstream school was the better choice for him and this school environment could stimulate his communication skill. And, I was a bit worried about his slow progress as opposed to his hearing peers. Hmm... I really hope he will catch up with his peers as best as he can."

In the following data 40, Parent Song mentioned 'inclusive education' multiple times. Most Chinese hearing parents like Parent Song tried their best to provide their deaf children with the environment of mainstream schools. They also seemed confident in inclusive education and wanted their deaf children to receive inclusive education at mainstream schools until adulthood.

### (40) Parent Song [line 32-34]

"I don't want lose an opportunity of getting him in the inclusive education by person at his early years. And I attempted to explore a way of raising him until he would be a sensible adult."

#### 5.1.4 Parents' views on their child with a hearing impairment

Most Chinese hearing parents in this study talked about their deaf child's characteristics, personality, likes and dislikes, when referring to their children with hearing impairments. These parents also saw the whole child not the disability.

#### 5.1.4a Parents' attitudes towards their deaf child's character

In the following example (data 41), some parents like Parent Li praised their deaf children for being both naughty and clever. They described two relevant different situations for their child, studying and playing. In addition, they were hesitant to identify whether their child was obedient or not. However, it could be claimed that parents seemed confident to manage their child's temper.

#### (41) Parent Li [line 270-273]

"She was very naughty and smart. My daughter was usually in my control when we were learning language at home. Sometimes she was crazy and curious about something new when she was playing outside....erm....it is hard to say she was very obedient."

Some parents like Parent Chen (data 42) seemed to struggle to control their child's behaviour and also described the two contrasting situations of practice and play. Furthermore, deaf children prefer play, and this typical development is the same as their hearing peers. These parents also found it difficult to balance time in playing and studying including coaching them in language learning.

#### (42) Parent Chen [line 78-80]

"She was naughty and she often liked playing. When I said 'lets start practice', my daughter became low in spirit. When I said 'lets play for a few minutes', my daughter became excited with eyes open wide."

Additionally, some parents like Parent Chen (data 43) described their child's emotional expressions when they did not understand their child's meaning, especially when their child became upset, showed quick temper and started crying.

# (43) Parent Chen [line 50-52]

"My daughter became very upset and had a quick temper, when we misunderstood her unclear words. Sometimes she started to cry out and I needed to be patient with her to understand her true idea."

Some parents like Parent Xue (data 44) described their child's crying to gain attention when their child's need was not met in time. They had empathy and felt distressed that their deaf child has more painful experiences than a hearing child. They also felt worried about their child's crying and these difficulties in communication upset them.

# (44) Parent Xue [line 73-75]

"You know, he cried out to gain our sympathy when we did not meet his needs. Well, when I think he suffered much more pain than a hearing child, I feel empathy for him. Now I feel very frustrated about his naive behavior sometimes."

Some parents like Parent Zhang (data 45) praised their child's determination and strength of character. They also explained that their child seldom cried at a young age when they took medicine or received an injection.

# (45) Parent Zhang [line 130-132]

"He was sensible. He has learned patience, for example, he seldom cried when he drank Chinese traditional medicine. And he clenched his fists and tried not to cry when he was given by an injection. He is strong of will."

Some parents like Parent Chen (data 46) believed their child's strong character would help to improve communication skills. These parents were patient with their child's temper when their child did not speak well. They also encouraged their child to speak more, no matter how inaccurate they were.

#### (46) Parent Chen [line 83-85]

"I do think my daughter is a gift and she is a nature genius. She could communicate well and she is always strong. I often praised her and encouraged her to say more words, although she spoke not clearly sometimes."

Some parents like Parent Xue (data 47) felt angry about their child's behaviour and personality, and were often impatient with them. From this perspective, they seemed to have a negative attitude towards their child's character.

#### (47) Parent Xue [line 30]

"My boy is a mischief maker and I am at my wits end with him."

In the following example (data 48), some parents like Parent Xue seemed to have only a partially negative attitude towards their deaf child's character and described them as 'cute' and 'manic'. Parent Xue was not able to control their deaf son sometimes when they did not know how to meet their son's needs. The son used body language to express his inner feelings when unable to communicate with his parents. Therefore, the interaction between these hearing parents and their deaf child was not beneficial in a way of oral language, and this could affect the emotional positions of both. In addition, Parent Xue could not manage their deaf son's behaviour and this made them feel grief. Parent Xue then blamed many of these difficulties on their son's deafness.

#### (48) Parent Xue [line 66-70]

"My little son is quite cute and sometimes his temper is strange. When he was sometimes obstinate, I tried to coax him and met his needs. Otherwise, he would break toys in the house. I understood his emotion because he felt helpless to communicate with me sometimes. So, he became a cranky person. And I felt very guilty about his deafness."

Some parents like Parent Liu (data 49) not only expressed their views on their child's character, but also mentioned their child's teacher's feedback. They had a similar judgement on the deaf child's character. Perhaps, Parent Liu was not confident in talking about her deaf son's character and use the teacher's feedback to support this comment.

#### (49) Parent Liu [line 164]

"He was fine and he was not naughty. His teacher thinks he was a bit quiet."

#### 5.1.4b Parents' expectations for their deaf child

In this PhD study, most Chinese hearing parents had quite high expectations for their deaf children and expected their children to be happy and healthy.

Chinese hearing parents had three main types of expectations for their children with hearing impairments: social function, the social 'usefulness' role and future happiness.

#### Social function

Some Chinese hearing parents in this study expected their children with hearing impairments to be a deaf person who could be involved in the hearing world, and they thought of their child's role in terms of social function.

In the following example (data 50), some parents like Parent Li hoped their child would be a hearing-impaired person who is a benefit, instead of a burden, to society.

#### (50) Parent Li [line 111-112]

"I have a dream to educate her to be a deaf person who could be a benefit to the society."

Similarly, Parent Zhang (data 51) not only hoped her deaf son would be a benefit to society but also become a 'normal' child.

# (51) Parent Zhang [line 130-131]

"My goal was to wish him to be a 'normal' child and to be a person who would benefit to society when he became grown-up."

Another parents like Parent Song (data 52) not only hoped their deaf children would be a benefit to society, but also wished their children would be able to live by themselves in a hearing world, and not always depend on their parents when growing up.

#### (52) Parent Song [line 14-16]

"I hope my son to be an adult who will be a benefit to society. That would be great if he could support himself to live in society."

## Social 'usefulness' role

Some Chinese hearing parents in this study expected their children with hearing impairments to fit into a social 'usefulness' role and be deaf people who benefit society.

In the following example (data 53), Parent Li hoped that her deaf daughter would be a deaf person gaining a good education and positive development.

#### (53) Parent Li [line 107-108]

"As her mom, I really hope my daughter will be well-educated and well-rounded in development."

Some parents like Parent Liu (data 54) held an unreasonable hope that if their child's normal hearing returned, it would reduce their pain. Furthermore, these parents did not lower their expectations for their deaf children when they knew this was improbable. Instead, these parents would be satisfied if their children communicated with hearing people in society.

#### (54) Parent Liu [line 177-178]

"If his ears are normal, I may save my pains. I am content as long as he can communicate with hearing people in a society to some extent."

Additionally, some parents like Parent Song (data 55) held a realistic hope for their child and had a sensible attitude towards their child's development when considering their practical ability. These hearing parents wished that their deaf children could speak Chinese and communicate well with hearing people.

# (55) Parent Song [line 41-42]

"I believe my son could speak Chinese according to his ability, and I wish he could be involved in a hearing world to some extent."

# Future happiness

Some Chinese hearing parents did not place high expectations on their children with hearing impairments and only wanted them to be happy and healthy.

In the following example (data 56), some parents like Parent Wang held a sensible wish for their deaf children and hoped that their children would be happy and healthy, not demanding on their child's achievement. These parents hoped their children would be a well-rounded, developed person with many skills.

#### (56) Parent Wang [line 93-95]

"I am looking forward to seeing my daughter who becomes a great person with well-developed skills. I always hope my daughter is happy and healthy and don't want give her pressure."

Some parents like Parent Mei (data 57) were forced to change their expectations because they were afraid to see their children experiencing a painful learning process in an attempt to achieve high academic results. These parents protected their children from being harm when competing with hearing peers. Therefore, they lowered their original expectations and only wished their child would be happy.

#### (57) Parent Mei [line 52-54]

"I don't expect her to achieve to a high level of academic through hard working, otherwise she could suffer much pain and I also feel the same. And I just hope she is happy to live in the world."

# 5.1.5 Parents' perspectives on the fundamental principle of coaching deaf children

In this PhD study, the majority of Chinese hearing parents like Parent Li (data 58) emphasized the importance of the responsibility that they shouldered and they felt

confident about coaching their deaf children at home and helping them to receive an education in mainstream schools.

#### (58) Parent Li [line 192-193]

"I should have this ability and responsibility to do that because she is only my lovely daughter in my family."

In the following example (data 59), Parent Li further explained how she managed her daughter's nature and sensible behaviour in changing situations while coaching her daughter at home. She also knew how to make use of interaction strategies for educating her daughter and how to make her words be visualized to help her daughter to understand the educational dialogue.

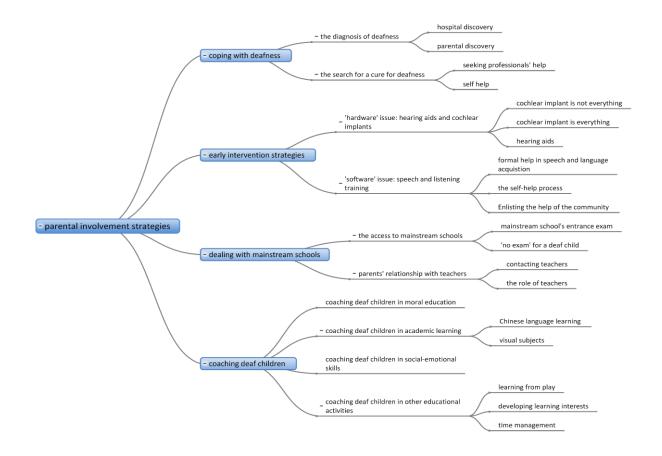
#### (59) Parent Li [line 277-281]

"It depends...erm... If her problem was fine and based on her nature, that was ok, I did not like to deprive her inherent nature at her young age. If her problem was seriously, it was necessary to have an educational dialogue with her. If she did not understand my talking, I would like to interpret my words into action repeatedly until she could understand this principle one day."

#### 5.2 Parental involvement strategies

With regard to parental involvement strategies, Chinese hearing parents discussed their 'tried and tested' strategies for raising their deaf children in the early years, as shown in Figure 5.3.

Figure 5.3 Parental involvement strategies



# 5.2.1 Coping with deafness

The majority of Chinese hearing parents talked about how they coped with deafness and discussed their involvement in the diagnosis of deafness and the search for a cure for deafness.

# 5.2.1a The diagnosis of deafness

Most Chinese hearing parents taking part in this study did not expect to have a deaf child in their lives and did not have knowledge about deafness before their child was diagnosed as a deaf child. Furthermore, some parents had not noticed their child's hearing problem until the hearing problem became obvious. Other parents had concerns about their child's hearing loss in the process of curing their child's illness, before the diagnosis of deafness was confirmed. Thus, Chinese hearing parents got to know their child's deafness either through hospital discovery or parental discovery.

## Hospital discovery

Most hearing babies in this study became deaf following medical treatment (for example, injection) in hospitals after high fever or organ infection. After the treatment, these babies had hearing problems and became deaf.

The majority of Chinese hearing parents reported that their deaf children received antibiotics such as streptomycin, gentamicin and so on, which could damage their baby's hearing. Many parents said that they felt that the doctors gave their deaf children the wrong medicine.

In the example below (data 60), Parent Liu stated that her son became deaf at 3 years old because of an injection, and she assumed her son had received the wrong medicine to cure a fever.

## (60) Parent Liu [line 5-6]

"When he got high fever at his three years old, he became deaf after he was given by an injection."

In the following example (data 61), Parent Zhang intuitively knew that something was wrong and took her son to hospital to cure his high fever. She kept asking the doctor details of the medical treatment that he received, and the doctor was impatient to give an explanation and then undertook the treatment anyway. Finally, her son's fever was stopped by the treatment, and she explained that inappropriate medicine would damage his hearing.

# (61) Parent Zhang [line 5-7] [line 15-17]

"My son had injections in a hospital when he had a high fever. I was worried that doctors might give wrong medicine, so I kept following the doctors until they were reluctant to tell details." "Well, his fever had remitted after he was back from this hospital. Then, he changed and he looked like another person, and he was less active."

#### Parental discovery

Some Chinese hearing parents did not notice that their child's hearing had worsened, so their children were initially not diagnosed with deafness. After they inadvertently realised their child's obvious difference in hearing at home, they became concerned that their child might have a problem and sought help at hospital.

In their interviews, some Chinese hearing parents described how they discovered their child's deafness. They occasionally discovered a possible problem in hearing loss through observing their child's behaviour while engaging in family activities at an older age. They also had little knowledge of deafness and they often thought that their child's speech development if a bit slower than their hearing peers. Furthermore, they strongly believed a Chinese superstition that if a young child speaks at a later age, they would be more intelligent when getting older. In this way, they hoped their child would be fine and still kept thinking there was no problem with their child's hearing.

In the following example (data 62), Parent Chen initially doubted his daughter's hearing and then went to hospital to check whether she was healthy. When the first diagnosis of deafness was confirmed, he did not accept this and immediately fell into grief, as described in an earlier section 5.1.1a. He also expressed his disbelief at first and also doubted the validity of the instrument used to test hearing. Later, he started to believe the report of deafness when a second and third diagnosis was confirmed.

### (62) Parent Chen [line 5-16]

"My daughter's deafness had been found until she was around 3 years old. There is a Chinese superstition that the wits usually develop speaking skills at an older age. I often thought she could start speaking as she grew older. As usual, I clapped my hands behind her and knocked stuff, she had no reaction all the time. I often thought she should be fine, her hearing would not be a problem. One day, something like a bowl dropped down, we had reacted except her. She was focusing on playing toy bricks. At that time, we felt there must be something wrong with her. We took her to a hospital and then the diagnosis of deafness came like a bolt from the blue for us. We completely not accepted the fact of her deafness. We asked the doctor again 'Do those measure machines have problems?'. And then, they checked with the diagnosis and assessed the hearing

of my daughter again. Finally it was confirmed as the same as the previous diagnosis."

In the example below (data 63), Parent Zhang explained that she could not accept the truth of deafness and feared the stigma after experiencing two different diagnoses from two different hospitals. At the beginning, she knew medical treatment would affect her son's hearing, although the doctor told her there was no problem with her son's hearing. After this treatment, she called her son's name in a loud voice at home but he did not respond. She then took her son to the local hospital and the doctor said her son's hearing was normal, before his deafness diagnosis was confirmed later in the city hospital. Finally, she thought that her son became deaf as a consequence of previous medical treatments.

## (63) Parent Zhang [18-25]

"One noon, I saw my son fall asleep and I occasionally shouted at him and called his name many times. There was no response from him. I was in a state of trepidation and I sensed the matter became serious. I took him to a local hospital to check whether everything was OK. The local hospital gave me the response 'Your child looks normal and he would be able to speak until he is older.'. I was still worried about the previous diagnosis and then I took him to the city hospital to check his hearing. Well, the latest diagnose was that my son's hearing has a problem. I became crazy. I cried every night until my eyes were painful."

### 5.2.1b The search for a cure for deafness

Most Chinese hearing parents in this study worked hard to search for a cure for deafness, for example by visiting doctors and doing acupuncture and Qigong <sup>13</sup>. They searched for information about the cure for deafness in newspapers, on radio and on the internet. Furthermore, many parents demonstrated anxiety and eagerness when they were looking for information. Some parents insisted on searching for a cure for years, and other parents stopped and then searched again for another new cure for

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<sup>&</sup>lt;sup>13</sup> Qigong can be translated as energy/spirit kong fu. Qigong is a kind of Chinese exercise method which uses breathing and physical and mental training movements to achieve mind, body and spirit health and balance.

deafness after a period of time. After a long pursuit, they learned the scientific fact that it is not possible to cure sensorineural deafness. In this way, these Chinese hearing parents were searching for a cure for deafness through professionals' help and/or through self help.

## Seeking professionals' help

Chinese hearing parents searched for many treatments for deafness, seeking professionals' help within Western medicine and/or Chinese traditional medicine.

## Western medicine

In the following excerpt (data 64), some parents like Parent Li visited different hospitals to search a cure for deafness, and they were disappointed each time. Their disappointment was caused by the disbelief as a part of the grieving process, as discussed in an earlier section 5.1.1a. In spite of this, they made great effort to remain motivated and insisted on spending time in looking for medicines to cure deafness. Finally, they accepted the truth of hearing loss when they were repeatedly told that itwas not possible to cure sensorineural deafness.

## (64) Parent Li [line 26-29]

"Before she was 5 years old, I took her around many hospitals in Beijing in order to cure her deafness. When each doctor said 'it is impossible' each time, I feel very painful and disappointed. My hope failed again and again. It was like air bubble. That is true. But I must I had to be strong for her and to raise new hopes again."

## Chinese traditional medicine

Some Chinese parents talked about how they doubted that there was no medical cure for deafness. These parents like Parent Chen below (data 65) did not accept the doctor's advice to get their deaf children into the language training with auditory equipment instead of looking for a cure for deafness. So they spent lots of time visiting hospitals and seeking Qigong and acupuncture.

### (65) Parent Chen [line 19-24]

"The doctor suggested that only if she was able to wear hearing aids and receive language training, she could speak Chinese. We don't believe the words from the doctor. We often think why deafness can't be cured? We visited lots of hospitals to seek medical advice all the time, large hospitals, small hospitals. In addition, I paid much attention to the advertisements on the newspaper, for example, Qi Gong, Acupuncture."

### Western medicine and Chinese traditional medicine

Some Chinese hearing parents in this study used both methods between Western medicine and Chinese traditional medicine, in combination to attempt to cure their child's deafness. They visited doctors and tried methods of acupuncture and injections. However, these methods were in vain and they started to accept their children's deafness and teach their child to speak.

## (66) Parent Liu [line 19-22]

"I looked for professional or top doctor to find out a cure for my son's deafness. We attempted many methods, for example, Acupuncture, injections. All efforts were in vain. I had to accept the fact of my son's deafness. And then I started to focus on teaching him to speak."

# Self help

Some Chinese hearing parents used the modern way of searching for information on deafness on the internet and social media before visiting hospitals and doctors.

In contrast to the previous examples (data 64-66), some parents like Parent Wang below (data 67) searched for information on deafness through the internet, such as Baidu<sup>14</sup>. At the beginning, they did not accept the truth of their child's deafness, so they were not willing to tell people that their daughter was deaf. Later, they accepted

<sup>&</sup>lt;sup>14</sup> Baidu is a tool for a search engine in Chinese website.

the diagnosis and became determined to find resources on deafness.

# (67) Parent Wang [line 18-23]

"I was reluctant to go outside when I was going through the hard time. I just sit in the front of the computer at home, and I only researched the knowledge about deafness. I was in an urgent feeling to look for a cure of deafness and I hoped one day my daughter could hear. I was so so crazy to find out different websites related to deafness knowledge. I researched the most words in the Baidu, for example, deafness, hearing impairments, hearing, hearing aids."

Some parents used traditional methods of going to hospitals to ask doctors, and spent a large amount of time travelling to find a cure for deafness, often due to the lack of internet access and poor technology before 1997.

In the following example (data 68), some parents like Parent Zhang accepted the truth of their child's deafness after a period and explained that they travelled the country with their deaf child to seek potential cures for deafness. When these parents received information on a cure for deafness through the newspaper or radio, they travelled with their child to find out more, regardless of time and cost.

## (68) Parent Zhang [line 28-31]

"Sometimes I heard the information from somewhere, such as a newspaper or radio, I had no hesitation to take him to those places as fast as possible, no matter how much for the cure for deafness. We spent a large amount of time travelling a lot in the country in order to find any cure that is effective against deafness."

### **5.2.2** Early intervention strategies

Early intervention strategies are classified into two main categories: 'hardware' and 'software' strategies of early intervention provided for deaf children. In this PhD study, 'hardware' strategies refer to hearing aids and/or cochlear implants, and 'software' strategies mainly include developing deaf children's skills of listening and speech in their early years.

## 5.2.2a 'Hardware' strategies: hearing aids and cochlear implants

After searching the cure for deafness, most Chinese hearing parents became aware of the importance of hearing aids and cochlear implants for children with a hearing impairment.

# Hearing aids

Before the introduction of cochlear implants in China, the majority of Chinese hearing parents only had a choice of hearing aids provided for their children. Therefore, most Chinese hearing parents in this study provided hearing aids for their children and chose hearing aids as the only one availability of auditory technology, before cochlear implants were introduced in China in the 2000s.

Aside from cochlear implants, hearing aids seemed to be more acceptable to people from the deaf community. From this perspective, it could be argued that hearing aids are applicable to all deaf people.

In the following example (data 69), some parents like Parent Li were aware of importance of hearing aids as early as possible and bought hearing aids for their deaf child in the 1990s, in order to develop their deaf child's language skill. Furthermore, these parents seemed to realize that hearing aids play an important role in language development.

# (69) Parent Li [line 44-45]

"In order to help her to learn language, I realized I need to buy hearing aid for her as soon as possible."

## Cochlear implants

Since cochlear implants have been popular in China after 2000, more and more Chinese hearing parents are aware of this technology and preferred to provide their deaf child with this technology, in order to support their child's ability to hear sounds.

In terms of accessing cochlear implants, some Chinese hearing parents in this study thought cochlear implants were essential for deaf children to hear everything, whereas others made a judgement that cochlear implants would not enable children with hearing impairments to hear everything.

### Cochlear implant is everything

Some Chinese hearing parents in this study thought a cochlear implant was everything for their children with hearing impairments.

In the following example (data 70), the majority of parents like Parent Song thought their deaf children could communicate with people through a cochlear implant and even thought cochlear implants would enable their children to hear everything.

## (70) Parent Song [line 6-7]

"He is wearing a cochlear implant. Right, my son could hear everything with a cochlear implant. So I thought he would improve his communication skills in the future."

Similar to the above example (data 70), some parents like Parent Zhao below (data 71) thought cochlear implants were the best aids for their child to hear the greatest level of sound. They also viewed cochlear implants as the best aids available for their deaf children.

### (71) Parent Zhao [line 6-8]

"My daughter wears the best Cochlear Implant and she could be able to hear the sounds around her, I guess."

### Cochlear implant is not everything

In contrast to the previous examples (data 70 and 71), some Chinese hearing parents like Parent Chen (data 72) consulted professionals about cochlear implants before making their judgements on their decision on cochlear implants. These parents looked for an accessible aid and decided to choose a cochlear implant because of its

popularity and function as a way of accessing 'normal' voices. Furthermore, they were informed that children with cochlear implants should have training in speech and listening provided by professionals. Following the professionals' suggestions, these parents became aware of the fact that cochlear implants were not everything. Thus, the function of a cochlear implant was good but practice in speech and training is also needed.

# (72) Parent Chen [line 32-37]

"We chose a cochlear implant because a cochlear implant has been popular at that time. It was said that a cochlear implant can hear the sound of nature. One day, we met a professional and he advised we must train our daughter's skills in listening and speaking in spite of the aid of a cochlear implant. After meeting the professional, we realized that a cochlear implant is not everything. Rehabilitation in hearing and speech for people who starts to wear a cochlear implant is needed."

In their interviews, some Chinese parents like Parent Wang (data 73) provided the most accurate description of the function of cochlear implants. The phrase 'to hear as more diverse sounds as possible' could reflect these parents' views on cochlear implants, and they explained that cochlear implants would only help their children with hearing impairments hear a limited range of sounds compared to hearing people.

### (73) Parent Wang [line 42-43]

"Cochlear implants could enable children to hear as more diverse sounds as possible."

# 5.2.2b 'Software' strategies: speech and listening training

Most Chinese hearing parents wanted their child with hearing impairments to develop language skills and to speak Chinese. These hearing parents not only mainly talked about the purpose and process, but also discussed their experiences in and the barriers to the training itself. Therefore, these parents tried to use different strategies to coach their deaf children through formal help, self-help and other-help.

### Formal help in speech and language acquisition

Formal help refers to seeking help and advice from professionals and staff who work in early intervention institutions.

The majority of Chinese hearing parents did not know how to train their deaf child's skills in speech and listening and therefore sent their child to a speech and listening training centre to seek the help of doctors, professionals, teachers, other people, and materials and so on.

In the following example (data 74), some parents like Parent Li consulted doctors and professionals about educational methods at hearing centres. These parents explored two main methods that could be helpful in fostering their deaf child's learning interest, namely nature observations and game playing.

## (74) Parent Li [83-85]

"I asked many doctors and professionals who worked in the hearing centers and then explored a suitable educational method for her. Through observing nature and card playing, I encouraged her to be very interested in language learning."

Similar to the above example (data 74), some parents like Parent Chen (data 75) made use of diary communication with teachers who work at hearing and speech training centres to coach their deaf child and train their child's skills in speech and listening at home.

# (75) Parent Chen [line 41-43]

"We sent her to a hearing and speech training centre to develop her language skill. Also, we have a diary to communicate with teachers, for example, what teacher said in the daytime. After finishing at the centre, I could strategically coach her at home."

Unlike the previous examples of help from professionals (data 74 and 75), some parents like Parent Zhang (data 76) made use of materials to raise their own awareness on training in speech and listening skills. For example, Parent Zhang

learned the concept of speech and listening training through materials such as a letter. Following the advice in this letter, she started to train her deaf son's language skills together with speech and listening skills.

## (76) Parent Zhang [line 39-43]

"I looked for materials related to deafness knowledge and then I was lucky to get a letter from a hearing and speech centre. That is the first source on deafness rehabilitation. I have kept it until now. I have thought many strategies for encouraging and enabling him to speak. For example, I kept talking with him and training him in the skills of hearing and speaking."

## The self-help process

Most Chinese hearing parents trained their deaf child in speech and listening when they explored the methods of training to accommodate their child's needs. These parents persevered in training their child in speech and listening skills on a daily basis and developed their own most appropriate method of language training. Thus, most Chinese hearing parents not only trained their deaf children to develop speech skills of Chinese pronunciation and words, but also trained them in listening skills.

## Speech training

When Chinese hearing parents trained their deaf children to speak, they often focused on Chinese pronunciation and Chinese words learning. Also, some of them were creative and used tools to help their child to learn pronunciation, and made use of the child's own visual advantage of observation to watch lip and tongue movement.

## Speech training: pronunciation

In the examples below (data 77-83), Chinese hearing parents (e.g. Parent Li, Parent Liu) explained how they used different strategies for teaching their deaf children in Chinese pronunciation, although they found it hard to explore and find out the best method of speech and listening training.

In the following example (data 77), Parent Li explained the repetitive and detailed training work through using chopsticks and torchlight to teach pronunciation.

## (77) Parent Li [line 48-50]

"I usually used chopsticks and torchlight to teach her to pronounce Chinese basic words. And then we practiced word by word over hundred times."

Similar to the above example (data 77), Parent Li (data 78) further explained how she taught her daughter to pronounce 'a' by using chopsticks and hands to encourage her to repeatedly imitate the correct process. She used chopsticks to aid her daughter's tongue movement and used her hands to aid her understanding of the origin of sound.

## (78) Parent Li [line 53-56]

"For example, when I taught her to pronounce 'aaa....', I used chopsticks to press her tongue to make sure her tongue was flat when she was ready to pronounce 'a'. And I put her hands on my neck to feel that the sounds are from throat. I say 'a' and she followed me, backs and forwards."

In the example below (data 79), Parent Li praised her child's pronunciation of 'b' after hard work, and also explained why her daughter did well in pronouncing 'b'.

### (79) Parent Li [line 59-61]

"She pronounced clearly 'ba-ba' when she started to learn Chinese words. ('Ba-ba' means Dad.) As you see, 'b' is easy for her to pronounce, like a sudden bump. She did a good job!"

In the example below (data 80), Parent Li compared the pronunciation of 'b' with 'm' and praised her child's pronunciation of 'm' in spite of their difficulty in the pronunciation practice.

## (80) Parent Li [line 64-66]

"I thought it is easier to pronounce 'b' than 'm'. As you know, 'm' needs more nasal sounds, and 'b' doesn't need. After a period, she could pronounce 'ma-ma'.

It made me feel touched. I was so so so proud of her."

In another example below (data 81), Parent Liu talked about the importance of making language learning fun and how they strived to find ways to do this.

## (81) Parent Liu [line 31-36]

"I started to train him in speaking the basic pronunciation: a,e,o,i,u. I asked him to watch my mouth and to take practice in language learning. It was quite boring. I would use many strategies for adding joy to his practice. For example, when I taught him to pronounce 'a', I bited an apple and my mouth shape looked like 'a' pronunciation. And then I encouraged him to imitate what I did."

In the example below (data 82), some parents like Parent Liu described how they taught their child to pronounce 'a' and 'e', as these two letters are very difficult to distinguish in pronunciation according to Parent Liu's comments.

## (82) Parent Liu [line 39-55]

"I think it was easy to teach him to speak through demonstrating the vivid materials. But sometimes it was quite difficult to teach. For example, it was not easy to demonstrating any materials to aid pronouncing 'e'. He could not distinguish the pronunciation between 'a' and 'e'. Well, the normal people can hear the difference in sounds and similar pronunciation. So, I showed him the different mouth shapes while I was pronouncing 'a' and 'e'. The mouth shape of pronouncing 'a' is bigger while the mouth shape of pronouncing 'e' is smaller. At first, he was not good at imitating the big and small mouth shape. He got to know that the bigger mouth shape aids pronouncing 'a' as opposed to the smaller mouth shape that aids pronouncing 'e' after keeping remembering these different mouth shapes that I demonstrated. And I slowly strengthened the practice of his pronunciation in 'a' and 'e'. And then, his pronunciation between 'a' and 'e' was not wrong anymore after keeping practice over three months. After a period, he forgot the pronunciation difference between 'a' and 'e'. And then, I would need to correct his wrong pronunciation. If I was lazy to correct his pronunciation, he easily fell into a bad habit of speaking with a wrong pronunciation. So I paid much attention to his pronunciation anytime. I reminded him and told him how to pronounce accurately when he pronounced in a not right way."

After training their deaf child's basic pronunciation for a period, some parents like Parent Liu (data 83) used the strategy of correcting their child's incorrect pronunciation, in order to enable their children to remember the right pronunciation.

## (83) Parent Liu [line 68-69]

"If I heard which word he spoke not clearly, I would correct his wrong pronunciation at most time".

# Speech training: Chinese words

In the following examples (data 84-86), the majority of Chinese hearing parents used the outside learning environment to teach their deaf child Chinese words and speech skills according to their deaf child's needs.

In the example below (data 84), Parent Li seemed to master her daughter's personality and taught her daughter to learn Chinese words outside. When Parent Li noticed her daughter's fatigue, she encouraged her daughter to play and stopped practising.

# (84) Parent Li [line 70-74]

"She was a bit naughty and active. And she could not learn language at home for a long time. So I make use of outside time to teach her Chinese words although she could not pronounce clearly. For example, I took her to the park and taught her to know the names of existing things, eg: tree, flower, water, etc...If she was tired to learn, I would like to stop teaching for a while and to let her play."

Similar to the previous example (data 84), some parents like Parent Li below (data 85) expressed their worries and concerns that training their child's skills in speech and listening at home might not be effective or helpful. A few parents viewed speech and listening training as a tiresome aspect of their family life. In order to avoid learning boredom, Parent Li explained that she took her daughter to the park and taught her to learn Chinese words there.

## (85) Parent Li [88-92]

"She was too young to learn language at home for a long time. So I often took her outside and played games with her. For example, when I took my daughter for a walk in the park, I taught her some names of things existing, like 'shu' ('shu' means tree), 'hua' ('hua' means flower), 'niao' ('niao' means bird) etc. These activities could encourage her to increase her interests in language and to keep her passion."

In another example below (data 86), Parent Zhang talked about how she attempted to motivate her son to pronounce the word 'sweet' by giving favourite sweets.

## (86) Parent Zhang [line 46-58]

"I remembered I was teaching him one word 'tang' ('tang' means sweet) for 20 days. I constantly demonstrated the sweet into my mouth while showing him to pronounce 'chi tang' ('chi tang' means eating sweet), 'tang chi wan le' ('tang chi wan le' means sweet is eaten) each time, and then do the same action again and again. Well, my little son still did not understand how to utter a sound. I felt very painful. Later, I realized I need to teach him the simplest sound 'tang' directly to make himself understood. Otherwise, he never understood more than one word. Hmm... I attempted the other new method again and again and it made me feel annoying through teaching him after 10 days. Last, I decided to use the method of refusing to give him any a sweet in order to enable him to utter a sound. Well, you know, a child might want sweets in a crying need. One day, he was so eager to get sweet from me and he was finally forced to pronounce a kind of a similar sound 'dan' with crying tears. I was quite shocked by his sudden first sound-like word and it was out of my surprise."

## Listening training

Unlike the use of hearing aids, most Chinese hearing parents often asked their deaf child to watch lips while training their child to speak. Due to the new developments of cochlear implants, more and more hearing parents became aware of the importance of listening skills.

In the following example (data 87), some parents like Parent Wang thought that a cochlear implant was better than hearing aids to help deaf children to develop listening skills without lip reading. These parents did not encourage their deaf child to depend on lip-reading.

## (87) Parent Wang [line 35-38]

"When I taught my daughter Chinese, I always bear in mind that I don't want her to depend on lip-reading. Well, cochlear implants are quite better than hearing aids. In this way, it is necessary to reduce the lip-reading training. I believe children with a cochlear implant could listen to others without lip-reading skill."

During the period of listening training, some parents like Parent Wang (data 88) spoke with their child the same way they would with hearing people. They drew attention to different sounds to train their deaf child in listening skills and looked to identify the sounds their child found most difficult. They also communicated with their child without showing their lips in order to train their child's listening skills. Through training backwards and forwards, these parents could identify their child's strengths and weaknesses in practice and then strengthen the weakness. As a result, this training approach could be viewed as one of the most effective strategies for the interactive interaction between parents and children with hearing impairments according to Parent Wang's comments.

# (88) Parent Wang [line 46-52]

"I tried to call her name behind her ears every day. During the period of training, I tried to talk with her in a low voice as same as the way of speaking to hearing people. I also tried to talk with her behind her ears in order to train her listening skill. Furthermore, I encouraged her to speak and distinguish similar sounds, no matter how accurate she spoke whatever the outcome. So I could make a judgement which part of listening words is her strength and which other part is her weakness. Then, I could particularly strengthen the weaker practice of her language training."

# Enlisting the help of the community

In the following example (data 89), some parents like Parent Liu were not afraid to ask external people to correct their child's pronunciation. External people often felt empathy for the child's deafness and did not like to hurt them by correcting any wrong pronunciation. According to comments from Parent Liu, the term 'other people' in this instance refers to members of the local community<sup>15</sup>.

# (89) Parent Liu [line 62-65]

"I told people 'You must tell him if my son pronounced not clearly' when we were outside. Some people would like to offer help, and other people might feel ashamed when they would correct my son's pronunciation. Maybe, they thought my deaf son is a poor child, so they don't want to embarrass my little boy."

In another example below (data 90), parents like Parent Liu invited external people to come to their house and create social events to thus increase and diversify the language their child was exposed to. Furthermore, parents asked the people to help their children with a hearing impairment to join in conversation. According to comments from Parent Liu, 'people' in this instance refers to neighbours in a local community.

## (90) Parent Liu [line 155-156]

"I tried to invite people that I know to my house and asked them a favor to talk with him as much as possible."

### 5.2.3 Dealing with mainstream schools

Most Chinese hearing parents in this study preferred to choose mainstream schools for their child with a hearing impairment while struggling to identify the optimum education settings over a certain period. After their decision on a mainstream school, they make a determined effort to look for and seek an appropriate learning

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In Beijing, Chinese people live in an area based on community and are quite friendly when meeting people from the same community. Sometimes, people get to know each other through attending various activities based in the community and may even ask people for favours if needed.

environment within a mainstream school for their child.

### 5.2.3a The access to mainstream schools

Most Chinese hearing parents used different strategies for helping their deaf children to register at a mainstream school after they decided to choose this educational pathway. There were two main ways to access mainstream schools, either via an entrance exam or 'no exam'. Chinese hearing parents of deaf children experienced different ways of accessing mainstream schools. Generally speaking, almost all mainstream schools have a set of entrance exams or application forms for all children, including children with hearing impairments. Compared with hearing students who have an entrance exam before studying at local schools, the access to mainstream schools for deaf children is contingent upon individual family situations and local school circumstances.

## Mainstream schools' entrance exam

The majority of Chinese hearing parents faced great pressure when their deaf child was preparing for the mainstream school's entrance exam. They were hoping their child would pass the entrance exam. Furthermore, the outcome of the entrance exam, whether deaf children passed the examination to gain access to the school or not, depended on the child's own effort and preparation. In their interviews, these parents explained that their deaf children worked hard to prepare for the entrance exam to a mainstream school and passed the exam after great effort.

In the following example (data 91), Parent Wang was so excited to know his deaf daughter had passed the exam without informing the mainstream school staff of her daughter's deafness. Parent Wang also strongly praised his child's intelligence because he felt content to know his deaf child's academic level was on a par with hearing peers in a class.

## (91) Parent Wang [line 55-58]

"I remembered my daughter did a good job when she passed the entrance exam to a primary mainstream school. You know, I never told the examiners and staff of this mainstream school about my daughter's deafness before we went to this school. All efforts were credited to her and I was very proud of her. Yeah... She is so smart and excellent!"

Compared to the children who passed the exam, some deaf children were lucky to get a place in a mainstream school despite losing few marks.

Unlike the example of data 91, Parent Song below (data 92) felt disappointed to know her deaf son did not pass the exam by only a few marks. Parent Song also tried to ask the teachers who worked at the mainstream school whether it was OK to be acceptable to recruit her son, and then her son was fortunately accepted. In this way, Parent Song became aware of a gap in academic performance between her son and his hearing peers at this mainstream school.

## (92) Parent Song [line 19-23]

"My son nearly passed the exam. And it was a pity that he missed by a few marks, and this made me to feel upset and disappointed. After that, I tried my best to ask this mainstream school whether it was ok to accept him. Then, it was surprising for me to know he got a place in this mainstream school, however, I was aware that my son needed to spend more time studying to follow the standard school program in a process."

In addition, some mainstream schools opened the door to deaf children and students with disabilities directly, and required their parents to hand in an application form. This form was regarded as a kind of an entrance exam to mainstream schools and to generally evaluate the child's skills and ability. For example, Parent Liu (data 93) talked about how her deaf son had access to a mainstream school.

## (93) Parent Liu [line 86]

"The application for the entrancement to this mainstream school was going well."

#### No exam for a deaf child

In order to lower the standard of the enrolment criteria that accommodate the ability and skills of the students with disabilities including deaf students, some mainstream schools made them exempt from entrance exams. In this way, deaf children were likely to be involved in a mainstream school if this school did not set up an entrance exam for students with disabilities. Such deaf children were fortunate to have not an exam, and their parents had no struggle to help children to access mainstream schools. Thus, both Chinese hearing parents and their deaf children would not face great pressure from the entry requirements.

Despite the lack of entrance exam, some Chinese hearing parents worked very hard to help their deaf child to access mainstream schools through either self help or their friends' help.

## Self help

The majority of Chinese hearing parents encouraged their deaf children to go to mainstream schools and they visited these mainstream schools to ask whether their child could be involved. Furthermore, some hearing parents consulted professionals and head teachers who worked at mainstream schools. They also learned further details of the environment for deaf students when visiting.

Some hearing parents got to know that mainstream school teachers had difficulty in accepting deaf students at mainstream schools because these teachers had little experience in teaching deaf students. This issue was often raised by head teachers when these parents visited them to consult on the matter of their child's registration. After the head teachers raised their concerns, parents insisted on persuading them to accept their child as a student because of their strong belief that their child could be successful at a mainstream school. Additionally, these parents often did not care about teachers' qualifications in special education. For example, Parent Li (data 94) talked about how she worked hard to get a place for her child at a mainstream school.

## (94) Parent Li [line 96-104]

"My daughter started her first mainstream school life. Before registering at a mainstream primary school, I contacted the head teachers to ask if it is ok to locate her at a mainstream school. It was very difficult at that time because that mainstream school never had children with a disability, not to mention deaf children. Also, staff had little experience of teaching deaf children and classmates had little experience of playing with deaf children. I attempted to persuade them to believe that my daughter could be well-educated at a mainstream school. At last, the head teachers were very kind and gave us an opportunity and finally accepted my daughter to be one of students studying at a mainstream school."

## Friends' help

Some Chinese hearing parents had a network of friends who work at mainstream schools, they would ask them, as a favour, to recommend their children to the head teacher. This would help them to persuade the head teacher to accept their child. This also became an easier route for Chinese hearing parents to help their child get a place at mainstream schools, particularly when compared to those who used the self-help strategy.

In the following example (data 95), Parent Zhang felt it was easier to visit the mainstream school with her friends' help, so she found it less difficult to find a place for their deaf child. She further explained that the teachers of the mainstream school were pleased to accept her deaf child, although they had a few concerns about the teaching of a deaf student in a class with hearing students.

### (95) Parent Zhang [line 89-92]

"After a while, I started to do the hard task of finding a mainstream school. Under my friends' recommendation, we visited the mainstream school teachers. The teachers were very nice and we were lucky to meet great teachers, although they were in a bit hesitation to think how to teach him in a class."

Similarly, in another example (data 96), Parent Liu knew one of their friends was a primary school teacher and visited this teacher to see if it was acceptable for her to teach her deaf child. This teacher was not confident enough to teach her child and asked her to speak with the head teacher. Parent Liu insisted on persuading the head

teacher to recruit her child in the mainstream school through telling the story of her deaf child's hard work in developing skills in listening and speaking in spite of the great difficulty in learning oral language. Then, the head teacher and the teachers felt touched by the story and agreed to teach the deaf child in their mainstream school. Perhaps, hearing people like teachers thought it was easy to learn an oral language because they were exposed to a language environment throughout their daily lives, and therefore cannot imagined the difficulties deaf children faced. Following this, the head teachers and the teachers began to understand that deaf children must spend a large amount of time learning spoken language through intensive and special training in listening and speech skills.

## (96) Parent Liu [line 76-83]

"One of my colleague's friends was a primary school teacher in my local area. When I got to know this network might be of benefit to my son, I visited the teacher to see whether my son could be educated at her school. That teacher was in hesitation and she said she could not make a decision on her own. She adviced us to consult the headteacher. Following her suggestion, we visited the head teacher. We told him our story of hard working for training my son's skills in speech and listening. The head teacher felt touched and he agreed to accept my son as a student of this mainstream school."

In summary, Chinese hearing parents' avenues of self help and friends' help are different pathways to help their children to access mainstream schools. However, these hearing parents still had to attempt to gain permission from the head teacher if they wanted their deaf child to register at the school, with or without a network.

## 5.2.3b Parents' relationship with teachers

Most Chinese hearing parents of children with hearing impairments used many strategies for creating a beneficial and dynamic relationship with teachers who taught these children. Teachers would play an important role in promoting the home-school relationship between teachers and parents of children with hearing impairments.

# Contacting teachers

The majority of Chinese hearing parents talked about the importance of their responsibility to create a dynamic relationship with teachers and to maintain active contact with teachers who worked at mainstream schools. Furthermore, some parents built a good relationship with teachers through regular visits. Some other parents also communicated with teachers to discuss their child's performance and development through the telephone and/or a diary. In this way, many parents viewed their children's teachers as their own teachers, and some viewed their children's teachers as their own friends.

# Parents' viewing teachers as their own teachers

Chinese hearing parents in this study created and maintained a good relationship with teachers who worked at mainstream schools through visiting them and/or regular telephone conversations. They also consulted their deaf child's teachers about academic issues arising from their deaf child's learning at mainstream schools. These parents consulted teachers in the same way as children could ask teachers in classrooms. These parents felt that their child's teachers were their own teachers. Furthermore, mainstream school teachers were responsible for making notes in the diary, such as what knowledge children with hearing impairments had learned at schools. These parents also benefited from the use of diaries by teachers and this enabled them to effectively communicate with these teachers in a closed way. Thus, it was essential to create a good rapport between mainstream school teachers and parents of deaf children, as both stakeholders' support can facilitate their deaf children's achievements. For example, Parent Li below (data 97) talked about how it was her responsibility to create a relationship with her daughter's teachers.

## (97) Parent Li [line 144-149]

"When my daughter came home every day, I could look at the diary written by her tutor. Through the diary I knew the outline of daily knowledge. And then according to my daughter's academic level, I separated the knowledge into piece and then explained it to her based on her current understanding. If I could not teach her about some knowledge or face some academic questions, I would ask her tutors at school next day, sometimes telephoned teachers."

Similar to the above example (data 97), some parents like Parent Zhao below (data 98) talked about the importance of creating a dynamic partnership with schools, maintaining active contact with teachers, asking for feedback on their child's progress and continuing school work at home. For example, Parent Zhao praised teachers' efforts in making a diary. Furthermore, he benefited from the diary as a way of building communication dialogue between teachers and parents. Through diary communication, he mainly discussed his deaf daughter's current development and the expected learning process, in order to help his daughter to develop learning skills. He was sincere in making use of the diary to reflect on what he had done for his daughter and examined the knowledge his daughter had received at mainstream school.

## (98) Parent Zhao [line 24-27]

"Her tutor was so great! We kept records of my daughter's learning process on the diary and mainly recorded what she learned and what she should improve. This diary was very useful for my daughter in the learning process. And this would help me to reflect the way of educating her at a mainstream school."

### Parents' viewing teachers as their own friends

In the following example (data 99), some parents like Parent Zhang viewed their deaf child's teachers as their own friends and did regular visits to maintain this good relationship. Parent Zhang also explained that she and teachers reached an agreement following their discussions on educating their child with a hearing impairment.

## (99) Parent Zhang [line 103-105]

"In order to enable my son to catch up with peers, I often visited his teachers and discussed with teachers regarding educating my son. Sometimes we reached agreement and we kept close friendship."

### Parents as home teachers

In their interviews, some parents like Parent Li below (data 100) explained that they

were willing to act as a home teacher to share responsibility with their child's teachers and to cooperate with their approaches. They were active in creating and maintaining a good relationship with teachers, in order to help their child to adapt to the new environment of mainstream schools. These teachers were thoughtful in understanding the situations of these parents and their deaf children.

# (100) Parent Li [line 138-141]

"I decided to be her home teacher at home and tried to contact her tutors to keep a good partnership with school. Her tutors were very kind-hearted and would like to help my daughter at school."

## The role of teachers

Most Chinese hearing parents praised the efforts of teachers and appreciated great help from these teachers. Also, these parents were lucky enough to meet a good teacher who showed a warm heart and great responsibility. For example, Parent Zhang below (data 101) talked about how she appreciated having good teachers for her deaf child and maintained a good relationship with them.

## (101) Parent Zhang [line 99-100]

"It was lucky for my son. The teachers were nice to him, and our relationship kept well."

When compared with the role of parents in influencing deaf children's education in schooling life, some Chinese hearing parents appreciated the value of teachers and they understood that the importance of the role of the teacher is undeniable for their deaf children. In the following example (data 102), some parents like Parent Chen praised the important role of teachers in educating their deaf child, and explained that teachers were held in deep affection by their deaf children.

## (102) Parent Chen [line 71-75]

"I think the role played by teachers is significant for my daughter. After school, my daughter often told me 'that is what my teacher said' when I used my own education methods to coach her homework. Actually, the contexts between what

I taught my child and what her teachers told are the same or similar. Hmm... My daughter really loves her teachers. Maybe that is the power of teachers."

In another example below (data 103), Parent Zhao explained that some Chinese words and vocabularies were easier for his deaf child to learn at school than at home, based on the fact that these Chinese words that vividly display school life are not easily taught at home. Therefore, the important role of teachers would be obvious when Chinese hearing parents had difficulties in teaching children Chinese words at home.

# (103) Parent Zhao [line 30-33]

"I remembered, her teachers gave her exam papers to show her, and taught her to understand the word 'kaoshi' ('kaoshi' means exam.). The word 'kaoshi' was not easy for me to teach her at home. I taught her this word 'kaoshi' at home and I could enable her to understand. Finally, she got to understand this word until her teacher demonstrated exam papers at school."

In the following example (data 104), some parents like Parent Liu sometimes realized they were not effective in delivering education at home at the beginning of their deaf child's studying at mainstream schools. These parents then became aware that their deaf child faced difficulties settling in to mainstream schools and started to pay attention to their child's needs. These parents also consulted their child's teachers about the educational plan in order to help their deaf child adapt to the new learning environment. Finally, these parents started to take responsibility for coaching their deaf child at home and built a good relationship with the teachers.

## (104) Parent Liu [line 92-98]

"I was working daytime and I felt exhausted after work, so I did not accompany my child well at home and I did not help him to overcome the difficulties in the new semester. And then, I visited his tutor to know the basic situations of my son's performance at school. We discussed this issue and made an agreement. The tutor would be pleased to offer her help in making notes, for example, recording what my son learned at school each day. And then, I would coach his study at home and learn with him together."

## **5.2.4** Coaching deaf children

Chinese hearing parents played an important role in coaching their deaf children at home during the period of their schooling life. These parents took the responsibility of coaching their child with a hearing impairment in various contexts, for example moral, cognitive and social-emotional education.

According to the national curriculum standard in China, a student should develop in a holistic way: morally, intellectually and physically. Following this, moral education is seen as the most important subject, followed by cognitive and physical education. Therefore, the sub-section 'coaching deaf children in moral education' will be addressed firstly, followed by other sub-sections, such as coaching deaf children in academic learning, social-emotional skills and other educational activities.

## 5.2.4a Coaching deaf children in moral education

It can be argued that moral education is a small but core part of social and ethical education in China, including common sense, ethical issues, and societal rules and so on.

In this study, the majority of Chinese hearing parents found it difficult to teach and coach their child with a hearing impairment in moral education. Furthermore, some parents coached their child through outside activity to raise moral awareness, and some other parents coached their child through communication to strengthen their child's understanding of morals. Some parents found it difficult to educate their children with hearing impairments to understand moral issues.

To take an example of using an honorific word 'nin', it is important to pronounce the final letter 'n' in the word 'nin' to distinguish it from 'ni'. The word 'nin' in the honorific expresses respect to guests or older people. The pronunciation of 'n' is viewed as a nasal sound, so children with hearing impairments find it very difficult to pronounce this through their throat and nose. Thus, forgetting to use an honorific word could suggest impoliteness in Chinese society.

In the following example (data 105), The majority of Chinese hearing parents like Parent Li spent lots of time teaching their deaf child how to properly use an honorific word. Parent Li did not give up on the issue of the pronunciation of 'n' and insisted on teaching her child to overcome this difficulty through pronunciation exercises. Furthermore, she believed her daughter could speak well with a nasal sound after practice, and also believed that her daughter could flexibly use an honorific word in different situations. Parent Li was also worried that if her daughter did not add an honorific word, it would be misunderstood by senior people. She further explained that her family members did not care about this issue because they understood her child's difficulties in pronunciation when her daughter did not properly use an honorific title to communicate with them.

## (105) Parent Li [line 284-298]

"I remembered an example. I spent large time teaching her how to use honorifics in different situations. Sometimes she was too lazy to add honorifics when she said hello to people. If she forgot to use honorifics, you know, the senior would think my daughter is not a well-educated daughter. For example, she was not good at distinguish 'ni' ('ni' means you for the peer or the younger people) from 'nin' ('nin' means you for the guest or the elder people). Sometimes it was obvious that she said 'shu shu ni hao' or 'a yi ni hao', and I often corrected her to say 'shu shu nin hao' ('shu shu nin hao' means hello uncle) or 'a yi nin hao' ('a yi nin hao' means hello aunt). Yeah...I know it was quite hard for her to pronounce nasal sound 'n' at her young age. And she could not hear the 'n' sound because she could not make a resonant noise. This really made me feel disappointed. And I couldn't explain why she could not say 'nin hao' each time ('nin hao' means say hello to guest or the elder people). My family or other relatives could understand her pronunciation issue. So I must strengthen her pronunciation exercises about nasal sound every time and she did better after practising a hundred times."

In the following example (data 106), some parents like Parent Wang found it difficult to deal with issues related to their deaf child's emotion and behaviour. Also, they felt that their child with a hearing impairment could not fully understand the 'normal life'

of hearing people. In this situation, these parents were patient when teaching their child common sense, doing so frequently and in different places, in order to help their child understand life rules in society.

## (106) Parent Wang [line 69-72]

"It is quite hard to educate my daughter to cope with unusual emotion and behavior problem. And I need to explain this matter related to general knowledge many times at different places until she understood a kind of the normal way in which normal people behave."

In another example below (data 107), Parent Wang explained how they educated her daughter to stand in a queue on multiple occasions. At the first time, Parent Wang tried to use simple words to demonstrate the principle of queuing. Her daughter did not understand why Parent Wang asked her daughter to leave the queue. Parent Wang then used the simple example of 'older sisters look after younger sisters' to explain what a queue is, but her daughter still did not understand the meaning of queuing. And this made Parent Wang feel exhausted and disappointed. At the second time, Parent Wang found an appropriate approach to teach her daughter and showed her daughter how to stand in a queue. Finally, her daughter got to know what the queuing is through Parent Wang's vivid demonstration in showing the principle of queuing.

### (107) Parent Wang [line 75-84]

"One day I took my daughter to the park with other younger deaf children. When they started to play games in a queue, I saw my daughter jumped into the first place of the queue. And I was a bit angry because I found my daughter did not know how to look after her younger friends. So I took my daughter out of queue. At the beginning, my daughter did not understand what I said and it made me feel exhausted. And then I used the simple words which suit her understanding to explain that the elder sister should look after her younger brothers and sisters. Well, she seems slightly understood this reason but she still don't understand the whole principle. Later, we started another games, I guided her and showed her how to look after her friends through taking her to stand the last one of the queue. And then she understood more and then she did better in next games."

### 5.2.4b Coaching deaf children in academic learning

Most Chinese hearing parents paid great attention to their deaf child's academic performance while coaching their child in academic learning. Some of them had a capability in coaching their child on different subjects, for example Chinese, maths and so on. These hearing parents talked about how they used different strategies for helping their deaf child to improve academic learning at home. Additionally, in terms of subject coaching, some Chinese hearing parents found it easier to teach their deaf child maths than Chinese.

# Chinese language learning

Most Chinese hearing parents found it the most difficult to teach their deaf child the Chinese language. Some of them coached their deaf child in Chinese by exploring a self-help method, which was seen as suitable for their child's individual learning. Furthermore, some parents made use of their personal knowledge and learning methods and then applied these to their child's learning. Some other parents used the strategy of developing their child's reading skills as a starting point to foster learning skills in Chinese.

In the following example (data 108), Parent Li made a great effort to coach her deaf daughter in Chinese at home. She found it difficult to teach her daughter Chinese step by step due to her daughter's poor understanding.

### (108) Parent Li [line 158-160]

"It was very difficult to teach Chinese her as she could not understand lots of words. It took me large time to teach her Chinese at home from words to words, even from alphabet to alphabet."

Similar to the above example (data 108), some parents like Parent Li below (data 109) found it difficult to teach their deaf children how to use different appropriate words with the same meaning in different language contexts. These parents not only helped their deaf child to understand words that would be applied to life language, but also talked about their difficulties in teaching Chinese words. Sometimes, they were

diligent in teaching their deaf children how to distinguish between two words of the same meaning in different contexts, although they still understood their deaf child's unusual expressions that were not often used.

### (109) Parent Li [line 221-232]

"Two words have the same meaning but used in different contexts or language environment. For example, it is very hard to distinguish 'bu' from 'mei' according to different contexts ('mei' 'bu' mean not). I remembered that one day I taught her 'che mei lai' ('che mei lai' means the bus have not come yet) when I pointed out the No. 106 bus and then taught her 'che lai le' ('che mei lai' means the bus is coming). When we both got on the bus, she told me 'ren mei duo'. I felt a bit strange about this sentence but I knew her meaning. And then I corrected her and taught her to say 'ren bu duo' ('ren bu duo' means not many people are on the bus). She still did not understand this difference and asked me why to use 'bu' not 'mei'. I had no idea to answer her question and kissed her puzzled face. Yeah...it is really difficult to teach her how to select the right words and used the appropriate word in the right context."

In another example below (data 110), some parents like Parent Zhang made use of their previous methods of learning of Chinese and then applied these, based on the fact that their own Chinese learning foundation was good. These parents thought that their own learning method in Chinese could be transferred to their deaf child's learning. These parents also seemed to successfully attempt to transmit their own learning skills as a type of coaching strategies.

# (110) Parent Zhang [line 108-109]

"His Chinese was always not good for a period. My Chinese was not bad before. I would try to use my own method of learning Chinese to teach him."

In the following example (data 111), Parent Zhang explained how to use a self-help method to develop her deaf son's reading skills step by step. This was viewed as a stimulus to fostering his learning interest in Chinese.

# (111) Parent Zhang [line 112-118]

"When I developed his reading skill, I taught him to recognize the Chinese characters, understand the meaningful words and sentences, understand the questions to ask, divide context into the different levels of paragraphs, explain the gist of a paragraph within context, find out the topic sentence and understand its meaning in the text, summarize the central idea and dominant theme of the passage, highlight the cohesion and coherence between paragraphs and the next one, understand the intention and context of the main text."

Following the above example (data 111), Parent Zhang (data 112) further explained that her individual approaches to teaching her son Chinese would be useful when her son's reading and writing improved. She suggested that other hearing parents of deaf children could apply this method to developing their children's reading skills.

# (112) Parent Zhang [line 121-124]

"If a deaf child is learning to read in the way as described above, it would be of benefit. Our child became a good habit of reading following my learning method. His Chinese became better and better and he developed language skill. And now he has a strong capacity of written expression."

### Visual subjects

The majority of Chinese hearing parents found it easy to coach their children with hearing impairments in visual subjects, such as maths, science and so on. Some parents thought it is easier to teach their deaf child maths than Chinese, because visual subjects do not require deaf children to master complex language.

In the following example (data 113), Parent Liu talked about why she found it easy to teach her deaf son in maths and science. Parent Liu also explained that these subjects could be taught in a direct way of visual teaching approaches. According to Parent Liu's comments, she assumed that if the subject did not require too much of a language foundation, it may be considered as a type of visual subjects for deaf people. In other words, it could be argued that Chinese would not necessarily belong to one of visual subjects.

### (113) Parent Liu [line 130-132]

"It was quite easy for him to learn maths and science. These subjects are easily demonstrated through vivid materials. I think that might be the main reason."

In the following example (data 114), some parents like Parent Zhang effortlessly coached their deaf child in visual subjects based on the fact that their child was skilled in these areas. According to Parent Zhang's comment, the phrase 'other subjects' refers to visual subjects, such as maths and science and so on.

# (114) Parent Zhang [line 127]

"He did not bad in other subjects and I did not coach him much on these subjects."

Similar to the above example (data 114), Parent Liu below (data 115) talked about what visual subjects were. She also explained that her deaf son's strong ability in learning visual subjects made her feel more comfortable when teaching her son at home.

### (115) Parent Liu [line 126-127]

"For example, maths, science, etc. These subjects were fine for him to learn and it was quite relaxed for me to teach him in these subjects."

In the following example (data 116), some parents like Parent Li found it less difficult to coach their deaf children in maths than in Chinese.

# (116) Parent Li [line 155]

"For her, the most difficult subject is Chinese and the less difficult one is mathematics."

Furthermore, some parents like Parent Li below (data 117) talked about why they found it easy to teach their deaf child in maths subject. For example, Parent Li explained that the characters used in maths represented a much simpler language than that in Chinese. Parent Li also thought that the function of her daughter's intelligence in maths was undeniable. Additionally, some parents like Parent Li used

the strategy of games and poker playing to foster their deaf children's interest in maths and to develop their mathematical skills.

### (117) Parent Li [line 196-199]

"It was a bit easier to teach her maths. Maybe maths consists of symbols, a few amount of language. I used games playing and poker playing to raise her interest in maths. She may be very potential in learning maths and she learnt very fast. And this surprised me at her young age."

## 5.2.4c Coaching deaf children in social-emotional skills

Most Chinese hearing parents expected their child to be a deaf person who could communicate with hearing people as discussed in an earlier section 5.1.4.2, so they made every effort to coach their deaf children in social-emotional skills. Some of them had explored an effective method of developing their deaf child's social-emotional skills through interactive activities and communication dialogue. Other parents had not the faintest idea how to teach their deaf children to develop communication skills with hearing peers, although they acknowledged their child's needs.

In the following example (data 118), some parents like Parent Mei found it difficult to teach their deaf children how to use oral words to communicate with hearing peers. These parents talked about how their deaf child forgot the simple Chinese words that are taught at home.

## (118) Parent Mei [line 14-16]

"I feel difficult to teach her how to communicate with her peers in her kindergarten and I showed her how to use simple words to express what she wanted. However, she often forgot what I taught at home."

Similar to the above example (data 118), some parents like Parent Mei below (data 119) thought that their deaf children found it difficult to use oral words and to express what they wanted. These parents blamed themselves for not being able to educate their child all the time. They also realized that it was impossible to be with

their deaf children at all times and to correct every behaviour.

### (119) Parent Mei [line 38-41]

"It is quite hard for her to use simple words to express her needs at her young age. I could not be able to accompany her all the time. It needs to take many times to repeatedly educate her to do her behavior in right way. So she was not good at remembering the mode of expression."

In another example below (data 120), Parent Mei talked about how she found it difficult to teach her daughter to understand different styles of expressing the same meaning at different times. Furthermore, Parent Mei attempted to use different methods to teach her daughter to understand a simple dialogue consisting of a question and an answer, in order to develop her daughter's social skills. After many attempts, Parent Mei felt exasperated when there remained her daughter's difficulties in understanding the changing words within the same meaning.

## (120) Parent Mei [line 24-35]

"For example, I taught her a couple of dialogue 'what is your name?' 'my name is XXX' three times and she learned fast. The next day, I asked her 'what is your name?' and I got her right answer after thinking a few seconds. I just wanted to know whether she totally understood my question and asked her the same question in another way 'how do you spell your name?'. She did not understand the other question and asked me 'Daddy, what do you mean?'. I was at a loss whether to laugh or to cry. And then I explained the meaning and I taught her how to answer the question 'how do you spell your name' twice. Last, she got to know two questions that I asked had the same meaning. After a few days, I asked her 'how do you spell your name?' and she was thinking for at least five minutes. And then I asked her another question with the same meaning 'May I have your name please?'. Well, you know. She still did not understand these questions again and I was at a loss what to do next."

In the following excerpts (data 121 and data 122), some Chinese hearing parents gave examples of where their deaf child's behaviours were mistaken for rudeness. Parent Mei (data 121) gave an example of exchanging toys in the mainstream

kindergarten. She talked about how her deaf daughter's behaviour was perceived as rudeness by her teacher and hearing peers in a class. Afterhearing the details, Parent Mei understood that her action was not rude in this case. Instead, the lack of understanding was caused by her child's own poor ability to communicate.

## (121) Parent Mei [line 44-48]

"For example, she wanted to exchange her toys with the other toys from her peers or she wanted to play with her peers together. But she was not able to say clearly 'Could I exchange my toys with yours?' or 'Could we play toys together' at her young age. So people think she always grabbed other's toys. Well, her behaviors sometimes make people misunderstood."

Similar to the above example (data 121), some parents like Parent Xue below (data 122) found it difficult to teach their deaf children to distinguish between the same words that were expressed in different situations. These parents did not think their deaf child's behaviour was rude after this issue was reported by teachers and hearing peers, because they understood their deaf child had much difficulty in using oral language to express themselves with appropriate actions.

## (122) Parent Xue [line 14-22]

"I remembered my son's teacher reported his rude behavior to me one day. He often touched his peers' head or hair, and sometimes hugged his peers with a bit rush at his school. It might make some peers getting scared, especially for the timid peers. After that report, I was thinking why he did that behavior at school. Hmm...I suddenly remembered my little son said sweetly to me 'Mum, I love you. Mum, I give you a hug.' So I guessed he wanted to say 'I love you' while hugging his peers. It should be a better way if he could use his oral words to say 'I love you' or he could make use of friendly actions with his peers, for example, holding hands. Well, you see, it is a kind of inappropriate way to express the same meaning for him."

In the following examples (data 123 and data 124), some parents expressed their increasing concerns of their deaf children's social-emotional skills along with the growth of the age. For example, Parent Liu below (data 123) talked about how she

encouraged her deaf son to play with friends. She also explained that her son found it difficult to make friends due to his heavy academic workload and delayed language development.

### (123) Parent Liu [line 156-161]

"I would encourage him to find a few friends to play with and it was quite hard. I also encouraged him to being outgoing. Sometimes he liked himself to stay at home and spent time in studying. He played with friends when he was in a good mood. When his age became older, the pressure of academic in the middle school and high school became greater. So I guess he would not have much more time to play with his peers."

Similar to the above example (data 123), some parents like Parent Liu below (data 124) took it for granted that their deaf children could transfer their own academic learning skills to life when their children grew up as adults, for example in interpersonal relationships. Parent Liu found it difficult to teach her deaf son about the skills of 'interpersonal relationships', although she was confident in teaching their child to develop learning skills and communication skills. Parent Liu then asked the researcher a question on this problem to explore solutions as she was aware that the researcher was a deaf adult. She was very concerned about her son's development in social skills as time went on and made great efforts to seek any tips to help her son.

## (124) Parent Liu [line 149-152]

"[It is more difficult for him to learn language when his age became older]. He developed learning skills already when he was grown up. However, I felt much worried when teaching him how to communicate with people, so called 'interpersonal relationship'. I don't know whether you met this kind of problems before?"

# 5.2.4d Coaching deaf children in other educational activities

Chinese hearing parents used different coaching strategies for teaching their deaf children in other educational activities to accommodate their children's individual needs, for example, how to do learning through play, how to develop learning interests and how to deal with time management.

#### Learning through play

Some hearing parents like Parent Wang below (data 125) not only taught their deaf children how to balance learning and playing, but also talked about how to do learning through play. These parents believed that learning through play can encourage deaf children to take part in the learning activities and help them gain knowledge and language through play.

## (125) Parent Wang [line 62-66]

"It is important to educate deaf children to balance the time of learning and playing. In her spare time, I would like to take her around rather than studying at home. For example, in her spare time, I often take her to the parks, play grounds and tourist attractions. It could not only open her mind and broaden her horizons, but also develop her communication and social skills."

#### Developing learning interests

In the following example (data 126), some parents like Parent Chen used an intensive interaction approach to encourage their deaf children. These parents made use of what their deaf children were interested in and then worked with that to develop their children's learning interests in academic learning.

For example, Parent Chen talked about how he used his daughter's interest in picture drawing to foster her learning interests. At the beginning, Parent Chen used an effective educational dialogue to encourage his daughter to express what she was drawing in the picture. Following his daughter's drawings, he expanded the contexts of previous dialogues to stimulate her imagination and to enlarge her vocabulary. Parent Chen then used intensive interaction to encourage his daughter to keep motivated to study at a mainstream school and this intensive interaction can be a child-led coaching method. Finally, Parent Chen successfully applied his daughter's skills of drawing to fostering her interests in learning other subjects.

### (126) Parent Chen [line 55-67]

"I remembered, one day, I found that she is very interested in drawing pictures. And then I was thinking of a question to solve: was it possible to help her to increase her interest in study through transferring drawing skill to her study? For example, she drew a beautiful community with some buildings and surrounding garden in a picture. I asked her some simple questions, such as 'what color is it?', 'what object is it in your picture?'. And then I thought it was such a good point to help her realize the importance of study through asking her further questions step by step. In this way, I talked with her and made a dialogue by asking a question and answer based on her very small amount of vocabulary, such as 'how could you be able to buy tall buildings?', 'you could earn your own money to buy your favorite house.', 'how could you make money?', 'you could get a job after hard working in study.' and so on. I often repeated such these words and kept talking with her, no matter how much she understood. It is quite useful for her. At last, she started to love studying."

#### Time management

In the following example (data 127), some parents like Parent Xue talked about the importance of time management in managing their child's learning and resting. They taught their deaf children to manage time step by step, and they used rewards to encourage learning the skills if needed.

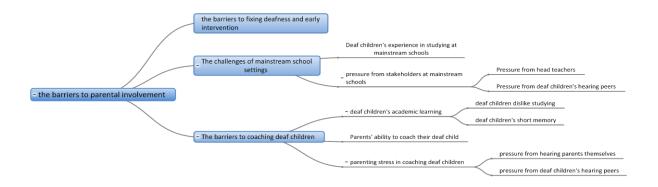
### (127) Parent Xue [line 43-48]

"After a period, I tried to use a method of setting time for him and it was quite helpful. For example, all homework should be finished in two hours. It was quite difficult for him to concentrate on homework for two hours. I would help him to arrange time for each task, one hour for homework, twenty minutes for rest, another one hour for homework, another twenty minutes for rest. During this period, I could praise him with a small reward if he did well, such as sweet."

#### 5.3 The barriers to parental involvement

Chinese hearing parents talked about the key aspects that caused barriers to their involvement, as shown in Figure 5.4.

Figure 5.4 The barriers to parental involvement



## 5.3.1 The barriers to fixing deafness and early intervention

After their baby was diagnosed as deaf, most Chinese hearing parents recalled wanting to find a cure for deafness and realized the importance of early intervention only at a later time. Some of them had been informed earlier that it was not possible to cure the deafness. For example, Parent Zhang below (data 128) talked about how she regretted the time that she spent trying to find a cure for deafness. She not only wished she had provided her deaf son with speech and listening training earlier, but also wished she had realized the importance of early intervention in supporting her son.

# (128) Parent Zhang [line 34-36]

"I wish I had known about the knowledge earlier that it was not easy to cure deafness. I would get him to train in his skills in listening and speaking at his earlier age."

After attempts to search for a cure for deafness, the majority of Chinese hearing parents like Parent Li below (data 129) met barriers when teaching their deaf children language skills in the early years. Parent Li raised the issue that her deaf daughter was not good at remembering Chinese words. She also thought that limited

memory would inhibit progress when training language skills. She then used the strategy of repeatedly practising to strengthen her daughter's language development.

## (129) Parent Li [line 77-80]

"She seemed easy to forget what I taught if I did not strengthen the practice. So I realized language learning for her needs much more time and practice to make sure she could remember how to pronounce words. There is an old saying 'practice makes perfect'."

In the following example (data 130), some parents like Parent Liu observed that their deaf children were not sensitive to listening and hearing in the training process, so their training method was not appropriate to some extent. Parent Liu talked about how she became a woman with a louder voice when practising Chinese words with her son at home. She also reported that she used to explain that it was because of her son's deafness when she worried about disturbing her neighbours' rest. Parent Liu used the word 'poor hearing' to describe her son's deafness. This perhaps reflects her attitudes towards deafness. Parent Liu might be uncomfortable with the word 'deaf' or 'hearing impairment' to explain her son's disability.

#### (130) Parent Liu [line 25-28]

"It was very hard [to teach him to speak]. I talked loudly with him every day. Sometimes it kept neighbours awake and I would explain this situation to them. 'My son has poor hearing. He can hear only if I speak loudly.' You know, I speak in a small voice before and now I become a woman with a loud voice."

# 5.3.2 The challenges of mainstream school settings

After successfully registering at a mainstream school, Chinese hearing parents faced many challenges of the school and their deaf children also has experienced many difficulties when studying there. Both hearing parents and their deaf children were unprepared for the specific challenges of mainstream schools, as the reality of life in such a setting was beyond their expectations and much harsher than they imagined. Thus, these parents endured different types of pressures from mainstream settings while their children were struggling to become involved in the mainstream school.

## 5.3.2a Deaf children's experience in studying at mainstream schools

In their interviews, the majority of Chinese hearing parents reported that their deaf children faced unexpected challenges and many difficulties in studying at mainstream schools, especially when they faced the new learning environments on the first day. Furthermore, these parents talked about how they felt empathy when they saw their children were exhausted in body and mind after one day in the mainstream school.

In the following example (data 131), Parent Li described how her daughter had different emotional expressions before and after the first day of the mainstream school. She tried to understand what had happened to her daughter. Her daughter had difficulties in explaining events because of her limited oral language. Eventually, Parent Li came to understand this matter after contacting her daughter's tutor.

## (131) Parent Li [line 116-123]

"Her journey was full of challenge. I remembered that on her first day at a mainstream school, she went to school with happy mood in the morning and she came back home in tears in the afternoon. So I asked her what happened and she tried to explain something, however, she couldn't explain it clearly because of limited words she mastered. She just repeated two words 'teacher' and 'classmate' and I was trying to understand what she wanted to say and what happened on her. And then I telephoned her tutor to ask how the first day of school was going. After a short chat with her tutor, I understood why her cried."

Some parents like Parent Li below (data 132) talked about some difficulties that their deaf children faced in mainstream schools and also found those difficulties were beyond their children's capabilities. Firstly, their deaf children could not depend on their skill of lip-reading to completely follow their teachers' speech in a class. Secondly, their deaf children were not good at communicating with their hearing peers in the same class and they had difficulties in expressing themselves orally. Thirdly, Hearing peers' rejection and prejudice would affect the emotions of the deaf child. So these parents had not been aware of the unexpected challenges that their

deaf child would face at mainstream schools.

#### (132) Parent Li [line 116-123]

"I did not realize she would face great difficulty on the first day. Yeah, everything was new for her and out of her control. In class, she tried to follow the lip-reading of a tutor and classmates, but she was too young to focus on a tutor in 45 minutes. After class, she wanted to play games with her classmates, but she did not know how to communicate. When her classmates asked her why she wore hearing aids, she tried to explain its function but she couldn't express because of her poor oral language and unclear pronunciation. Yeah...everything was out of her comfortable zone. So it made her feel disappointed and a bit rejected. Yeah...I could not imagine she could face unexpected obstacles."

Similar to the above example (data 132), some parents like Parent Liu below (data 133) talked about the great difficulties that their deaf children faced in the mainstream school. They were unable to find a strategy for coping with the unexpected challenges. Parent Liu talked about how her deaf son had a premonition of studying at the mainstream school. She further explained that her son was anxious to adapt to the new environment. So Parent Liu felt empathy for him and also felt helpless to reduce his pain.

#### (133) Parent Liu [line 87] [line 90-92]

"My son felt difficult after starting to be educated at this mainstream school." "He did not adjust to the environment around him at the beginning of the first week of new semester. I did not expect that issue before. Everything was so new to him. When he arrived at home with his crying tears every day, my heart ached for him."

In the following example (data 134), some parents like Parent Mei had little idea about the education in mainstream schools. They did not mind too much whether their children was educated well there or not. Parent Mei did not cope well with the pressure of managing her deaf daughter when she started studying at the mainstream school. Parent Mei was prepared to compromise on the choice of either going to mainstream school or staying at home according to her daughter's changing

emotions.

## (134) Parent Mei [line 51-52]

"My daughter sometimes went to the mainstream school and sometimes stayed at home, it depends on her feeling."

#### 5.3.2b Pressure from stakeholders at mainstream schools

Children with hearing impairments were under pressure when in the mainstream school environment. It was clear that Chinese hearing parents coped better with pressure than their child with a hearing impairment. When children with hearing impairments were ready for mainstream schools, Chinese hearing parents faced pressure from different stakeholders; either from their children's head teachers or hearing peers, and tried their best to handle these pressures.

## Pressure from head teachers

In the following example (data 135), some parents like Parent Li felt pressured when their deaf children's head teachers seemed to lack confidence in accepting these deaf children at mainstream schools. These parents were anxious about their deaf children's performance at the mainstream school and their children's difficulties in catching up with hearing peers. These parents in particular had high expectations of their child to attain success in a mainstream class. For example, Parent Li talked of the pressures when the head teacher appeared hesitant about her daughter's ability to study at a mainstream school and to survive within the learning environment.

## (135) Parent Li [line 171-179]

"I think I gave her much pressure and asked her to do the tops. And I was also afraid she could lag behind her peers. Before registered in her mainstream school, the head teacher said sincerely to me 'we could have a try and we haven't met any student with disability. However, you ought to be prepared for some unpleasantness in the future. If your daughter could not follow the program schedule for a period, we think we might have another arrangement and might suggest you could locate her in a special school. I hope you could understand

this for her development in the long run. However, we could help your daughter to be well-involved in my school as best as we can"

## Pressure from deaf children's hearing peers

The majority of Chinese hearing parents were concerned about their child's ability to study at mainstream schools. Some parents expressed mixed feelings over their ability to support their deaf children. These parents were unsure whether to register their deaf children at a mainstream school or not. These parents were also aware of the fluent communication between hearing students and their teachers which may not be so easy with their deaf children. Additionally, some parents mentioned that both parents and their deaf children should be made more aware of the reality of life. They should prepare for the difficulties realistically; without false hope.

In the following example (data 136), Parent Zhang encouraged her deaf son to gain interest in studying at a mainstream school, although she knew the great challenges that her son would face. She did not want to negatively affect his confidence nor alter his positive attitudes towards learning in mainstream schools. She sensed, however, that her son may not be strong enough to prepare for the many possible barriers that may occur.

## (136) Parent Zhang [line 76-89]

"Before registering at a mainstream school for my child, I saw the hearing students answering teacher questions fluently outside classroom windows. I assumed how my son could follow the teachers and peers in a class according to his poor pronunciation. I started to hesitate and I wondered whether my son could manage in a mainstream school. However, I was reluctant to see my son remain in a silent world. I made attempts to take my son to any mainstream school to observe after one day in a hearing and speech centre to see whether my son was interested in a mainstream school. After a few days, my son asked me 'why do they wear a red scarf on their neck? (red scarf means the average students are qualified for young pioneer in primary schools)', I was happy to know he was interested in it. Then, I explained and I grabbed this opportunity to ask whether he wanted to study in a mainstream school, although I deeply knew

he would face great difficulties ahead. Finally, I was surprised to hear his firm voice 'I want!'. And I was so excited to embrace him in my arm and tried to control my tears."

In the following examples (data 137 and data 138), the majority of Chinese hearing parents (e.g. Parent Liu and Parent Li) were able to getting their deaf children to be enrolled at a mainstream school at the age of 7 or later. Compared to hearing children who started schooling life at 5 or 6 years old, these deaf children lagged behind by at least one or two years in the same local area. This increased their gaps in skills and knowledge development compared to their hearing peers. As a result, Chinese hearing parents of deaf children felt greater pressure compared to parents of hearing children.

For example, both Parent Liu (data 137) and Parent Li (data 138) expressed how they were proud of their deaf child's enrolment age and they thought this was a great success for their family.

## (137) Parent Liu [line 72-73]

"[He went to a mainstream school when he was] Almost 7 years old. It was quite good news for him."

## (138) Parent Li [line 96]

"My daughter started her first mainstream school life in 1993. [My daughter started her first mainstream life when she was 7 years old.]"

# 5.3.3 The barriers to coaching deaf children

The majority of Chinese hearing parents faced barriers on the issue of coaching their child in social skills. Most Chinese hearing parents in this study faced difficulties in coaching deaf children at home, particularly when considering both the impact of the child's level of understanding and the parent's level of ability in coaching. These parents talked about how they felt very frustrated and stressed when coaching their deaf children at home. They often became impatient, particularly when repeating coaching tasks. A few parents felt less powerful when coaching their children at

home, particularly when comparing their child with hearing peers. In addition, a few parents could not find a way to coach their child in academic subjects.

In this PhD study, three main barriers for hearing parents when coaching their deaf children were found. Firstly, from the perspective of deaf children's learning, some deaf children disliked studying and have issues such as a short memory. Secondly, hearing parents' ability to coach varied and their skills in managing children were different. Thirdly, both hearing parents and their deaf children faced great pressure from either themselves or hearing peers.

## 5.3.3a Deaf children's academic learning

Some Chinese hearing parents found it difficult to coach when their deaf children disliked studying and were not interested in learning. Some other parents talked about how they found it difficult to ask their deaf children to remember and not forget what they taught them at home.

#### Deaf children dislike studying

Some Chinese hearing parents like Parent Chen below (data 139) were exhausted by their deaf child's dislike of studying, and also felt helpless to foster their deaf child's learning interests through communication and/or dialogue. For example, Parent Chen had not the faintest idea how to develop his deaf daughter's learning interests after he observed that his daughter was reluctant to learn knowledge at the mainstream school every day.

## (139) Parent Chen [line 46-47]

"At first, my little daughter disliked studying at home after school and I was in vexation to know that she had been fed up with studying curriculum day by day."

In the following example (data 140), some parents like Parent Xue talked about how they felt frustrated when educating their deaf children to do school work and trying to make them follow school rules in submitting course work. These parents tried to use harsh language to punish their deaf children, however these children seemed not be able to understand this oral punishment. Interestingly, deafness could actually protect these children from punishment, because they could not fully understand the words expressed by parents.

## (140) Parent Xue [line 30-35]

"Sometimes, he made lots of different excuses for not doing schoolwork at home and at school. And his teacher was anger about his excuse each time and I was forced to meet his teacher every time. Therefore, I often swore at him, however, this way did not work for him. He always put my words behind himself when he was ready for play outside. Well, actually, I did not know how to educate him to do schoolwork."

Similar to the above example (data 140), some parents like Parent Xue below (data 141) reported that a disciplined approach could make their deaf children lose interest in learning and loseconfidence.

# (141) Parent Xue [line 59-62]

"I used the stern way to encourage him to do homework. His learning interest became little by little. And then, I realized I sometimes spoke in a tone of command, such as 'What? Playing? It wastes time. You should go ahead for your study. Look slippy!', 'You should play after finishing your homework. Be a good boy!'"

In the following example (data 142), some parents like Parent Xue had not the first idea how to persuade their deaf children to do homework when they wanted to play. These parents tried to use the strategy of learning through play to stimulate learning interest but this did not always work.

# (142) Parent Xue [line 51-56]

"It is not useful as each day grows. My little son is very naughty and hates doing homework after school. When he is bored in doing homework, he often said 'Daddy, I am so tired. I want to play outside for ten minutes and then I could focus on study.', 'Daddy, just to play for ten minutes', 'Daddy, please, please,

please.'. I have no words to say and I am forced to yield to his repetitious request. I have no idea how to stimulate his learning interest."

In another example below (data 143), a few parents like Parent Zhao had experienced barriers in their own learning and this may lead to embarrassment when coaching their deaf children at home. For example, Parent Zhao talked about how he felt guilty about not using his knowledge to teach his deaf daughter in Chinese. So he consulted her daughter's teachers about any academic problems, for example pinyin <sup>16</sup>, and then helped her daughter to develop learning skills.

## (143) Parent Zhao [line 16-21]

"I was disappointed to develop her learning interests. I was fed up with her excuses for not doing homework. Sometimes I refused her request. Sometimes I had no choice but let it to be. My heart melted, when she was crying and weeping. My poor daughter experienced the great pain of studying. It was shame for me to have little opportunity to receive high education. I often asked her teachers about pinyin if I was not sure how to teach her the standard Chinese words at home."

#### Deaf children's short memory

The majority of Chinese hearing parents observed their deaf children were not good at remembering Chinese language. They thought that their deaf children had a short memory to some extent. Some of them (e.g. Parent Mei and Parent Liu) had not the faintest idea how to solve this problem, and this may lead to their lack of confidence in developing their children's memory skill.

In the following example (data 144), some parents like Parent Mei talked about how they found it difficult to foster their deaf children's memory skill after they taught their children the same knowledge many times.

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Pinyin refers to 'a system for romanizing Chinese ideograms in which tones are indicated by diacritics and unaspirated consonants are transcribed as voiced' (http://www.merriam-webster.com/dictionary/pinyin).

## (144) Parent Mei [line 19-21]

"So I had to teach her again and then she could remember the meaning. But I was not sure whether she remembered the words through her mind. Therefore, it is undoubted that she is not good at remembering."

Similar to the above example (data 144), Parent Liu below (data 145) talked about how she found it difficult to teach her deaf son to remember and understand the Chinese phrase many times at home. She also reported that her son's teacher felt helpless to solve the problem of forgetting and remembering.

## (145) Parent Liu [line 108-115]

"I remembered I taught him a Chinese idiom 'san xin er yi' many times. ('san xin er yi' literally means three hearts two thoughts. It can be used to describe someone who spilits his energy between many things rather than focusing on one task at a time.). I taught him how to use a word 'san xin er yi' and explained its meaning at home. The next day, the sentence-making of the same word was examined by his teacher. However, he forgot this meaning. As a result, all classmates except him can answer the question of 'san xin er yi' and also made a sentence. So, his teacher was very angry and I was too impatient to cry."

In the following examples (data 146 and data 147), some parents tried their best to develop a strategy for fostering their deaf children's memory skill.

In order to overcome their deaf children's difficulty in short memory, some parents like Parent Li below (data 146) used the strategy of intensive practice to increase their children's ability to learn Chinese language and remember vocabularies.

## (146) Parent Li [line 219-221]

"It is interesting to find that my daughter is soon learnt and soon forgotten. To overcome this, I often strengthened her language words exercises every day and night."

In another example below (data 147), Parent Liu talked about how she solved the problem of her son's short memory. She further explained that there were two

different approaches to solve this problem. One was to help her son to preview the knowledge earlier than it would be delivered in class next day. The other was to help her son to learn language through outside life and books.

## (147) Parent Liu [line 136-145]

"Actually I taught him Chinese many times, however, I don't know why he could not remember Chinese word well. If I would have my work to do over again, I might ask him to learn Chinese knowledge a year in advance. However, it would cause great stress on him. He had great difficulty in learning language at that time, and he also learned the new Chinese knowledge every day. So it was very hard for him to digest all the information within one day. At home, he spent much time in reviewing the knowledge that learnt from school at the same day, and then he started to preview the new knowledge the next day. This Chinese learning process was quite painful for him. Actually I personally think the language learning is a good way to learn through living and books."

# 5.3.3b Parents' ability to coach their deaf child

Some Chinese hearing parents had ability to coach deaf children, as described in the previous sections. In contrast, some other parents seemed out of their depth in managing their deaf children when coaching at home.

In the following example (data 148), some parents like Parent Xue talked about how they felt incapable of teaching their deaf children when they received the feedback from their children.

### (148) Parent Xue [line 25-27]

"I was so impatient to teach my son when his face is filled with doubts. And this made me feel very incapable. I always thought he was too young to understand outside and this caused me to make a concession to his age."

Similar to the above example (data 148), some parents like Parent Song below (data 149) talked about how they had mixed feelings of guilt and optimism regarding their children's experience in mainstream schools. They also made the excuse of being

tired after work to escape the responsibility of coaching their deaf children at home.

## (149) Parent Song [line 37-38]

"I thought it was enough for him to follow curriculum in his mainstream school. And I was too tired after work to care about him. But, I believed he could do well at his school."

In another example below (data 150), some parents like Parent Mei explained that monitoring their deaf children's academic work was a particularly difficult task. These parents were exhausted when they used the strategy of asking the same questions every day in order to monitor their children's learning progress. However, this repetitive strategy for mentoring their deaf children was not effective, according to Parent Mei's comment.

## (150) Parent Mei [line 10-11] [line 64-67]

"Can I say another matter about the difficulties in coaching her? I don't want to talk about the hard memory". "I was often fed up with caring about her study, and, I developed a habit of asking questions 'What do you learn at school today?', 'What Chinese character does your teacher teach today?' and so on. I nearly acted like a robot with asking her the same questions everyday. This made me to slouch."

Similar to the above example (data 150), some parents like Parent Xue below (data 151) talked about how they felt helpless to teach their deaf children to stay focused on homework instead of cartoons at home, although they understood that studying was a bitter task for their children in the early years. In other words, these parents' efforts to foster their deaf children's learning interests were in vain to some extent.

## (151) Parent Xue [line 38-40]

"I got headache to educate my son to keep focus on homework after school every time. He especially hated homework each time when he was addicted to cartoons at school and home. Well, the study seems a kind of pointlessly tiresome drudgery in his life."

#### 5.3.3c Parenting stress in coaching deaf children

The majority of Chinese hearing parents made every attempt to cope with their own pressures when they coached their deaf children at home. These parents had their own stresses when they tried hard to motivate their deaf children to follow the learning progress in mainstream schools. Some parents feared that their deaf children would fall behind their hearing peers in a mainstream class.

# Pressure from hearing parents themselves

The majority of Chinese hearing parents like Parent Liu (data 152) talked about how they had immense pressure when they worried about their deaf children's academic learning progress. These parents further explained that they must motivate their deaf children to keep learning every day in order to keep following the teachers' lessons. The gap in academic achievement between hearing children and deaf children would grow, if learning was not continuous.

## (152) Parent Liu [line 101-105]

"I coached him in academic knowledge at home following the lecture notes recorded by his teachers. My son must not stop learning knowledge and my son must not lag behind in his class every day. If he lagged behind a little, he could not completely catch up with teacher's lessons next time. It is not an exaggeration [to describe this issue of falling behind]."

Similar to the above example (data 152), some parents like Parent Li below (data 153) talked about how they had the mixed feelings about their deaf child's academic performance at mainstream schools. For example, Parent Li described her feelings of happiness and sadness when she knew why her daughter cried about the exam.

## (153) Parent Li [line 163-168]

"I remembered one thing gave me deep impression. One day when I picked up my daughter after school and found she had tears, her tutor told me what happened. After that I felt happy and sad for my daughter. My daughter prepared for her first exams with great effort, but next day she did not understand the meaning of questions on the exam paper. I thought she cried sadly because she was so worried about the exams...erm...She might think she could be excluded from school because of exams."

In the following example (data 154), some parents like Parent Li talked about how they coped with stress while coaching their deaf children. They further explained that their deaf children's love could motivate them to carry on with coaching and relieve their pressures. For example, Parent Li was touched by her deaf daughter's loving gestures and believed her daughter could excel in speech and lip-reading. With this love, she had been determined to help her daughter to live in a hearing world.

Perhaps, in other words, Parent Li held a negative attitude towards the deaf community and deaf culture.

## (154) Parent Li [line 182-189]

"Sometimes I was so stressful to hold myself in as if weep were a disgrace. My daughter was very clever and she tried to use eye contact to understand why I was crying sadly although she could not say much more words. When I saw the innocence face and shining eye on my daughter, my heart was full of love from my daughter. After I calmed down, I felt so stronger and stronger that I could teach her to be a deaf girl who could speak clear Chinese and could lip read. I also believed that she will be if I could be determined to do that with great responsibility and efforts. I don't want her to be in the stunted lives deprived of language and education."

### Pressure from deaf children's hearing peers

The majority of Chinese hearing parents had their own stresses when they compared their deaf child's academic performance with hearing peers' in a mainstream class.

In the following example (data 155), some parents like Parent Li talked about how they felt guilty about using their deaf children's leisure time to coach their children at home to avoid falling behind hearing peers in a class.

# (155) Parent Li [line 149-151]

"She lost most of time to play outside with peers after school. Sometimes I feel sorry for her leisure time at young age. In order to keep pace with her classmates, good work deserved her most time."

Similar to the above example (data 155), some parents like Parent Mei below(data 156) talked about how they had a mixed feeling when they encouraged their deaf children to do extra homework, in order to achieve good academic performance and compete with hearing peers in a class.

## (156) Parent Mei [line 57-61]

"After school, my little daughter was weary in body and mind almost each day. I had every sympathy for her each time when I saw her tired face. I also understand homework is very important to help her to catch up with her peers. Therefore, I felt very sorry to ask her to do extra homework except her schoolwork for the sake of academic achievement."

In another example below (data 157), some parents like Parent Liu talked about how they had more stresses with their deaf children's increasing age compared with hearing peers' academic performance. For example, Parent Liu explained that she found it more difficult to develop her son's language skill and teach her son Chinese compared with hearing peers' at senior grade of the mainstream school.

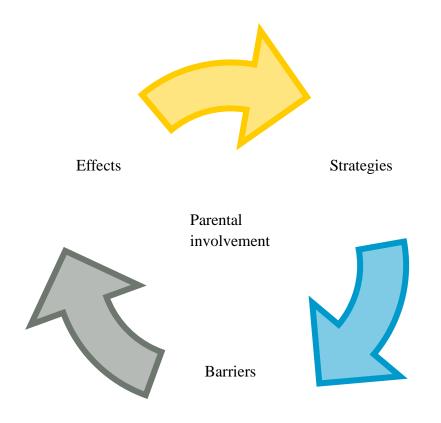
#### (157) Parent Liu [line 111-113]

"[It was very difficult for him to learn the Chinese idiom of four Chinese characters when he was] Around Year 3 or Year 4. Most of his peers were fluent in writing down the sentences consisting of phrases. His Chinese academic was not good enough. For this reason, it is the most difficult for me to teach him Chinese, and other subjects are quite ok for me to teach."

# **Chapter 6 Discussion**

As analyzed in the Findings Chapter, Chinese hearing parents talked about their perceptions and experiences of supporting their deaf child to be ready for and educated at mainstream schools. The analysis of these intensive interviews has identified three major themes as 'the effects of parental involvement', 'parental involvement strategies' and 'the barriers to parental involvement' and these three themes has produced a model of parental involvement theory. To simplify the name of this model of parental involvement, these three themes are presented as 'effects, strategies and barriers' (ESB) model of parental involvement theory. Thus, the ESB model of parental involvement theory is presented in Figure 6.1.

Figure 6.1 A model of parental involvement theory 'effects, strategies, and barriers' (ESB)



As shown in Figure 6.1 above, the main context of a theoretical model of ESB is that the effects of parental involvement (i.e. Chinese hearing parents' attitudes towards deafness, early intervention, school settings and their view of their child with a hearing impairment) exert a strong influence on strategies of parental involvement in the different life stages of raising their deaf child in the early years (i.e. coping with deafness, early intervention strategies, dealing with mainstream schools and coaching deaf children). Also, during this period, Chinese hearing parents face many challenges and difficulties, such as the barriers to fixing deafness and early intervention, mainstream school settings and coaching deaf children. In turn, these barriers to parental involvement may have potential influence over the effects of parental involvement and parental involvement strategies.

## **6.1** The effects of parental involvement

Under the theme of the effects of parental involvement there are five key sub-themes: parents' attitudes towards deafness, parents' attitudes towards early intervention, parents' attitudes towards school settings, parents' views on their child with a hearing impairment, and parents' perspectives on the fundamental principal of coaching deaf children.

#### 6.1.1 Parents' attitudes towards deafness

All Chinese hearing parents in this study had similar responses to deafness when their baby was diagnosed with deafness, such as shock and guilt, and they also struggled to deal with issues of 'normal' behaviour versus deaf behaviour.

#### Parents' response to deafness

It could be argued that Chinese hearing parents' response to deafness is quite similar to the stage model of parental reaction to disability written by Gargiulo (2012). Gargiulo (2012) suggests that parents who have a disabled child experience three stages of response: shock and depression, ambivalence and shame, and acceptance and adjustment. For example, all Chinese hearing parents in this study talked about

feeling shocked by being informed of their baby's deafness and often cried for their baby. This could fit into the first stage of parental reaction to disability – shock and depression (Gargiulo, 2012). The majority of Chinese hearing parents explained that they spent a period struggling with the truth of deafness and felt frustrated and confused about the condition, which could fit into the second stage of parental reaction to disability – ambivalence and shame (Gargiulo, 2012). Some of them eventually accepted their baby's deafness and adjusted their attitudes towards deafness over time. This could fit into the third stage of parental reaction to disability – acceptance and adjustment (Gargiulo, 2012).

In this PhD study, all Chinese hearing parents initially experienced a period of joy when having a new baby, before their baby's deafness was diagnosed. Following this all Chinese hearing parents experienced grieving through their emotional and/or physical response to deafness. This finding agrees with other studies (Densham, 1995; Marschark, 2007; Adams, 1997), which showed that grieving for the child's deafness may be complicated by depression, guilt, anger and so on. This also accords with the study of Beazley and Moore (1998), who argued that when parents faced sudden news of their baby's deafness, they experienced bereavement.

It could be argued that there are three main reasons why Chinese hearing parents experienced months of grieving. Firstly, Chinese hearing parents were not ready for the truth of their child's deafness. Secondly, there were few predictable signs of the child's deafness among hearing families, and these parents lacked knowledge of deafness. Thirdly, Chinese hearing parents had never imagined a deaf baby would be part of their hearing family, and their neighbours and their friends usually had hearing babies in their local area. This finding is consistent with other studies (Kampfe, 2004; Feher-Prout, 2004; Vernon and Wallrabenstein, 2004; Marschark, 2007; Beazley and Moore, 1995) which show that many hearing parents spent a large amount of time coping with stress and going through diverse emotions when they realised their baby was deaf.

The way of Chinese hearing parents' coping with grief was different depending on their attitudes towards their baby's hearing loss. In their interviews, some parents could adjust to a situation of having a deaf baby after a period of grief and became positive and strong. Unlike these parents, a few parents could not accept this truth and became negative and wanted to blame something. This finding supports the idea of Brown *et al* (2006), who found that families experience a period of adjustment to having a new baby and re-adjustment to a new circumstance of raising a deaf baby when their baby is diagnosed with deafness. This also accords with the study of Marschark (2007), which showed that hearing parents find it difficult to adjust to the new family circumstance of having a deaf baby. They tend to take day-to-day responsibilities for their deaf children after a period of denial, grief, depression and guilt.

It was normal for Chinese hearing parents to adapt to grief and/or avoid sadness when they found out that their baby was deaf. Even when Chinese hearing parents learned the causes of the deafness and realised their child's deafness cannot be changed, they still did not understand. From this perspective, these hearing parents felt more grief from the strange and unfamiliar term 'deafness' than the diagnosis itself.

## Parents' understanding of the 'normal' related to deafness

All Chinese hearing parents in their interviews talked about their attitudes towards deafness and hoped their baby or their baby's hearing would be 'normal' in the future. Their understanding of 'normal' varied. Some said that their 'normal' baby disappeared because of deafness, and others said that their child's hearing could appear to be 'normal' through wearing audiology aids. Furthermore, the group of hearing parents felt sad and thought that their 'normal' baby disappeared because of deafness. They had a relatively negative attitude towards deafness, because they thought that they had also lost a 'normal' baby with typical development in cognition, language and social-emotion, not simply focusing on the loss of 'normal' hearing alone. By comparison, the other group of hearing parents were relatively positive, even over-optimistic, because they thought that their baby's hearing losses could be back to the 'normal' through audiology aids. They had a 'normal' baby except for deafness, based on the fact that their baby's hearing was dead but their baby's body was alive. Some of them had a bias for audiology aids because they thought that their deaf children with audiology aids would be equal to children with 'normal' hearing.

Nevertheless, it is worth noting that children with hearing impairments wearing either hearing aids or cochlear implants are not equal a typical child with normal hearing. From this perspective, the concept of 'normal' that the former group understood is likely to be wider than that of the latter to some extent.

It could be argued that there is a slight difference in understanding between the two terms of 'hearing losses' and 'deafness'. According to the author's personal experience, 'hearing losses' focuses on the loss of 'normal' hearing compared with children with typical development, whereas 'deafness' emphasizes that 'normal' hearing is permanently lost, thus affecting children's development of language, cognition and social-emotion. As discussed in Literature Review Chapter section 2.2.3 and section 2.3.3, the term 'hearing impairments' is related to the starting point of the social model of deafness, whereas the term of 'deaf' and 'hard of hearing' originates from the medical model of disability. From this perspective, hearing parents' difficulty in accepting deafness could influence their belief that their 'normal' baby with deafness would be lost.

In this PhD study, most Chinese hearing parents understood that life would never be the same when they received the news of their baby's deafness, as they knew their deaf child would not be a 'normal' child anymore. These hearing parents found it difficult to get over their grief of the loss of 'normal' hearing. This finding is consistent with other studies (Webster, 1994; Beazley and Moore,1995), which suggested that parents' experience of loss for their baby's 'normal' hearing was similar to the reaction to be eavement.

All Chinese hearing parents in their interviews explained that they found it difficult to digest and accept the new concept of deafness. Their understanding of the 'normal' could affect their attitudes towards deafness. They also wished that their deaf child would be a hearing child, no matter how much they accepted deafness. For example, some hearing parents came to understand their baby's deafness and thought that the 'normal' child would not be back in reality. However, they might still have a hidden memory of imagining having a 'normal' baby in their mind. Later, these parents also had to adapt to a new family environment of having a deaf baby, no matter how they viewed the 'normal' issue in relation to deafness. Thus, these Chinese hearing parents

experienced grief and hold unrealistic views of their deaf child when their original imagination of the 'normal' child had to be reframed. This finding is consistent with other studies (Marschark and Hauser, 2012; Henderson and Hendershott, 1991; Bodner-Johnson, 2003) which suggest that the truth of having a deaf baby can change the parents' position from parents of a hearing baby to parents of a deaf child, and alter the family dynamics from normal to the family with a deaf person.

Nevertheless, not all hearing parents have an appropriate understanding of the position of a deaf baby in a family system. In other words, it could be argued that some hearing parents might think a deaf baby can change the whole family, because they start to think of the needs of their deaf baby and try to adjust to this life, such as by learning a new language sign language. However, other hearing parents might think a deaf baby will not affect the whole family, because they want their deaf baby to learn to speak and adjust to the life of a hearing family (Marschark and Hauser, 2012; Henderson and Hendershott, 1991; Bodner-Johnson, 2003).

Correspondingly, it is quite difficult for parents without deaf children and/or professionals without experience of hearing loss in the field of special education to understand why hearing parents had such varied emotions. This is because parents and/or professionals with a 'normal' child can never feel the impact of the loss of 'normal' hearing that would happen to them. They find it hard to personally immerse themselves in a new family environment with a deaf child.

# 6.1.2 Parents' attitudes towards early intervention

During the period of their child's pre-school age, the majority of Chinese hearing parents took their deaf children to listening and speech training centres, and some of them actively created a method of training their deaf child in skills for listening and speech. For example, some hearing parents (e.g. Parent Li) actively fostered their deaf child's language interests through diverse activities such as playing cards and walking in the park, although they knew it was a difficult task to teach their deaf child to speak Chinese. Furthermore, most Chinese hearing parents appreciated how hard it was for their deaf child to learn and acquire oral language in the early years. All Chinese hearing parents never forgot the moment when the first word was

pronounced by their deaf child. Some of them felt very excited and remembered tears.

All Chinese hearing parents sent their deaf child to a listening and speech training centre eventually, when they became aware of the importance of language development and early intervention. In their interviews, they explained that they wanted their deaf children to develop spoken language and to help their children to be educated at mainstream schools. These hearing parents were willing to spend lots of money and time in helping their deaf children to receive language education at listening and speech training centres and to maintain high hopes for their children. Chinese hearing parents often regarded listening and speech training centres as the path to prepare for education in mainstream schools. This finding seems consistent with the study of McCabe (2013), which found that Chinese parents of children with autism perceived early intervention as a way of curing autism or training their child to be ready for mainstream schools.

Chinese hearing parents who knew the concept of the 'three early' theory (i.e. early discover, early diagnosis, and early treatment) often had an awareness of the critical period in children's language development. Furthermore, with the help from staff who worked at listening and speech training centres, Chinese hearing parents developed their understanding from the 'early intervention' within the 'three early' theory to the 'early education' in the early years, including the critical period of language and intelligence development. Therefore, these hearing parents' awareness of the 'three early' theory not only contributed to their positive attitudes towards early intervention, but also increased their high-level involvement in educating their deaf child as early as pre-school age, such as wearing hearing aids/cochlear implants, and training their deaf child in listening and speech skills before going to mainstream schools. This finding supports the idea of Marschark and Hauser (2012), who suggested that parents of deaf children benefit from early intervention programmes as they promote the relationship between parents and their deaf children, leading to more opportunities for deaf children's exposure to a hearing world. This also accords with the study of Hu (2010) which described teachers' perspectives of early childhood inclusion in China, who found that high levels of parental involvement contributes to positive engagement with early childhood inclusive education programmes provided for disabled children.

By comparison, some Chinese hearing parents who were not aware of the importance of early intervention were often passive and negative in raising their deaf child, for example by spoiling their deaf child at home. Furthermore, they could not see any hope for their deaf baby and were forced to give up their original expectation for their child, as they were both unaware of positive deaf role models and lacked access to information about early intervention. As a result, their deaf children may not access education as early as pre-school/school age because these hearing parents had already given up hope for their education. This finding is in agreement with Human Rights Watch (2013), which suggested that parents are viewed as the primary obstacles when they have negative attitudes towards their disabled children's school life. This report also showed that parents would not bring their children with disabilities to school if they felt that their children did not have the capacity to learn skills.

## 6.1.3 Parents' attitudes towards school settings

Most Chinese hearing parents in this PhD study viewed spoken language as a priority and this determined their subsequent choice of mainstream schools for their deaf child. From this perspective, Chinese hearing parents' attitudes towards school settings could be affected by their choice of communication mode, either sign or spoken language. Therefore, parental attitudes towards the language environment and communication mode are a major factor in determining their choice of school settings, either deaf or mainstream schools.

## Parents' attitudes towards language environment and communication mode

Nearly all Chinese hearing parents in their interviews explained that they encouraged their deaf child to learn oral language instead of sign language, no matter how positive their attitude towards sign language was. Some hearing parents did not have a positive attitude towards sign language and they felt reluctant to learn sign language themselves. By comparison, the other hearing parents appreciated the value of sign language and explained that sign language is visual for their deaf children.

These hearing parents viewed sign language as their deaf children's mother language, but they insisted on encouraging their deaf children to learn the spoken language. They also understood their deaf child's difficulty in learning an oral language and delivering its abstract meaning because it is not visual. Therefore, most Chinese hearing parents actively created an oral language environment for their deaf children and coached their language development.

Chinese hearing parents talked about their attitudes towards spoken language learning for a number of reasons. These hearing parents explained that they were hearing themselves and had little opportunity to learn sign language. Their deaf child was the only deaf member of their family, therefore, other relatives might not be keen to learn sign language. There were only a few pre-school institutions with inclusive education programmes that could provide sign language for deaf children aged 0-6. A small number of deaf schools that provided sign language environment recruited deaf children aged over 6 years old. These situations could lead to hearing parents and their deaf child being exposed to spoken learning environments. There were not many deaf communities in China. Quite a lot of hearing parents were not aware of a deaf community before their deaf child became an adult. There were few resources on deaf culture, although this situation changed with the popularity of the Internet and Chinese sign language. Chinese hearing parents would experience barriers to access sign language early in their child's life. In their interviews, most hearing parents explained that the status of spoken language is much more important than that of sign language, because they considered the advantages of language popularity and information avenues from the perspective of a hearing culture. They also set a goal of raising their deaf child at mainstream schools and were proud of their deaf child's achievement when well educated at a mainstream school. This would increase their exclusive exposure to spoken language instead of sign language. A few hearing parents were worried about their deaf child's future in a society surrounded by hearing people if their child did not learn and use the spoken language. They considered sign language to be a possible barrier to developing interaction between deaf and hearing people when no interpreters would be available. Although the use of Chinese sign language is increasing, the numbers of hearing people who use sign language is insufficient to meet every deaf child's needs. This may have resulted in additional pressure being placed on deaf children to learn the spoken

language.

Chinese hearing parents' decision on oral language might not always take their child's opinions into account. Unfortunately deaf children are often too young to make a decision on their communication modes before the age of mainstream schools. Furthermore, deaf children and their hearing parents are often not exposed to sign language, and this affects their interactions and their relationships. Additionally, sign language resources were not widely accessible in China until hearing parents gained access to them through the popularity of the internet in the 2000s, and this clearly impacted on its usage. For this reason, the choice of communication modes were primarily made by Chinese hearing parents of deaf children in this study.

Deaf children may not have the ability to use oral words to clearly express their preferences of language choices when they cannot communicate with their hearing parents via sign language. Similarly, deaf children found it difficult to learn the spoken language and this reinforces the disadvantages of language learning. As a result, deaf children found it hard to communicate with their hearing parents via oral language, so that they may not be able to develop intensive interaction with their parents about their opinions on communication choices. From this perspective, the language environment chosen by hearing parents can be a barrier to developing a deep-seated interaction beyond superficial communication between hearing parents and deaf children. This finding seems to support the idea of Marschark (2007), who suggested that it is often not beneficial for deaf children with severe-profound pre-lingual hearing losses to only learn and use spoken language. He also argued that there is no one correct choice among the multiple options of communication mode that can be applied to all deaf children. However, the importance of sign language cannot be ignored, and its value should not be underestimated (Marschark, 2007).

# Parents' choices of mainstream schools

All Chinese hearing parents in this study aimed for mainstream schools when their deaf child reached primary school age. In this way, they regarded the choice of educational settings as a milestone in their deaf child's schooling trajectory. In their

interviews, they explained that they preferred mainstream schools to deaf schools after struggling with educational options for their deaf child over a period, particularly when they had become committed to the use of spoken language as the main communication mode for their deaf child at the pre-school stage. Furthermore, some Chinese hearing parents considered a number of possible difficulties of mainstream schools in spite of this optimum learning environment provided for their deaf child. For example, some hearing parents in this study were aware that mainstream schools mainly provided a 'normal' learning environment. In other words, lots of mainstream schools only provided a spoken language environment for deaf children, and deaf children must be able to speak Chinese and to use oral language to communicate with hearing peers and hearing teachers if they want to survive in this educational setting. When hearing parents decided on oral language as the mode of communication, they clearly preferred to send their deaf children to mainstream schools.

Chinese hearing parents talked about what influenced their choice of mainstream schools. Firstly, most hearing parents viewed a mainstream school as an ideal place to stimulate their deaf children's oral language development and to provide them with comprehensive educational activities underpinned by all-round skills. Deaf schools in comparison could provide children with sign language learning and diverse educational activities with visual strength. Secondly, some hearing parents often set higher goals for their deaf children and believed that the highest achievement would be to speak Chinese. In this way, they tended to believe that oral language learning would offer the greatest benefit to their deaf children who would then play a full part in society when they reached adulthood. Thirdly, some hearing parents were not only over-optimistic about their capability to support their deaf child in mainstream schools, but also underrated the challenges and difficulties that might arise.

Some Chinese hearing parents would not choose a deaf school, because it only provided sign language learning. Perhaps, these parents thought that sign language learning could interrupt the process of oral language learning and offer an easier and less rewarding option for their child. This finding conflicts with the study of Marschark (2007), which suggested that there is no evidence that sign language

learning can impair the ability to acquire spoken language and that deaf children who do not learn oral language are limited in intelligence of language acquisition skills.

It could be argued that the choices of mainstream settings were primarily made by the hearing parents. In other words, some hearing parents' decision on mainstream schools might not take their deaf child's opinions into account. On the one hand, hearing parents are often regarded as authority figures with the power to make decisions on behalf of their deaf children in the early years. On the other hand, choosing a mainstream school for their deaf children automatically follows a logical train of thought after their decision on oral language. Furthermore, these hearing parents might automatically consider themselves as having their child's best interests at the centre of all their decisions on communication modes and educational settings. However, it was quite hard for hearing parents to judge which option was appropriate for deaf children, especially when their children were too young to contribute to decisions. This finding supports the idea of Gregory and Knight (1998), who showed that parents' decisions on school placements for their deaf children were not as easily made as those with hearing children.

There are two main factors, language environments and school settings, affecting Chinese hearing parents' choice of mainstream schools. In other words, Chinese hearing parents' different attitudes towards language environments and school settings could individually affect their choice of mainstream schools, particularly when the consideration of language choices would take priority over that of school settings. Thus, these parent's attitudes towards inclusive education were not necessarily representative of their deaf child's preferences. However, the decision on educational settings made by hearing parents will not always be beneficial, and it may actually prove to have negative long-term consequences. This is echoed in an example given by Marschark (2007), who found that some deaf adults with excellent speech skills do not use sign language because of the negative impacts of language training in their youth. They recalled being frustrated to have been deprived of a 'normal' childhood and positive self-esteem.

Chinese hearing parents should be careful when choosing educational settings for deaf children, and they should be aware of the challenges of mainstream schools and their deaf child's potential difficulty in learning oral language. Parents should not be fooled by the numbers of deaf children being trained in listening and speech training centres and educated in mainstream schools. Such achievements might not guarantee that their deaf child's success in developing oral language and studying at mainstream schools. As Marschark and Hauser (2012) suggested, it is important to consider all of the options based on sound evidence instead of hypothetical assertions before making decisions and developing action plans.

## 6.1.4 Parents' views on their child with a hearing impairment

Most Chinese hearing parents have a positive attitude towards their deaf child, in spite of their positive or negative attitudes towards deafness. Their attitudes toward deafness did not impact on their judgement of their deaf child's character but may influence their adjustment to varied expectations.

## Parents' attitude towards their deaf child's character

Most Chinese hearing parents talked about their deaf child's personality which was not based on his or her deafness. For example, some parents (e.g. Parent Chen, Parent Li, etc) praised their deaf child as clever and naughty, while other parents (e.g. Parent Chen, Parent Xue, etc) were worried about their deaf child's temper and behaviour. Some of them described their deaf child as a child who cannot hear clearly, rather than a child with hearing impairment. Chinese hearing parents viewed their deaf children as children, not simply focusing on them as deaf children. This finding supports other studies (Young, 1999; McCracken and Sutherland, 1991) which suggested that a deaf child should be viewed as a child first and then as a child with special needs.

In their interviews, some hearing parents (e.g. Parent Li, Parent Zhang, etc) explained that they felt confident in controlling their deaf child's temper. By contrast, others (e.g. Parent Xue, Parent Chen, etc) were more likely to lose the control when they did not know how to meet their deaf children's needs and/or understand what they were saying. This finding is consistent with the study of Young (1999), which showed that some parents perceived their deaf child as a child, while others

experienced a sense of not being able to understand their deaf child's world. This also supports the study of McCracken and Sutherland (1991), which demonstrated that it is easy for parents to forget that their deaf child is the same as any child in every development except where hearing is concerned.

Some hearing parents (e.g. Parent Xue, Parent Chen, etc) did not know how to comfort their deaf children when they were crying. For example, Parent Xue felt angry about their deaf child's behaviour and felt exhausted to deal with their child's bad behaviour, such as breaking toys. Eventually, this parent could not communicate with their deaf child and felt guilty about deafness. This finding supports the idea of Young (1999), which illustrated that parents found it difficult to understand the relationship between childness and deafness, and some felt sad about their child's deafness. This also reinforces the study of McCracken and Sutherland (1991), which suggested that all deaf children have the same emotions as hearing children, such as joy and sadness, and as a result their bad behaviour should not be judged in relation to their deafness.

In addition, Chinese hearing parents' views were based on the fact that each deaf child had a unique character. This finding is supported by Marschark *et al* (2002), who claimed that most psychological tests are based on a large sample of hearing individuals. Many tests on personality and social-adjustment do not meet the criteria of validity and reliability, or address the cultural circumstances of deaf people.

# Parents' expectations for their deaf child

All Chinese hearing parents had different expectations for their deaf child, such as social function, social 'usefulness' or future happiness. More than half the hearing parents (e.g. Parent Li, Parent Zhang, Parent Song, Parent Liu) had high expectations for their child within social function and social 'usefulness', and they hoped that their deaf child would be a person who could find a place in and/or commit to society. In this way, Chinese hearing parents made a great deal of effort so that their deaf child would be well educated at mainstream schools and overcome the difficulties in learning with hearing peers. In turn, they put great pressure on their deaf child. However, some of them had to lower their expectations for their deaf child during

their development. This was particularly in areas such as communicating with hearing peers and competing with peers in a mainstream class. These children would not always benefit from being in the same learning environment as their hearing peers. They also faced great pressures from their hearing parents and hearing peers, although their parents attempted to help them to overcome these difficulties. Additionally, a small number of hearing parents (e.g. Parent Wang, Parent Mei) had more appropriate expectations for their deaf child and wished them to be happy and healthy. This finding is consistent with two academic papers (McCabe, 2008; Wang and Michaels, 2009) which found that most Chinese families expected too much from their disabled child, and this created increased tension.

# 6.1.5 Parents' perspectives on the fundamental principle of coaching deaf children

In this PhD study, almost all Chinese hearing parents had different values and opinions on educating and coaching their deaf child. For example, Parent Li further explained that the fundamental principle of coaching deaf children is to respect their nature and foster good habits to develop skills. Some of them (e.g Parent Li) talked about the importance of responsibility and confidence in raising their deaf children. This finding is consistent with Marschark's study (2007), which suggested that hearing parents of deaf children should be as confident as deaf parents of deaf children, although this may require hearing parents to pay more attention to their deaf child's personality development.

The number of mothers (n=6) who took part in the current research is slightly larger than that of fathers (n=4). Only one couple of parents took part in this study. Mothers were more involved in raising their deaf child than fathers in this study. Marschark (2007)also found that mothers tended to take greater responsibility for their deaf children, not only in developing their child's skills in language and social-emotion, but also in looking after them in day-to-day life. However, Chinese hearing fathers were often earning money for the family, which is particularlyrelevant increased financial burdens from hearing aids/cochlear implants, batteries, and tuition from rehabilitation services and schools and so on. This finding seems to corroborate Holroyd's work (2003), which found that Chinese fathers of disabled children were

often absent when Chinese mothers took part in research studies, and some of those fathers never took their child outside or on holiday.

#### 6.1.6 Overall conclusion on the theme of the effects of parental involvement

Chinese hearing parents who had a positive attitude towards their child's deafness were likely to seek available resources and make use of them to create an appropriate educational environment for their deaf child. In this way, they often responded to issues quickly and positively. They made every effort to overcome barriers and make attempts to find solutions to surmount obstacles, in order to support their deaf child in compulsory education at mainstream schools. This finding is similar to Harr (2000), who suggested that parental attitudes, expectations and support can facilitate a deaf child's successful achievement and academic performance.

## **6.2 Parental involvement strategies**

Under the theme of parental involvement strategies, there are four key sub-themes: coping with deafness, early intervention strategies, dealing with mainstream schools and coaching deaf children.

# 6.2.1 Coping with deafness

Chinese hearing parents mainly used two ways of detecting children's deafness through hospital discovery and/or parental discovery, and then spent a large amount of time and money in searching for a cure for deafness through either doctor-help or self-help. Furthermore, these parents from both types of discovery had different emotional reactions to their child's deafness. This impacted both on their involvement in coping with deafness and the subsequent process of early intervention.

## The diagnosis of deafness

Chinese hearing parents explained that they eventually learned of their baby's deafness in the hospital through two main methods either from doctors and/or their

own discovery. More than half the hearing parents (e.g. Parent Zhang, Parent Liu, Parent Li, Parent Wang, etc) learned of their baby's deafness in the hospital when their baby had high fever, organ infection, earache and so on. Some babies were given an injection to prevent their illness from rapidly deteriorating. The injection was often made of ototoxic antibiotics which would negatively affect human hearing, and the drugs were gentamycin, kanamycin, streptomycin and so forth. Deafness in the remaining babies was caused by unknown factors. This finding is consistent with Callaway's work (2000), which showed that the majority of babies' deafness was caused by the injection of aminoglycoside antibiotics given to cure neonatal jaundice, fever or a cold. Less than half the hearing parents (e.g. Parent Chen, Parent Zhang, etc) unwittingly discovered the deafness at home having observed their child's unusual behavioural response to loud sounds. This led to uncertainty over their child's hearing status, which led them to take their child to hospital for a check-up. These parents realized their child was deaf after noticing their child's changing behaviour. For example, two hearing parents (e.g. Parent Chen, Parent Zhang) explained that they believed the Chinese superstition that a wise man often starts speaking at a later age, so they delayed the diagnosis of deafness. Chinese hearing parents convinced themselves even when concerned that everything would be okay. Later, they sensed that something was wrong and only then they did take their baby to hospital. They did not want to believe that there was a problem until deafness diagnosis from multiple hospitals was given. This finding corroborates the work of Callaway (2000), which showed that the majority of parents suspected that their child was deaf because of their delay in responding to sounds or late speech development. It also reinforces Marschark's work (2007), which found that parents appeared to be afraid to find out the truth when they felt something was wrong with their child or were informed by friends and relatives of their concern about deafness. They tried to comfort themselves with the thought that they were just nervous as new parents, and were 1 ignorant of early hearing loss (Marschark, 2007). Moreover, this finding is supported by Boison (1987), who discussed that the reasons for the delay in seeking diagnosis by parents are that some parents often make excuses, for example their children are late developers and will speak at a later age. Some parents also believe in superstition, for example the masters say later talkers will become famous.

In this study, one parent's discovery was more complex compared to other parents.

Parent Zhang explained how she felt frustrated when her child was not quickly diagnosed as deaf in the hospitals. Parent Zhang reported that her baby was not diagnosed with deafness at an early age in hospital but she inadvertently discovered her baby's hearing problem at home. She visited doctors in a community-based hospital but she was told that her child was 'normal'. Later, she travelled to a city hospital to check her baby's hearing and her child's deafness diagnosis was confirmed. This finding is corroborated by previous research (Densham, 1995; Schlesinger and Meadow, 1972) which found that parents often have increasing anxiety, anger and frustration when their child is checked in multiple hospitals. Marschark (2007) also showed that parents who live near a city hospital with an audiology service are likely to get a prompt diagnosis of deafness compared to those who live in rural areas or far from city hospitals.

Furthermore, some Chinese hearing parents explained that their child's hearing loss was diagnosed at an older age, probably when the baby was 2 or 3 years old, whereas children who were diagnosed as deaf in hospitals were often very young, probably around 1 year old or earlier. This finding is reinforced by Williams and Darbyshire (1982), which demonstrated that the average delay between parents' first suspicion and final diagnosis of hearing impairment is about 14 months, and the child's profound hearing loss is diagnosed at an average age of 4 years, ranging from 11 months to 7 years.

Some Chinese hearing parents (e.g. Parent Zhang, Parent Chen) who discovered deafness themselves were actively involved in further examining their baby's deafness, such as by clapping hands behind their child and/or making noises at home. These parents were concerned about their child's potential hearing problems after observing their child's unusual behaviour. They became suspicious and continued observing their child for a long period before they felt the need to take their baby to hospital. This finding is in an agreement with other studies (Densham, 1995; Harris, 1978) which found that parents' suspicion that there was something wrong with their child often continued for several months before a deafness diagnosis occurred. Parents and families were always anxious and uncertain during this period.

Some Chinese hearing parents who were given the diagnosis in hospital experienced

less doubt than other hearing parents who discovered their child's deafness themselves (e.g. Parent Li, Parent Wang, Parent Zhang, Parent Liu). The technology of the hospital was used to eliminate any doubt. However, the level of shock in parents who were told by doctors was higher compared to those who used self discovery. These parents were forced to quickly accept the diagnosis of their baby's deafness. They did not have the opportunity to gradually learn the concept of deafness which reduces the shock of diagnosis. On the contrary, other parents (e.g. Parent Zhang, Parent Chen) who identified their baby's hearing problem at home felt brief shock, but this then reduced when they tried to convince themselves that their child might just develop speech slowly. This finding of late discovery in deafness supports the work of Marschark (2007), who suggested that deaf children might not be easily discovered at home at a very young age if they were sensitive to vibration and pressure change caused by loud sounds, for example clapping behind their head or slamming doors. A possible explanation is that some deaf babies can make use of visual and/or tactile clues to respond to hearing parents' instruction, reducing the likelihood of a hearing problem being picked up. If children's hearing loss is profound, they tend to make use of visual, tactile, olfactory and gustatory sensation to explore the world and interact with different people. They are also inclined to react to loud sounds that are displayed within their sense range of sight and/or touch at home. This results in hearing parents' belief that their child's hearing status is not a problem at an early age (Marschark, 2007).

It could be argued that Chinese hearing parents' personal discovery prior to a hospital diagnosis could act as a buffer against the impact. However, this may come late for these parents to develop their baby's language skills. Such a late discovery by parents themselves affects their involvement in developing their baby's language skills and social interaction during the critical period between 0 and 3 years old.

Some parents (e.g. Parent Zhang, Parent Li) who knew of their baby's deafness in hospitals were relatively inactively involved in further investigations. The sudden news was often a significant blow to them. Hearing the diagnosis in this way often left them unable to act. Unlike these parents, other parents (e.g. Parent Zhang) became slowly aware during parenting, although they still tended to reject the deafness. They reflected on the causes of deafness, and attempted to find a solution

to their child's psychological problems. This approach gives them more time to think about their child's deafness and this would impact on their subsequent attitudes. This finding supports the idea of Densham (1995), who showed that some parents felt relief after receiving the diagnosis, whereas other parents perceived the diagnosis as having a devastating effect on their lives.

Chinese hearing parents did not take their child to hospital for a check-up until their child's development was no longer on a par with his or her hearing peers. They began to recognise their children's problems when they were unable to say more complex words or form complete sentences at a late age. They were concerned that there was something wrong with their baby, although they were reluctant to admit that their baby had a hearing or psychological problem (e.g. mental health, autism, learning disability, etc.). Later, when they received the diagnosis from the doctors, they were upset, but not as shocked as when they discovered their baby's hearing problem. This finding is in agreement with the work of Marschark (2007), who indicated that the deaf child of hearing parents is typically diagnosed at the age of about 30 months, or even older, without the support of newborn hearing screening. In turn, such a late discovery of deafness can affect hearing parents' emotional reactions. These parents often come to realise that their child's behaviour and performance is lagging behind traditional development, and this can create a negative emotional reaction to deafness (Marschark, 2007).

Some Chinese hearing parents who were uncertain about their baby's hearing problems they reassured themselves that the problems were not significant because their child could make some oral sounds, like 'a-a-a' or 'a-ya-a-ya'. Later, their baby's speech developed a little, but he or she was not able to make a sentence, compared to hearing children who were able to make simple sentences with two or three words at the age of 2 and could ask questions beginning with 'what', 'who' and 'where' at the age of 3 (Sheridan, 2008). These hearing parents felt that there must be something wrong with their baby and eventually checked the hearing problems at hospital. Thus, these hearing parents found it difficult to recognize the early onset of their child's deafness at home without overt signals of potential factors leading to deafness. This finding supports the study of (Harris, 1978), who pointed out that hearing parents often do not notice that their deaf children do not receive information,

because they make noises like a normal child and their hearing loss is invisible.

Unfortunately, Chinese hearing parents did not have an opportunity to access the universal newborn hearing screening (UNHS) in their locality since this new technology has only been widely used in city hospitals throughout China since 2007. Thus, underdeveloped medical technology for deafness diagnosis and inadequate information about deafness in the past has led to late discovery of deafness. This finding corroborates the study of Liu and Raver (2011), which showed that UNHS was not available in China until the technology was introduced in 1999, and this often led to a delay in the diagnosis of hearing loss. The technology of UNHS would be useful for parents to quickly know their baby' hearing status. This suggestion is consistent with Marschark's work (2007), which showed that newborn hearing screening programmes might contribute to deafness awareness in society and minimize complaints from parents. From this perspective, it could be claimed that the present generation of parents might be more aware of a deafness diagnosis than their predecessors.

In summary, Chinese hearing parents felt under pressure when faced with a late deaf diagnosis and the resultant impact on their emotional reactions to deafness and expectations for their deaf child. This pressure further influences their involvement in deaf awareness training, and their recognition of the importance of early intervention and early childhood education.

### The search for a cure for deafness

After their child was diagnosed with deafness, most Chinese hearing parents spent a large amount of time and money searching for a cure or treatment for the condition. There were two different ways in which hearing parents sought help, self-help or professional-help. The group using self-help is more likely to increasingly gain deaf awareness during the period of searching, because they had more opportunities to access information about deafness and a fuller range of exposure to deaf knowledge. However, it is unclear whether the group using professional-help tended to have less active involvement than the group using self-help because of the limited access to the internet in the 1980s and early-mid 1990s.

Both groups of Chinese hearing parents realized their efforts on finding a cure for deafness were fruitless after a long period of searching. They were disappointed to stopped seeking a cure. A few parents persevered because they found it difficult to accept their child's deafness. This finding is consistent with Callaway's work (2000), which found that Chinese parents made great efforts to solve the problem of their children's deafness. They persisted in visiting more hospitals to find the best and most advanced medicine for curing deafness in Beijing and Shanghai. Hospitals in these cities had high reputations, but these parents were informed of impossibility of curing deafness (Callaway, 2000). Likewise, McCabe (2013) found that Chinese parents of children with autism spent large amounts of money and time on early intervention services, because they believed that earlier intervention would cure their child's condition.

The interview data discusses potential reasons for parents' motivation to find a cure for deafness: firstly, hearing parents might want their deaf child to be like a hearing child (Luterman, 1987, cited in Marschark *et al*, 2002); secondly, most hearing parents have a strong desire to educate their deaf children to listen and speak like a hearing family (Marschark and Hauser, 2012); thirdly, hearing parents might feel less capacity to deal with their child's deafness or might be at a loss as to how to meet the needs of their deaf child (Marschark, 2007); and fourthly, hearing parents might feel great pressure in a local community surrounded by hearing people.

Chinese hearing parents explained that they felt disappointed that they had wasted time on searching for a cure, instead of diverting their attention to their deaf children's cognitive and language development in the early years. They were not aware of the importance of their involvement in early intervention and early education is more essential than a cure for their children's deafness. This finding is in agreement with the study of Callaway (2000), which found that Chinese parents strongly believed that there should be a successful treatment for deafness, overlooking the cost and potential successes of such approaches.

Delays in seeking help meant that Chinese hearing parents lacked awareness of the critical period in the child's early milestone developments. This results in delayed

engagement in early intervention and early childhood education, such as appropriate fitting of hearing aids and/or cochlear implants, speech and listening training and so on. In other words, hearing parents who knew the importance of language development in the early stages could contribute positively to the development of their deaf child's skills in communication.

Information available for parents with deaf children had improved since the internet has become a predominant part of mass media. The present generation of hearing parents will be more aware of the importance of early childhood education and child development compared to the previous generation, because more information about deafness is available on the internet, and listening and speech training centres have spread the importance of early intervention.

#### **6.2.2** Early intervention strategies

All Chinese hearing parents in this study not only encouraged their deaf children to wear hearing aids and/or cochlear implants, but also to attend speech and listening training centres to develop their language skills at a pre-school age. most Chinese hearing parents made use of the two the indispensable strategies of 'hardware' (e.g. hearing aids, cochlear implants) and 'software' (e.g. speech and listening training), in order to support their deaf child in early intervention and early childhood education.

#### 'Hardware' strategies: hearing aids and cochlear implants

On the subject of 'hardware' strategies (e.g. hearing aids and/or cochlear implants), Chinese hearing parents of deaf children can be categorized into two groups according to the era of the availability of cochlear implants in China. One group is hearing parents of children born before the popularization of cochlear implants in the 2000s, and the other group whose children born after their introduction. It could be argued that the former group had only one choice- hearing aids, and they had little exposure to deafness knowledge because of the inadequate available resources in the 1980s and early-mid 1990s. By contrast, the latter group had two choices of hearing aids and cochlear implants. They preferred cochlear implants for their children when diagnosed with profound hearing loss.

Furthermore, it could be claimed that both groups of hearing parents have different emotional responses to their choice within the 'hardware' strategies. On the one hand, the group of hearing parents whose children were born before 2000s are likely to feel frustrated by attempts to fix the problem of their child's deafness due to the limited technology available. In contrast, the other group seemed to have a wide choice in either using hearing aids or cochlear implants. There was a debate among Chinese hearing parents on whether cochlear implants were perceived as everything or nothing. In other words, they were inclined to be confused about the innate character of the cochlear implants, which leads to parents' debating whether the function of the cochlear implant is close to human hearing.

In their interviews, half the group of hearing parents who chose cochlear implants viewed the technology as a solution for their deaf children, whereas the rest of this group did not think cochlear implants have particularly changed their child's life. This finding is supported by Callaway (2000), who found that parents were often left with unrealistic expectations because of the lack of information about the advantages and disadvantages of hearing aids, leading to their increasing disappointment in the function of the technology, particularly for parents of profoundly deaf children. Marschark and Hauser (2012) also showed that the benefits of cochlear implants are not denied to children with hearing impairments. Cochlear implants can improve skills in listening and speaking, language and academia, leading to an incomplete perception that they are viewed as a cure for deafness or they can turn deaf children into hearing children.

It is acknowledged that hearing aids are not rejected by the deaf community, while cochlear implants might not be welcomed by these groups. Interestingly, most hearing parents did not consider the viewpoint of the deaf community when they decided on the use of cochlear implants for their deaf child. This finding corroborates those of previous research (Ladd, 2003; Marschark and Hauser, 2012; Lane *et al*, 1996), which found that deaf people who belong to the deaf community are concerned that cochlear implants might deprive deaf children of opportunities to develop deaf identity and choose their own communication mode.

#### 'Software' strategies: speech and listening training

With regard to 'software' strategies (e.g. listening and speech training), nearly all Chinese hearing parents had strong desire to train their child in listening and speech skills. All Chinese hearing parents used such strategies and sent their deaf children to a training centre, no matter how late they became aware of the importance of early intervention. Furthermore, some Chinese hearing parents (e.g. Parent Li, Parent Chen, Parent Zhang) were determined to accompany their deaf child to the listening and speech training centres, no matter how far they were from their home or how expensive the rehabilitation training services were. This finding is supported by Liu and Raver (2011), which showed that rehabilitation centres for deaf children play an important role in not only providing training in speech and listening for children with hearing impairments and their families, but also offering training for parents to support their deaf child's development in oral language, in order to prevent delayed language.

Most Chinese hearing parents sent their children to listening and speech training centres each day, and coached them afterwards at home, in pronunciation practice, Chinese word expression and listening skills. These parents mainly used two methods to promote skills in listening and speech through either formal help or self-help.

Although not all hearing parents had attended the speech and listening training themselves, more than half (e.g. Parent Li, Parent Chen, Parent Zhang) consulted rehabilitation teachers and professionals about language learning, attended class observations in speech and listening at the training centre, attended short training for parents, or read books and materials about listening and speech training. Some parents also explored the strategies of training their deaf child's skills in speech and listening and created a tool for developing their child's language skills by themselves. It could be argued that most Chinese hearing parents became an "expert" after training their deaf child in language development, although they were not professionals in the field of linguistics.

Chinese hearing parents not only constantly encouraged their deaf child to learn

language, but also fostered their interest in language learning through leisure activities, such as inviting people to visit at home or taking their child to the park. They mainly talked about their strategies for developing speech skill, and only a few explained how they taught listening skills. Only one hearing parent (Parent Wang) recognised the importance of listening skills without lip-reading. Furthermore, most Chinese hearing parents took it for granted that if deaf children could lip-read well they would be able to communicate with hearing people in society. However, lip-reading skills are not equal to listening skills for every deaf child. Speech training with lip-reading might not benefit some deaf children. This finding is supported by Marschark and Hauser (2012), who pointed out that lip-reading is a difficult and tiring task filled with errors, depending on the characteristics of the speaker and his or her familiarity with the context. A deaf adult can only understand approximately 30% of speech via lip-reading alone without additional clues of context background (Marschark and Hauser, 2012).

Chinese hearing parents of deaf children could be categorised into two groups, parents of children born before 2001 and parents of children born after 2001. The former group had only one choice to send their deaf child to rehabilitation centres, such as hearing and speech training centres. The latter group fortunately could choose between hearing and speech training centres and a limited number of kindergartens with inclusive education programmes. Furthermore, of hearing parents who were given two choices, only one parent (Parent Mei) chose to send their hearing-impaired child to a kindergarten after they had been well trained in language development at training centres for at least one or two years. The remainder chose to go to hearing and speech training centres. This finding is consistent with the study of Corter *et al* (2006), who explained that the amount of parental investment in early childhood education would determine the achievement of their disabled child's development in academia to a large extent.

It could be argued that the present generation of hearing parents is likely to have more awareness of the importance of early intervention strategies than their predecessors. Some possible explanations for this are that: firstly, more and more information about deafness is available on the internet in China after the popularization of computers and the internet in the 2000s; secondly, early

intervention and pre-school inclusive education has developed in big cities like Beijing and Shanghai since 2001; thirdly, there are now a small amount of parent-to-parent groups or non-governmental organizations (NGOs) for parental education. Specifically, China Disabled Person's Federation (CDPF) established a formal parent-to-parent group for those who have children with hearing impairments in Beijing in 2009. These findings seem to be consistent with other studies (Hu and Yang, 2013; McCabe, 2003; Jackson *et al*, 2010) which found that early intervention, pre-school inclusion and parent-to-parent groups are the three key factors in facilitating disabled children's early development in language and cognition during the critical period between 0 and3 years old. These factors can contribute to high levels of parental involvement in their child's inclusive education and the subsequent partnership between school and home.

#### **6.2.3** Dealing with mainstream schools

When the age of children with hearing impairments reached primary school enrolment, Chinese hearing parents started seeking available resources and strategies to access mainstream schools and built a partnership with teachers who worked at the school.

#### The access to mainstream schools

When Chinese hearing parents chose a mainstream school for their deaf child, they would identify all available resources to facilitate enrolment.

Some Chinese hearing parents (e.g. Parent Zhang, Parent Liu) knew teachers and/or head teachers through their friend's recommendation. This social network helped their deaf child to gain admission. Through this route, their children with hearing impairments were enrolled without having to pass school enrolment examinations. These parents may well experience less stress than others without the network. For those who did not have the advantage of friend's recommendation, they supported their deaf children to gain access to mainstream schools and pass school enrolment examinations. Therefore, regardless of whether there were set by entrance examinations or not, most Chinese hearing parents dealt with issues of their deaf

children's readiness for a mainstream school. This finding is supported by Lau *et al* (2011), who found that activities of parental involvement in their child's readiness for schools are multidimensional in China, and included physical development, social and emotional development, cognitive development and language development.

These findings may be explained by a number of different reasons: firstly, hearing parents might be aware that the challenge of supervising their deaf child's learning at home while at a mainstream school is much greater than that required during the pre-school stage; secondly, hearing parents might know that access to mainstream schools is a starting point for the transition from the home environment and/or a learning environment with a group of deaf children at a listening and speech training centre to a wider learning environment with peers without disabilities in a mainstream class; thirdly, hearing parents could acknowledge that the curriculum of mainstream school is completely different from that of listening and speech training centres and/or kindergartens with inclusive education programmes.

#### Parents' relationship with teachers

After the deaf child was successfully enrolled at a mainstream school, Chinese hearing parents not only made attempts to build a good relationship with teachers, but also appreciated the mainstream school teachers' help and kind-heartedness.

Most Chinese hearing parents (e.g. Parent Li, Parent Zhang, Parent Zhao, Parent Chen, Parent Liu) talked about the importance of creating a dynamic relationship with teachers, maintaining active contact with teachers, asking for feedback on progress and coaching their deaf child when doing school work at home. This leads to more positive parental involvement in the home-school partnership which could facilitate the child's development in and out of school. These parents (e.g. Parent Liu, Parent Zhao) not only actively created a good rapport with teachers in order to contribute to their understanding of deafness, but also promoted and kept a good relationship between the teachers and the deaf child in class. They actively contacted the teachers and discussed their deaf child's needs, in turn, the teachers also gained the deafness knowledge from these parents. This finding is in agreement with Harr

(2000), who found that parents were inevitably more aware of their deaf children's special needs. Parental involvement could facilitate better services for deaf children at school, offer suggestions to assist accommodating their children, and contribute to the school's knowledge and understanding of deafness. In their interviews, the majority of Chinese hearing parents (e.g. Parent Li, Parent Zhang, Parent Zhao) gave positive comments about teachers' efforts to help their deaf child to integrate into a mainstream class and also appreciated the teachers' input and warm hearts. This finding is consistent with other studies (Xu, 2012; Deng and Holdsworth, 2007), which found that teachers' offer of help is associated with empathy and compassion. These findings reaffirm Harr's work (2000) which reported that the home-school relationship can promote understanding of deaf children's development and learning difficulties.

Most Chinese hearing parents (e.g. Parent Li, Parent Zhang, Parent Liu, Parent Zhao) frequently visited teachers at schools, telephoned teachers and kept diaries with teachers as common approaches to creating a dynamic relationship. Through diary communication, they remained to be informed of the subjects that their deaf child learned at school. They could then facilitate a more effective home coaching and build a good relationship with the teachers. This finding is consistent with the study of Harr (2000), who found that school reports, school meetings and telephone calls are the most common ways of maintaining a positive home-school partnership.

Some parents (e.g. Parent Zhang, Parent Zhao) felt empowered to meet and know the responsible teachers at mainstream schools. However, this finding is conflict with the study of Harr (2000), which reported that too close a relationship might diminish teachers' professional capacity and school authority.

Chinese hearing parents like most parents showed respect for their deaf child's teachers and viewed them as authority figures in knowledge transmission. They also had some concern that their deaf child accepted everything that their teacher said without question, as they saw them as a figure of academic authority. Some parents talked about their difficulties in coaching at home when their child refused to listen to parents or take direction. In this way, it was not easy for Chinese hearing parents to coach their deaf child at home, because their deaf child had a strong belief that

knowledge taught by their teachers at school was true without doubt. In other words, deaf children were likely to view their teachers as an authority figure in the learning environment, no matter how much knowledge was taught by their hearing parents at home, which may lead to difficulty in perceiving hearing parents as being able to support children's learning.

This finding supports previous research (Chan and Chan, 2005; Yau *et al*, 2009), which demonstrated that the teachers' role is highly respected in transmitting knowledge and teachers are more likely to have authority than parents at school, on the grounds that children evaluate authority figures and make their own judgements according to the nature of events (whether it is moral, conventional or personal) and the environment (in public, in school or at home). This finding is also consistent with other studies (Pang and Richey, 2006; Chan and Chan, 2005), which found that Confucian ideologies emphasize unquestioning respect for professionals and educators, as it is deemed to be impolite to challenge a teacher's ideas.

In comparison with children with typical development, those with hearing impairments seemed to be more compliant to teachers than their parents when they were educated at mainstream primary schools around the age of eight or nine. Deaf children respected their teachers' authority for a number of reasons. Firstly, children are encouraged to develop cooperative and compliant behaviours in Chinese community, because achieving and maintaining social expectations is important within the values of collectivism that underpin Chinese society (Chen *et al*, 2003). Secondly, children may view school as symbolic of the social community, and perceive family as an individual unit of society, and the gap between those different outlooks could lead to their greater compliance within the former. Thirdly, children obey the commands of teachers more than those of parents when they are at the age of four or five and become capable of judging whether teachers or parents are the main authority figure with increasing age (Yau *et al*, 2009). Fourthly, parents are deemed as having more authority outside the home than teachers have outside of school (Yau *et al*, 2009).

Interestingly, none of Chinese hearing parents discussed teachers' qualifications or their ability to teach their deaf children. Chinese hearing parents hold few negative views of teachers who are highly respected in Chinese society because knowledge is mainly passed from teachers to students at schools (Chan and Chan, 2005). Families of children with disabilities respect children's teachers and regard professionals and educators as authorities within the values of Confucianism. They may be reluctant to express concerns about their disabled child and offer their opinions on educators and professionals (Pang and Richey, 2006). Chinese parents of disabled children are likely to be content and grateful when their child enters a mainstream school, and tend not to ask for extra help or care (Human Rights Watch, 2013). Chinese parents of disabled children may perceive themselves as being at the bottom of the social hierarchy, because they think their children with disabilities are likely to bring shame on themselves and their families (Holroyd, 2003). These parents know that it is not appropriate to question teachers on their educational background, family status and so on.

#### **6.2.4** Coaching deaf children

In this study, most Chinese hearing parents spent significant amounts of time and money in coaching their deaf children at home and were highly motivated to devote themselves to their children's learning. These hearing parents' high motivation in home coaching is consistent with the study of Lau *et al* (2011), who found that Chinese parents tend to carry out more home-based than school-based involvement when educating their only child in the early years. Lei and Deng (2007) also suggested that the quality of education that children with disabilities receive is contingent upon home education provided by their parents. Therefore, to a large extent, parents' involvement and their family values can predict deaf children's success levels of studying at mainstream schools. Better inclusive education provided for children with hearing impairments is primarily influenced by parental involvement in home coaching.

Strategies for home coaching are varied and diverse, and contingent on characteristics of the family environment and values. Nearly all Chinese hearing parents in this study used different 'tried and tested' strategies for home coaching to teach their deaf children in different learning contexts, such as moral education, academic learning, social-emotional skills and other educational activities. Some

parents were able to identify appropriate strategies in home coaching in visual subjects such as maths and science, Chinese subject and other educational activities (e.g. learning from play, developing learning interests and time management). Parental involvement in home coaching corroborates previous research (Calderon, 2000; Brown *et al*, 2006; Marschark *et al*, 2002) which found that not only parental involvement in deaf children's school-based education can contribute to better academic and language development, but also family interaction can positively influence children's literacy and social-emotional development. Parental involvement in home coaching has a positive impact on their deaf child's academic performance at school and at home.

When it comes to subject coaching, some hearing parents (e.g. Parent Li, Parent Zhang, Parent Liu) explained that they found it easy and relaxing to teach and coach their deaf child in visual subjects, such as maths and science. This finding is at odds with the work of Marschark and Hauser (2012), which showed that deaf children often have difficulty in understanding numbers and quantitative concepts, as maths requires skills of reasoning and problem-solving. There are three possible reasons for this: firstly, deaf children have a delay in language development and a relative lack of exposure to the outside world; secondly, deaf students often lack confidence and motivation in learning maths; thirdly, their parents may have had fewer opportunities to communicate with them on numerical concepts and maths vocabulary (Marschark and Hauser, 2012).

Some hearing parents (e.g. Parent Li, Parent Zhang) found it difficult and frustrating to teach conceptual subjects, such as Chinese subject, moral education and social-emotional education. This finding is consistent with the study of Marschark and Hauser (2012), which found that shared reading with parents and simplified reading materials can facilitate deaf children's literacy development.

Mainstream schools are an important aspect within hearing society. Inevitably barriers for children with hearing impairments arise, for example, the gap between deaf and hearing children's communication and social-emotional skills. Furthermore, deaf children's poor ability in language can affect their development in communication skills and inhibit their understanding of social rules.

Chinese hearing parents talked about how they found it difficult to identify a proper strategy for home coaching to develop their deaf child's moral and social-emotional skills. This finding is supported by other research (Calderon, 2000; DesJardin, 2007), which found that development in language and social-emotional skills is strongly related to improved parental communication, particularly mother-child interaction. Furthermore.

Some parents (e.g. Parent Mei, Parent Xue) reported that they understood their deaf child's behaviour in some situations, however, their child's behaviour may be misunderstood by hearing peers and/or mainstream school staff in other situations. In other words, deaf children's behaviour is likely to be easily misunderstood at a mainstream school. Thus, these parents had no idea how to teach their child to express their needs using appropriate oral language. This finding supports the idea of Roush *et al* (2004), who found that children with hearing impairments faced obstacles caused by factors beyond language skills in social development.

It could be argued that the deaf child might be afraid to develop social skills, and thus avoided making friends. Great pressure from academia could inhibit deaf children's social-emotional skills and leave less time for playing with hearing peers when growing up in either a high or a middle school.

Chinese hearing parents knew that their deaf children often dropped behind hearing peers in cognitive and social development, especially in social reasoning and social judgement skills. With hearing impairments, these children's capacity to receive information is much reduced. Deaf children appeared to lack social experiences that require the fuller range of abilities needed for listening to and seeing basic social interactions. This finding agrees with the study of Marschark (2007), who discussed that hearing parents found it difficult to explain to their deaf children what was going on in a social context, how to interact with people in a community, and why an argument and/or a conflict was occurring. Instead, they tended to simplify and/or avoid complex language which provided less information than what was actually required. This reduced interaction could directly affect deaf children's understanding of social rules and their ability to learn social and problem-solving skills (Marschark, 2007). In comparison, hearing parents seemed to be less confident than deaf parents

in adapting to the communication needs and social-emotional development of their deaf children (Marschark, 2007).

It could be argued that the channel of developing learning skills might be different from that of social skills for children with hearing impairments. Furthermore, deaf children might be less flexible in transferring skills from academia to wider society. Children with hearing impairments may not be particularly capable of connecting theoretical knowledge learned in mainstream schools to world outside. Inflexibility in behaving and dealing with matters in a hearing society may ensue.

Chinese hearing parents were overwhelmed and confused when exploring home coaching strategies for their deaf children's moral education and social-emotional skills. Moral education and social-emotional skills were based on conceptual subjects with abstract language. As these subjects were not visual, deaf children found it difficult to learn. Furthermore, moral education and social-emotional skills were not easily taught and coached through books and school curricula, so they were more likely to be learnt through the word outside school. Hearing impairments or loss could block deaf children's access to many aspects of daily life. Parents' difficulties in coaching social-emotional skills, social reasoning skills and culture value judgements could increase if their ideology would differ from contemporary society. The range of experiences and perspectives that children with hearing impairments have is relatively narrow compared to hearing children or children without disabilities. Deaf children could develop a misunderstanding of social rules and/or lack an understanding of social interaction compared to children with typical development, as they depended on visual information to develop an epistemology of the world. These deaf children had difficulties in exposing themselves to social language, and their parents struggled to provide full insights into the world for deaf children (Marschark et al, 2002; Marschark and Hauser, 2012; Marschark, 2007). Hearing parents were frustrated when choosing between sign and spoken language as the main communication mode. Their lack of competence in communicating with their pre-school aged deaf children could be a barrier to the development of social language (Marschark et al, 2002; Marschark, 2007). Hearing parents might lack awareness of the importance of fostering their deaf child's thinking ability. They might not realize that language is a bridge between mind and behaviour. They also

struggled to develop their deaf child's problem-solving skills and creativity through language. these skills could form a hidden and solid foundation for the development of moral, cognitive and social-emotional skills (Marschark and Hauser, 2012; Marschark, 2007).

With the changing circumstances of an increasingly competitive society and rapid development in economy and technology, more and more Chinese hearing parents are exposed to choices in early intervention and early childhood education provisions (either language training centres or pre-school inclusive institutions), audiology technology (either hearing aids or cochlear implants), and school settings (either deaf schools or mainstream schools). Chinese hearing parents of children who were born in the 2000s were likely to be more involved in home education and have better access to parental support than those whose children were born earlier. The present generation of hearing parents' decisions may well be less biased due to the greater availability of information and support services. Holrody (2003) also reported that the later generations of parents are more likely to be involved in their child's education and care as they have greater awareness of the need for self-expression and creativity.

Home coaching for deaf children is a multi-dimensional in China. Development in moral, cognitive and physical skills underpins an all-round development. Chinese hearing parents raised important issues of their deaf children's all-round development which includes moral, cognitive and social-emotional skills to become self-reliant in society in China. Marschark and Hauser (2012) suggested that families of deaf children and professionals should make more effort to understand the deaf children's development in different learning environments, rather than focusing on traditional debates over the impact of hearing loss and/or language choices on deaf children's academic achievement. There is an urgent need to understand that what kind of teaching approaches can be successful in what settings with which deaf students and at what ages (Marschark and Hauser, 2012).

#### 6.2.5 Parental involvement from deafness diagnosis to mainstream schools

In their interviews, all participants in this study were asked to describe their emotions

on hearing their child's diagnosis of deafness. Chinese hearing parents reflected on the experience in vivid details, although some of them were reluctant to indulge in thinking about such an unhappy time.

After the diagnosis, Chinese hearing parents experienced mood recovery and accepted the situation of having a deaf child. Some parents (e.g. Parent Li) became calm and strong after they had learnt to accept their child's deafness. Within those who had a positive attitude towards deafness, some parents felt it was nothing more serious than permanent hearing loss (Schirmer, 2001). In contrast, other parents had negative views and were reluctant to accept their child's deafness. They also felt confused when the information was given by professionals who interfered with their involvement in early intervention and education. As a result, hearing parents' various emotional responses altered their attitudes and beliefs, leading them to make certain decisions about their deaf child's life (Adams, 1997). Dealing with the diagnosis influences parents' realistic expectations of their deaf child and their subsequent involvement in educating them (Williams and Darbyshire, 1982; Young, 2010). However, there was no fixed approach for hearing parents to deal with a wide range of feelings, and this depended on the individual parent's beliefs and family culture (Adams, 1997).

As discussed in a previous section 6.2.1, there are two pathways to diagnosis of deafness, hospital discovery and parental discovery. It could be argued that hospital intervention reaches deafness diagnosis quicker than parental discovery. Hospital discovery tends to enable a longer period for learning language skills than that of parental discovery. Furthermore, the main reason for the delay between hearing parents' discovery and diagnosis is that the majority of Chinese hearing parents believed the Chinese superstition saying that those who speak at a later age will have greater intelligence. Following diagnosis, Chinese hearing parents experienced a range of feelings and were keen to find a cure for deafness before embarking on oral language training and mainstream schools. The period between listening and speech training and an education at a mainstream school is crucial for hearing parents, in order to develop their deaf child's language in the critical period of early childhood years. However, this period can be affected by the time of diagnosis, potentially giving parents experiencing hospital diagnosis a crucial advantage in their child's

core development. From this perspective, the earlier the diagnosis of hearing impairments, the more effective hearing parents' involvement in early intervention and education will be. Therefore, hospital discovery tended to be quicker in reaching the diagnosis and enabling hearing parents' involvement in their deaf child's preparation for inclusive education at mainstream schools.

It can be argued that Chinese hearing parents should quickly go through the stages of grieving to accept their child's deafness. Furthermore, parental investment in home coaching and early education should begin as early as possible rather than being wasted on hopeless quests for deafness cures. Deaf children may find it difficult to understand hidden meanings behind the facial expressions in their hearing parents when very young. Negative emotions, such as anger, anxiety, sadness and so forth may not be evident (McCracken and Sutherland, 1991). Deaf children's self-esteem will be affected and the understanding altered (McCracken and Sutherland, 1991). In short, the way in which Chinese hearing parents tried to secure a place in a mainstream school affected their involvement in their deaf child's readiness for school. Their emotional reactions play a key role when supporting their child to be integrated into inclusive education.

Most Chinese hearing parents (e.g. Parent Li, Parent Liu, Parent Zhang, Parent Wang, etc) reported that they spent large amounts of time and effort in raising their deaf child. This finding accords with the study of Jackson *et al* (2008), which showed that parents of children with hearing impairments experience a period of adjustment to diverse aspects of family life including time demands, decision-making and emotional wellbeing. Educating a deaf child requires great effort and time from hearing parents, and this dedication can last for the lifetime of the child. Hearing parents should seek appropriate approaches for their child based on their individual special needs.

#### 6.2.6 Overall conclusion on the theme of parental involvement strategies

In summary, it is not surprising that the role played by parents is particularly vital for children with disabilities. Chinese parents of children with disabilities not only cared about their children's regular life, but also helped them to achieve an education in either mainstream or special schools. Likewise, Chinese hearing parents played an essential role in raising and educating their deaf children. They not only coped with their child's deafness and early intervention during the pre-school period, but also dealt with matters of school settings, relationships with teachers and home coaching when their deaf child started schooling life.

Hepburn (2004) suggested that parents play two important roles in acting as educators and leaders while raising their children. According to Hepburn (2004), Chinese hearing parents are assigned to the two different roles in raising and supporting their deaf children in Beijing. On the one hand, as educators, Chinese hearing parents not only taught their deaf child to develop skills in speech and listening, but also supported their deaf children to be educated at mainstream schools. On the other hand, as leaders, Chinese hearing parents had to make decisions on different choices with regard to communication mode (i.e. sign language or oral language), early intervention and early childhood education provision (i.e. speech and listening training centres or kindergartens with inclusive education programmes), school settings (i.e. deaf schools or mainstream schools) and cultural identities (i.e. deaf or hearing).

#### **6.3** The barriers to parental involvement

There were several barriers to parental involvement in supporting their deaf children in China, particularly when their children were preparing to study at mainstream school or were integrated into a mainstream school. Chinese hearing parents played an indispensable role in determining not only whether their deaf child can be offered the right to an education, but also whether their deaf child can be supported to overcome the multiple barriers of learning at a mainstream school.

Firstly, a lack of information on disability and deaf awareness could lead to hearing parents being confused about what to do for their deaf children. They might have a negative towards the situation. This results in them avoiding supporting their deaf child's development and school readiness. Some Chinese hearing parents (e.g. Parent Zhang) reported that they would like to focus on language development instead of seeking a cure. Parental involvement in late engagement with early intervention, in

the study of Liu and Raver (2011), found that the China Research Centre for Deaf Rehabilitation (CRCDR), established in 1991, has recently developed training programmes in listening and speech training and deaf awareness in the community for professionals since 2001. This resulted in more awareness of early intervention for deaf children by delivering these training programmes to parents.

Secondly, Chinese hearing parents' lack of confidence in inclusive education, especially in terms of inclusive preschool education programmes, created a barrier to involvement in supporting the deaf children's development and growth in either kindergarten with inclusive education programmes or mainstream schools. In this study, the majority of Chinese hearing parents frequently discussed topics of listening and speech training centres and language development, and rarely mentioned pre-school inclusion. Furthermore, all Chinese hearing parents chose to send their deaf child to rehabilitation centres when their child was at pre-school age, because they believed that the purpose of the centres was to improve their deaf children's delayed language development at a pre-school age. However, Chinese hearing parents wanted to encourage their deaf children to be integrated into the kindergartens with inclusive education programmes, given that their children's development in language and speech could be good enough at a pre-school age.

Chinese parents seldom talked about the provision of pre-school inclusion in their interviews. There were no pre-school inclusive programmes available in China before 2001. Some parents were not aware of the available service of kindergarten with inclusive education if their deaf child was born after 2001. Some parents might find it difficult to travel to big cities to explore the available services. Deaf children who were born after 2001 might not be ready for pre-school inclusive education due to their delayed development in language and cognition. The majority of Chinese hearing parents may have little exposure to deaf adults and/or parent-to-parent groups. This results in them not having confidence to motivate themselves and failing to recognise ambition for their deaf child. These reasons may explain why the numbers of deaf children studying at pre-school inclusion were lower before the pilot programmes of pre-school inclusion were established in 2001 in Beijing.

As discussed in an earlier section 6.1.3, parents' choice of education at a pre-school

age suggests that sending deaf children to a listening and speech training centre may enhance their adaptive skills in the inclusive learning environment and improve their capacity for studying at a mainstream school with hearing peers. Education in listening and speech training centres may not fully prepare for deaf children for mainstream schools in China.

The majority of Chinese hearing parents was over-optimistic about the learning environment of mainstream schools and underestimated the difficulties and barriers to parental involvement. More than half Chinese hearing parents (e.g. Parent Wang, Parent Song, Parent Liu, Parent Li, Parent Zhang) preferred mainstream schools when their deaf child reached the age of school enrolment, although they considered special education schools as the other option. They further talked about thechallenges of mainstream schools, such as the access to mainstream schools, and the readiness for inclusive education at mainstream schools.

Nearly all Chinese hearing parents made many attempts to deal with the issues of mainstream schools, for example, dealing with the difficulties for deaf children's academic progress. Remaining on a par with students of typical development at mainstream schools within the oral language environment was a continuous challenge. Some parents (e.g. Parent Li, Parent Liu) reported that their deaf child felt exhausted while studying at mainstream schools and found it difficult to overcome the difficulties of lagging behind hearing peers in a mainstream class. This finding corroborates a great deal of the previous work in the field of 'sui ban jiu du' or 'Learning in Regular Classrooms' (LRC) (Deng *et al*, 2001; Deng and Manset, 2000; Hu, 2010; Human Rights Watch, 2013), which showed that many students with disabilities who physically attend mainstream schools and remain unable to learn with their peers without disabilities, and this situation was described as 'drifting in the regular classroom', 'sit along with the class' or 'muddle along with class'.

The reasons why a child with a hearing impairment had great difficulties in studying at mainstream schools are possibly that: firstly, there is a lack of support for teachers of deaf children and deaf children themselves in a mainstream class due to the large student-teacher ratio in China; secondly, there is a lack of teacher training programmes in the field of special education, which lead to teachers' preferring to

teach students without disability; thirdly, the learning environment of mainstream schools are based on examination-oriented competition that is closely related to the reputation of school conditions.

Next, the pressure on Chinese hearing parents of deaf children can be a barrier to their effective involvement in home coaching. Some parents (e.g. Parent Xue) pointed out that their parental stress was caused by finance and transport. These hearing parents worked hard to earn money for the cost of audiology devices and batteries as well as for payments for inclusive education. This finding is supported by Corter *et al* (2006), who found that the present social-economic environment demands great parental investment in their disabled child's education and rehabilitation during the period of early childhood.

Some parents (e.g. Parent Mei, Parent Xue, Parent Song) were gradually discouraged from educating their deaf child at home. They were trying to fill the gap between their hearing-impaired child's language development and the curricula standard of mainstream schools that are designed for children without disabilities. Other parents (e.g. Parent Liu) had more stress when they used strategies of intensive practice and previewing and reviewing knowledge, because these demanded extra time and effort when teaching Chinese language. Deaf children needed to spend a large amount of time learning Chinese, either reviewing the knowledge on the same day or previewing what would be taught the next day. Simultaneously, these deaf children could not do the two tasks of learning and understanding at the same time. In other words, more stress was created when they were learning Chinese language than for their hearing peers at mainstream schools. Consequently, these deaf children were more likely to become exhausted while studying at mainstream school and to lose learning interest compared to their hearing peers.

To take another example, examinations at mainstream schools raised stress levels further, and some parents (e.g. Parent Li) felt unable to support their deaf children in the learning processes. These exams were assessed on the same basis for deaf children as their hearing peers. These deaf children were trying hard not fall behind hearing peers and they developed fears from competing with hearing children as they grew older. Thus, Chinese hearing parents and their deaf children faced great

pressures together in pursuit of academic achievement. Similarly, Children with hearing impairments found it difficult to follow the national curriculum when they studied at mainstream school over one or two years. In other words, children with hearing impairments were likely to lag behind their hearing peers at senior or junior grade with regard to academic performance, although they could be on a par with hearing children in the first two years at mainstream schools.

Then, Chinese hearing parents' lack of problem-solving strategies could be a barrier to their involvement in supporting their deaf children's learning in inclusive education. Problem-solving strategies for home coaching varied, and these strategies depended on dominant factors among the stakeholders, such as parents, schools, individual deaf children and so on. Some parents (e.g. Parent Chen, Parent Xue, Parent Zhao, Parent Liu, Parent Mei, etc) revealed that they became frustrated when exploring effective ways of coaching their deaf child in spite of their desire for their child to be integrated into mainstream schools. Sometimes, hearing parents' own learning methods could be effective for developing deaf children's learning skills. However, it depended on each individual deaf child's personality and family approaches to coaching deaf children at home.

After this, Chinese hearing parents reported that the approach to learning through play only worked for some parents. Perhaps, these parents could not use the strategy of learning through play in an appropriate way, and their deaf child's needs may not be met. Thus, the strategy of learning through play could work for parents of deaf children at preschool stage to stimulate learning interests.

To take another example of learning the Chinese phrases, some Chinese hearing parents reported the issue of their deaf children's short memory after teaching their children many times at home. Perhaps, these hearing parents might not be aware that their deaf children's language development was not up to par. Or, these parents might lack the awareness of their deaf child's capacity for understanding rather than remembering. Thus, it would be worth exploring alternative strategies for teaching deaf children to learn the Chinese phrases.

Lastly, another a potential barrier to parental involvement is the lack of and

professionals' knowledge related to deafness and teachers' training in special education. In other words, teachers who lacked training in special education tended not to be able to guide parents' involvement in supporting deaf children's learning at a mainstream school. Furthermore, existing literature highlights a lack of teachers' and professionals' training in how to deliver teaching and learning that supports children with disabilities in China, and this directly affects the performance of disabled students in mainstream schools (Human Rights Watch, 2013; Deng *et al*, 2001; Yu *et al*, 2011). These teachers' lack of expertise and training in special education not only negatively affects the disabled children's opportunity to access learning, and therefore impacts on their performance, but also presents a barrier to parental involvement in supporting their children. Thus, teachers who lacked the trainings and qualifications in special education, not only found it difficult to understand the disabled children's learning needs, but also they were likely to be unaware of which way is the best for parents to support their children studying at mainstream schools.

# 6.4 The relationship between the effects of parental involvement and their involvement in raising their deaf children to be ready for and educated at mainstream schools

As demonstrated in the Findings Chapter, the journey to mainstream schools was complex and tortuous for Chinese hearing parents and their deaf children in China. Furthermore, with the approach to grounded theory coding, it was a process of discovering the appropriate balance in the relationship between the effects of parental involvement, their involvement strategies for supporting their deaf children at mainstream schools and the barriers to parental involvement.

Through data analysis within the methodology of constructivist grounded theory, it was discussed that the effects of parental involvement (e.g. Chinese hearing parents' attitudes towards deafness) begin a dynamic process; firstly influencing their involvement strategies, and subsequently affect the barriers to parental involvement, as shown in the Figure 6.1 in the beginning of this Chapter.

In this study, Chinese hearing parents' attitudes towards deafness are the deciding

factor in the effects of parental involvement, which could subsequently affect their attitudes towards early intervention, early education, and home coaching. Their attitudes could influence their involvement in coping with deafness, engaging in early intervention, getting their deaf children into mainstream schools, and coaching their deaf children at home. For example, Chinese hearing parents' attitudes towards deafness could affect their views of their child's deafness and their understanding of the 'normal' related to deafness. Furthermore, their attitudes towards deafness could influence their actions and behaviour in responding to their child's deafness. However, their action and behaviour response could be changed when they increasingly gained knowledge of deafness, in turn, their changing action could influence their attitudes toward deafness to some extent. As a result, Chinese hearing parents' attitudes and behaviours could be changed through information acquisition and interactive communication in a dynamic way.

Chinese hearing parents' involvement has a significant impact on their deaf child's development in language, cognition and social-emotion, but also promotes their deaf child's inclusive education and integration in a hearing world.

#### 6.4.1 What affects the attitudes of Chinese hearing parents towards deafness?

The findings of this PhD study suggest that parental involvement in raising a deaf child is greatly influenced by Chinese hearing parents' attitudes towards deafness and their perspectives of deafness.

All Chinese hearing parents frequently wished that they and their family did not have a deaf child in the beginning of the period of deafness diagnosis. These hearing parents lacked knowledge of deafness, which leads to the fact that they did not know how to raise and educate their deaf child and how to fit their deaf child into a hearing family. They were forced to abandon their original dreams and adapt to a new life after their children's deafness was confirmed. After a period of time, some Chinese hearing parents amended their expectations for their deaf children and finally accepted their children's deafness. This finding is consistent with previous research (Schwartz, 2007; Ogden, 1996; Adams, 1997), which showed that hearing parents experienced a period of grief over their child's deafness and amended their original

dreams of their children because they had not envisioned any problems with their children before deafness diagnosis.

It could be claimed that the different models of deafness either a medical model or a cultural-linguistic model could influence Chinese hearing parents' attitudes towards deafness. In this study, all Chinese hearing parents not only paid attention to finding a cure for deafness after their emotional response to diagnosis, but were also keen to encourage their deaf child to work hard on language development in preparation for mainstream schools. They spent large amounts of time and money in looking for a cure for deafness and training their deaf child's skills in listening and speech, in order to support their child to be ready for mainstream schools. This finding seems to be consistent with the study of Callaway (2000), which found that Chinese parents viewed deafness as a type of disease and abnormality, and devoted themselves to finding any cure for deafness and teaching their deaf child to speak, in order to normalize their deaf child. Consequently, the majority of Chinese hearing parents were likely to be influenced by the medical model of deafness. However, when they talked about their child's character, they viewed their deaf child as a child first and a child with a hearing impairment second. This finding is in disagreement with the study of Young (1999), which showed that parents of deaf children found it difficult to balance the relationship between childness and deafness.

### 6.4.2 The impact of Chinese hearing parents' attitudes towards deafness on their involvement in coping with deafness

The findings related to coping with deafness suggest that Chinese hearing parents' attitudes towards deafness could impact on their involvement in coping with deafness, and this has a strong influence on their subsequent attitudes towards the choice of communication modes and educational settings for their deaf child in the early years. According to the medical model of deafness, Chinese hearing parents were likely to expect their deaf child to be a child with typical development. These parents were predisposed to search for a cure for deafness and invest their money in hearing aids and cochlear implants for their deaf children, but also motivated them to train their children's skill in oral language and help their children to be ready for mainstream schools. Therefore, it could be argued that, in the process of raising deaf children in

the early years, the quality of parental involvement strategies may be crucially affected by Chinese hearing parents' attitudes towards deafness not by being dependent on their children's hearing losses.

# 6.4.3 The impact of Chinese hearing parents' attitudes towards deafness and early intervention on their involvement in early intervention

The findings related to early intervention suggest that the quality of Chinese hearing parents' involvement in early intervention could be affected by their attitudes towards early intervention through either the hardware strategy of hearing aids/cochlear implants or the software strategy of listening and speech training. Furthermore, Chinese hearing parents' attitudes towards deafness had a strong influence on their attitude towards early intervention. According to the medical model of deafness, Chinese hearing parents were likely to make decisions on hearing aids and cochlear implants on behalf of their deaf children, but also they preferred the choice of oral language as the main communication modes with their children.

It could be argued that Chinese hearing parents' attitude towards cochlear implants not only affects their attitudes towards communication modes, but also enhances their desire to develop their deaf child's skill in oral language. This finding is supported by other research (Aiello and Aiello, 2001; Meadow, 2005), which showed that the use of cochlear implants not only promoted interaction between hearing parents and their deaf children, but also developed deaf children's auditory skill.

# 6.4.4 The impact of Chinese hearing parents' attitudes towards deafness on their decisions on oral language and mainstream schools

It could be argued that Chinese hearing parents' decisions on oral language and, subsequently, mainstream schools would be greatly influenced by their attitudes towards deafness. Furthermore, Chinese hearing parents' viewpoints on the relationship between childness and deafness would impact on their choice of communication modes (sign or oral language) and/or educational settings (deaf or mainstream schools). Moreover, Chinese hearing parents who chose spoken language and/or mainstream schools often had a confused attitude towards deafness.

Shortly after a deafness diagnosis, Chinese hearing parents would cling to their original expectation of having a hearing baby in their mind. Some parents then accepted their child's deafness and appreciated the value of sign language. During this period, their acceptance of and adjustment to their child's deafness influenced their attitudes towards deafness. They also had a desire to improve their child's skills in speech and listening and encourage them to attend mainstream schools, in order to 'normalize' their deaf child. This finding supports the idea of Leigh (2009), who argued that the interpretation of acceptance and adjustment depends on families' perceptions of deafness and deaf children's individual development.

In their interviews, some parents (e.g. Parent Li, Parent Liu, Parent Zhang) talked about their limited opportunities of accessing deaf culture and meeting deaf adults. Under these circumstances, their deaf children who were exclusively educated at mainstream schools did not have a clear concept of deaf culture and deaf identity until they had an opportunity to meet deaf adults. This finding is consistent with the study of Moschella (1992, cited in Leigh, 1999), which showed that deaf people who were strictly educated in oral settings had a negative attitude towards deafness, and this influenced their social-emotional development and self-esteem formation. However, their negative attitudes could be changed through increasing contact with deaf peers and deaf adults.

#### The choices of oral language and the decision to avoid sign language

The majority of Chinese hearing parents explained that they preferred oral language to sign language. Some parents (e.g. Parent Li, Parent Liu) reported that they did not want to learn the new Chinese Sign Language. They thought spoken language was the dominant channel between hearing and deaf people, especially in a hearing family. They also were concerned that their family would need to learn Chinese Sign Language if their deaf child was taught in this way. Furthermore, Parent Li reported that sign language would interfere with their deaf child's all-round development. Parent Liu thought that Chinese Sign Language was not useful for their deaf child's future and it would limit the ability to connect with hearing people.

Some hearing parents (e.g. Parent Li, Parent Liu, Parent Zhang) appreciated the value of sign language, but did not find the available resources to learn Chinese Sign Language before the 2000s. Parent Li reported that the number of deaf people is far less than hearing people, meaning that the number of sign language users is much smaller than spoken language users. Other parents (e.g. Parent Li, Parent Liu) heard about sign language and compared it with spoken language before finally choosing oral language as a communication mode. A few parents (e.g. Parent Zhang) had never heard of sign language, so their deaf child learnt oral language in a straightforward way. Hence, they found it difficult to access Chinese Sign Language, and they were predisposed to teach their deaf child oral language.

#### The choice of mainstream schools as opposed to deaf schools

Following the decision on oral language, the majority of Chinese hearing parents (e.g. Parent Wang, Parent Li, Parent Liu, Parent Zhang, Parent Song) explained that they preferred mainstream schools to deaf schools. Furthermore, some Chinese hearing parents (e.g. Parent Li, Parent Song) chose a mainstream school because of its oral language environment. On the other hand, some other Chinese hearing parents (e.g. Parent Liu, Parent Li) expressed that they were not keen on choosing deaf schools, because they thought deaf schools were not able to provide an intensive spoken language environment. One parent (Parent Liu) commented that deaf schools only provided sign language as the main communication mode, and therefore had concern about how she would communicate with her deaf child with oral language.

Most Chinese hearing parents said mainstream schools would provide an oral language learning environment and promote their deaf child's all-round development through engaging in lots of activities. Some parents (e.g. Parent Li, Parent Liu, Parent Zhang) made decisions on mainstream schools to suit their own needs, often neglecting the choices of their child. However, some Chinese hearing parents (e.g. Parent Wang, Parent Zhang) struggled to find an educational setting for their deaf children. They had made a decision on spoken language as the main communication mode, when they did not have other options to communicate with their deaf children, such as Chinese Sign Language, written language and so on. One parent (Parent Wang) said he found it difficult to communicate with his deaf child over choosing

deaf or mainstream schools, because his deaf child's spoken language had not developed to the level to enable good communication.

A few Chinese hearing parents paid attention to their deaf child's needs and followed their wishes. For example, one parent (Parent Zhang) listened to her deaf child's needs and respected her interests. Her deaf child expressed an interest in mainstream schools and influenced her decision to select a mainstream school for her deaf child, although she knew that challenges awaited her deaf child. Chinese hearing parents (e.g. Parent Zhang, Parent Song) talked about how they felt stressed and worried about hearing-centred learning environments while thinking of the possible risks and challenges associated with mainstream schools, their deaf children's communication with teachers and hearing peers, and their learning pace in comparison to hearing peers were potential areas of concern. One parent (Parent Song) said she wished her deaf child could catch up with hearing peers in a mainstream class and worried about her deaf child's learning process being slow.

### The role of head teachers in the deaf children's access to mainstream schools

After Chinese hearing parents decided to choose mainstream schools, they faced difficulties in securing registration. Two main avenues of accessing mainstream schools were identified, either 'enrolment exams' or 'no exams' and 'social network' or 'self-help'. However, the destination was the same as both require permission from the head teachers of mainstream schools irrespective of the diverse avenues of access. The head teachers played a crucial role in making decisions on the inclusion of deaf children. For example, one parent (Parent Liu) explained that, when the head teacher heard about her deaf child's story, the head teacher had been touched and agreed that her deaf child could be educated in the school. Hence, a visit to the head teacher before their deaf children started school helped to allay fears.

# 6.4.5 The impact of Chinese hearing parents' attitudes towards deafness and home coaching on their involvement in coaching deaf children

Coaching deaf children showed that home coaching occurred during the period of early intervention and throughout schooling life. Chinese hearing parents'

involvement in developing their deaf child's listening and speech skills could be viewed as a rather narrow approach to home coaching. Home coaching diversified with the increasing age of deaf children. During schooling life, Chinese hearing parents' involvement in coaching deaf children focused on the national curriculum of mainstream schools in developing morals, cognition and social-emotion.

It could be argued that the quality of Chinese hearing parents' involvement in coaching deaf children was likely to be affected by their attitudes towards home coaching. Furthermore, their attitudes towards home coaching were likely to be influenced by their attitudes towards deafness. One hearing parent (Parent Li) talked about the fundamental principle of coaching deaf children and emphasized the importance of respecting her deaf child's nature rather than focusing on issues potentially caused by deafness.

Most Chinese hearing parents had a strong desire to encourage their deaf child to be exposed to a hearing world. They talked about their belief in spoken language and they mainly focused on speech training and Chinese subject teaching. Their belief would exert a great influence on their involvement in home coaching. For example, some parents (e.g. Parent Li, Parent Liu) emphasised pronunciation practice when they coached their deaf children in speech skills. Some parents (e.g. Parent Li, Parent Liu) created an innovative approach to training speech, such as biting an apple to shape the mouth into looking like 'a', and making use of chopsticks and torchlight to teach their deaf child to observe the movement of the lip and the tongue. This finding is consistent with the study of Biggs (2004), which found that Chinese hearing parents believed their deaf children could eventually learn to speak if they tried their best to create the maximum environment for spoken language.

To take an example of subject teaching and learning, most Chinese hearing parents explained they found it more difficult to coach their deaf child in Chinese than maths, because maths was visual for deaf children and this subject does not require much knowledge in language to access. One hearing parent (Parent Zhang) passed down her own individual learning approach to her deaf child, and made use of reading as a strategy of coaching deaf children in Chinese, in order to stimulate her deaf child's learning interest. As a result, almost all Chinese hearing parents were aware of the

important role played by speech training and Chinese subject teaching in developing their deaf child's language skills.

Therefore, Chinese hearing parents' attitudes towards deafness could affect the domain of home coaching during the period of their deaf children's pre-school and later school life.

### 6.5 The transition between listening and speech training centres and mainstream schools

In this study, the majority of Chinese hearing parents were not aware of change in the learning environments between listening and speech training centres and mainstream schools, at the time deaf children reached the age to start.

Most Chinese hearing parents (e.g. Parent Li, Parent Liu, Parent Zhang) were told that teachers who worked at mainstream schools were qualified as teachers in general education, but they might not be experts in special education and they might not be aware of deafness. In spite of this prior notification from head teachers, these hearing parents were not likely to care about whether teachers had qualifications in special education, but they cared about their deaf children's abilities and skills of entering into and engaging in mainstream schools. Under these circumstances, it is essential for Chinese hearing parents to create a dynamic relationship with their deaf children's teachers who worked at mainstream schools. Firstly, Chinese hearing parents' involvement would monitor and promote their deaf children's academic development, when they kept track of teachers' progress reports. More than half parents (e.g. Parent Li, Parent Zhang, Parent Zhao, Parent Liu) talked about the importance of diaries as the main form of communication between teachers and parents. They also built a good relationship with teachers through visiting them at school or occasionally telephoning them and so on. Secondly, Chinese hearing parents often consulted teachers about learning issues related to their deaf child, and this could contribute to teachers' understanding of deafness. They asked teachers about academic issues that they did not understand, such as their difficulties in coaching Chinese subjects. These teachers were kind to offer their knowledge to help their deaf children to understand Chinese words at school, considering that some words are not possible to teach at home without pictures and visual clues.

Most Chinese hearing parents (e.g. Parent Zhang, Parent Li, Parent Mei, Parent Liu, etc) raised matters related to their deaf children's hearing peers. Their aim was to help their deaf children to catch up with hearing peers in mainstream schools. These parents did not raise this issue during the period of their deaf children's pre-school life. Children who studied at listening and speech training centres were all deaf and they may not know Chinese Sign Language. Each deaf child had only deaf peers at training centres. Then, these deaf children would seldom have a deaf peer at a mainstream school. At school, hearing peers knew little about deafness and they did not know how to communicate with deaf children in a mainstream class. Teachers who worked at listening and speech training centres were often aware of deafness and some of them knew basic Chinese Sign Language. These teachers were generally considered to be 'speech therapists' or 'teachers of the deaf'. By comparison, teachers who worked at mainstream schools might not have much knowledge in disability and deafness, so their role was not viewed as teachers of the deaf. In this case, it could be argued that teachers who worked at mainstream schools would play an essential role in creating a friendly environment for deaf children and deliver deafness knowledge to hearing peers, in order to build friendship between all children in a mainstream class. In this way, deaf children could develop their social-emotional development through engaging with hearing children in activities with their teachers' help. One hearing parent (Parent Zhang) mentioned communication issues with hearing children before agreeing on working together to help her deaf child to embrace studying at a mainstream school.

The challenges from the transition for deaf children from listening and speech training centres to mainstream schools need to be brought to Chinese hearing parents' attentions.

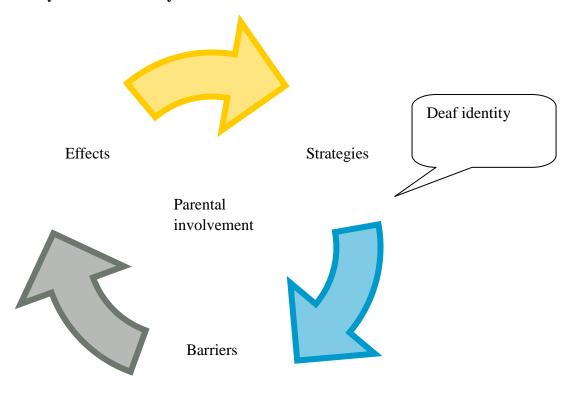
# 6.6 The relationship between the ESB model of parental involvement theory and deaf children's identity development from the perspective of autoethnographer

As discussed in previous sections of this chapter, the ESB model of parental involvement theory emerged from the interview data through grounded theory coding

analysis. It consists of three aspects including the effects of Chinese hearing parents' involvement, their involvement strategies and the barriers to their involvement. However, it could be argued that this theoretical framework (i.e. the ESB model of parental involvement theory) cannot be called as a theory without adding a concept of deaf identity from the perspective of autoethnographer. According to Ladd (2003), deaf children have deafhood when they are diagnosed with deafness. Deaf children experience different stages of deaf identity in spite of having same deafhood themselves as discussed later in this section in terms of the relationship between deafhood and deaf identity (Glickman, 1996).

A theory of parental involvement in this study builds a relationship between the ESB model and a concept of deaf identity as shown in Figure 6.2. The individual component parts of the ESB model are likely to exert an influence on deaf children's identity development.

Figure 6.2 The relationship between the ESB model of parental involvement theory and deaf identity



The findings suggest that during the period of raising their deaf children, Chinese hearing parents' attitudes towards deafness would be different depending on their understanding of deafness. Their attitudes might change with their changing understanding deafness. Chinese hearing parents' attitudes towards deafness are likely to have an influence on their deaf child's identity development during the period of their deaf children's pre-school and main school life.

When considering the effects of parental involvement, Chinese hearing parents in this study had different emotional responses to deafness when their child was diagnosed with deafness, such as shock, depression, shame, adjustment and acceptance, which is consistent with the theory of parental reaction to disability (Gargiulo, 2012). In terms of a concept of deafness, there is only one way to write deafness in Chinese way, illustrated as '聋', compared to deafness in English writing with a big D and a little d. In this way, the majority of Chinese hearing parents found it difficult to envisage how the Chinese character '聋' is linked with the deaf community and/or deaf culture in China. Chinese hearing parents were not likely to acknowledge sign language and deaf culture at deafness diagnosis. After diagnosis, Chinese hearing parents increased their awareness of their child's deafness in the process of searching for cures for deafness. They then started to look for services of early intervention for their deaf child, and most of them sent their deaf child to listening and speech training centres. Furthermore, these hearing parents gained additional knowledge in deafness through training their deaf children in language skills. At this stage, their choice of oral language and speech therapy could reflect their attitudes towards deafness, which seemed to be consistent with a medical model of deafness. From this perspective, it could be argued that their deaf children would have deafhood and they might not have a strong awareness of deaf culture. Thus, these deaf children were not likely to have an identity of being 'culturally deaf' (Glickman, 1996). This finding supports the idea of Biggs (2004), who found that Chinese hearing parents were likely to educate their deaf children to act as hearing children and to communicate in spoken language, in order to normalize their deaf children.

Before their deaf children started school life, the majority of Chinese hearing parents

struggled with their choice of school settings, either deaf or mainstream schools. Furthermore, some of them preferred mainstream schools to deaf schools although they considered the levels of their child's language acquisition. Their choices between mainstream schools and deaf schools reflect their attitudes towards deafness. Consequently, these hearing parents might have a different attitude towards deafness, moving from a medical model to a medical and/or a linguistic-cultural model of deafness. On the one hand, some Chinese hearing parents who chose mainstream schools insisted on the development of spoken language in order to ensure that their deaf children would live in a hearing world, which echoed a medical model of deafness that emphasised the importance of spoken language. On the other hand, some Chinese hearing parents considered deaf schools before choosing mainstream schools. These parents showed that they had an awareness of sign language as their child's language needs and language dominance. They understood deaf culture, including sign language and deaf schools, which seemed to be consistent with a linguistic-cultural model of deafness. Supporting their deaf child in a mainstream school can change their attitudes towards deafness, moving from a medical model of deafness to a social model of deafness. Under these circumstances, their deaf children continued in deafhood before going to mainstream schools, and some of them might embrace deaf identity when Chinese hearing parents considered sign language and deaf schools as the other options. These children might develop a blurred relationship between hearing-centred identity and deaf-centred identity.

With the increasing popularity of cochlear implants and Chinese Sign Language, some Chinese hearing parents would have more than mono-dimension choices on communication modes and educational settings. This trend could avoid their making extreme decisions on the environments of culture and language provided for their deaf children, but also could facilitate deaf children's bi-identity development between hearing-centred identity and deaf-centred identity. And what is more, the relationship between childness and deafness is likely to influence Chinese hearing parents' decisions on language use and educational settings, as discussed in the section 6.4.4. Their perspective on this relationship could motivate them to adjust to new approaches to biculture (i.e. deaf culture and hearing culture) and bilanguage (i.e. sign language and spoken language). Thus, these deaf children might experience different stages of deaf identity: 'culturally hearing', 'marginal' and 'bicultural',

according to Glickman (1996). These deaf children were not likely to have an identity of 'culturally deaf' at this stage (Glickman, 1996).

In terms of parental involvement strategies, Chinese hearing parents spent a large amount of time and money in searching for a cure for deafness, and seeking auditory aids and speech therapy in their deaf children's early years. Furthermore, it could be argued that Chinese hearing parents' attitudes toward deafness at the different stages could impact on their deaf children's development in self-concept and deaf identity. To take an example of cochlear implants the majority of Chinese hearing parents decided on this technology for their deaf children because they thought cochlear implants were perceived as bionic ears and as a medical approach to curing deafness. Their involvement in early intervention reflects a medical model of deafness, which impacts on their deaf children's identity development. For deaf children, the medical model could enhance their awareness of deafness and gain entry into their deafhood, but they may not have a sense of deaf identity because they lack sign language and deaf culture. In other words, a medical model of deafness may harm deaf children's language development and self-esteem, although this model increased Chinese parents' awareness of deafness in the early stages. This is consistent with the study of Shen (2010), who explained that a medical model of deafness can be viewed as a coin with two sides in China.

With respect to the barriers to parental involvement, the majority of Chinese hearing parents attempted to look for a cure for deafness and worked hard to develop their deaf children's skills in listening and speech. They also faced challenges within the environment of inclusive education and experienced difficulties in coaching their deaf children at home, when their children were educated at mainstream schools. In order to remove barriers to inclusive education for deaf children, Chinese hearing parents not only created a relationship and consulted with their deaf children's teachers who worked at mainstream schools, but also tried their best to coach their children at home. These findings suggest that the barriers to parental involvement may affect their attitudes towards deafness, moving from a medical model to a linguistic-cultural model of deafness, backs and forwards.

From the perspective of autoethnographer, deaf identity is more invisible than

hearing impairment. Identity is hidden within a deaf child's mind, and hearing impairment is apparent through wearing hearing aids and cochlear implants. Furthermore, it could be claimed Chinese hearing parents found it difficult to increase their awareness to help their deaf children to develop their self-concept and to shape a unique identity: hearing-centred identity, deaf-centred identity or both, when they raised their deaf children in the early years.

The findings from this study suggests that the environment of spoken language within a hearing family and mainstream schools could be a leading factor in the exclusion of deaf children from sign language and deaf culture. In this study, most Chinese hearing parents made great effort to seek a treatment for deafness and to introduce an approach to developing oral language. Their deaf children, who were trained in listening and speech training centres, were not much exposed to Chinese sign language, although they had deaf peers who knew a limited number of signs. At home, their deaf children were exposed to a hearing family and were coached by Chinese hearing parents in developing oral language skills. This did not mean that these deaf children were not allowed to use body language and facial expression to develop their language skill. it was acknowledged that simple hand movements and gestures are not enough to constitute sign language underpinned by the core values of deaf culture, instead, this is only a tiny part of deaf identity. In this way, these deaf children had a deafhood and their development of a self-concept would be varied. They were likely to have an identity of 'culturally hearing' and/or 'biculture', or 'marginal' at this stage, according to Glickman (1996).

During the period of schooling life, Chinese deaf children who were educated at mainstream schools were exposed to a learning environment of spoken language through communication with hearing teachers and hearing peers at school and through interaction with their hearing parents at home. Within the strong influence of hearing culture, these deaf children learnt to speak and dealt with difficulties in studying at mainstream schools. These deaf children were less exposed to deaf culture in mainstream schools than that of training centres, and they did not acquire skills in Chinese Sign Language. Thus, these Chinese deaf children were strongly surrounded by a hearing world, and this could lead to their identity to be the hearing-centred or the marginally hearing-and-deaf identity. The way of parents'

coaching deaf children as hearing children demonstrated that a belief in spoken language, which leads to hearingness-centred identity being mainly passed to their children. This finding is consistent with the study of Lin (2009), who stated that deaf people with an oral education background tend to be culturally hearing or culturally marginal.

In this study, most Chinese hearing parents not only focused on the cure for deafness and speech therapy in their deaf children's pre-school life, but also paid much attention to their deaf children's academic, moral and social-emotional development in their school life. In this way, Chinese hearing parents' attitudes towards deafness tends to be dominated by the medical model of deafness. Moreover, this medical model of deafness may not offer a flexible tension between hearing parents' attitudes towards deafness and their involvement in supporting their deaf child's inclusive education. However, in this study, these Chinese hearing parents' attitudes towards deafness tended to move from a medical model of deafness to a social relational model of deafness as their deaf children grew older. For example, most Chinese hearing parents viewed their deaf child as a child with typical development firstly and as a child with a hearing impairment secondly. For this reason, it could be also claimed that most Chinese hearing parents were not completely influenced by a medical model. Instead, they were likely to accept Chinese Sign Language and deaf culture as well as the advanced technology of cochlear implants. This finding disagrees with Weinberg and Sterritt (1986), who argued that hearing parents who educated their deaf children to act as hearing children had a negative attitude towards deafness.

Open-minded hearing parents (e.g. Parent Li), were not likely to reject Chinese Sign Language, although some of them did not actively learn sign language. These hearing parents continued oral education and developed their deaf children's skills in listening and speech. Their deaf children were not offered an opportunity to know and learn sign language, so their identity was likely to be mainly developed into 'culturally hearing' (Glickman, 1996) or a mixture of 'culturally hearing' and 'culturally deaf'. However, these deaf children met their deaf peers at training centres, no matter how much deafness knowledge they had, so they may have an identity of 'bicultual' (Glickman, 1996). Hence, deaf children would have various

types of identity in the early years, either hearing-centred identity or deaf-centred identity, or both, or neither. In other words, these deaf children might develop a tension between a hearing-centred and a deaf-centred identity. They would be offered a flexible choice of self-concept in order to develop a healthy identity and lead a life of their choosing. Unfortunately, some Chinese hearing parents were likely to increase their knowledge of deaf culture and sign language, so it was not possible for their deaf children to have a full sense of being 'culturally deaf' (Glickman, 1996). Based on these situations, these deaf children's identities mainly tend to be 'culturally hearing' and/or 'marginal' (Glickman, 1996). Therefore, it could be claimed that Chinese hearing parents' changing attitudes towards deafness would reflect their knowledge of deaf culture, and this largely affects their deaf child's identity development.

In summary, the findings of the current research suggest that the different strategies that Chinese hearing parents used for raising their deaf children could impact on their children's individual development in self-concept and deaf identity. These findings are supported by Densham (1995), who found that hearing parents' feelings on deafness and their behaviours not only have effects on their deaf children's development of self-concept and self-esteem, but also have an influence on their children's social skills and future lifestyles.

# **Chapter 7 Conclusion**

This chapter begins with the contribution to knowledge, and then critically examines the current research in terms of the strengths and limitations of the research design. Finally, it provides recommendations for future research followed by concluding remarks.

#### 7.1 The contribution to knowledge

The purpose of the research was to discover how a small group of Chinese hearing parents supported their deaf children to prepare for and be educated at mainstream schools in Beijing. As discussed in both the Findings and Discussion Chapter, the multiple analyses of interview data revealed a model of parental involvement theory, including three dimensions: the effects of parental involvement, parental involvement strategies and the barriers to parental involvement. This model can be called as the ESB model of parental involvement theory (i.e. effects, strategies and barriers), as shown in Figure 6.1. Furthermore, in this ESB model, the effects of parental involvement (i.e. the attitudes of Chinese hearing parents towards deafness, early intervention and school settings as well as parents' views on their child with a hearing impairment) would exert a strong influence on the strategies of parental involvement in the different life stages of raising deaf children, including coping with deafness, early intervention strategies, dealing with mainstream schools and coaching deaf children. Moreover, the findings showed that the effects of Chinese hearing parents' involvement and their involvement strategies played a crucial role in raising their deaf children during the periods of pre-school and school inclusion. Chinese hearing parents in this study faced lots of challenges and met difficulties while supporting their deaf children to prepare for and be educated at mainstream schools, such as the barriers to fixing deafness and early intervention, mainstream school settings and coaching deaf children. In turn, these barriers to parental involvement would have an influence on the effects of parental involvement and parental involvement strategies. In other words, it could be argued that this ESB

model is constructed by a dynamic process, begining with the effects of parental involvement that subsequently influence parental involvement strategies and the barriers to parental involvement.

It could be argued that there has been little literature offering knowledge of parental involvement programmes of educating deaf children to be ready for and educated at mainstream schools until recently. It is worth noting that McCabe (2008) pointed out the importance of parental support groups in supporting children with autism in China, however, this particular study was not about parental involvement of deaf children. Furthermore, the frameworks of parental involvement and inclusive education that have arisen in the West might not easily transfer to suit Chinese sitations. According to Chinese culture, Lei and Deng (2007) pointed out that the quality of compulsory education for disabled children largely depends on parental involvement and the quality of home education. There has been little discussion about the relationship between parental involvement and deaf identity, although two authors Yang (2010 and Lin (2009) mentioned Chinese deaf identity development. In response, this PhD study created a theory of parental involvement, consisting of the ESB model and a concept of deaf identity, as shown in Figure 6.2. The findings of the current research could uncover the idea of the impact of Chinese hearing parents' involvement on developing their deaf child's deaf identity in the early years. Therefore, this parental involvement theory could provide a guideline for Chinese hearing parents to work with deaf children to form their child's identity during their early years and to support their deaf children to be ready for and educated at mainstream schools.

In addition, the findings of the current research add substantially to the understanding of the relationship between the ESB model of parental involvement and deaf identity from the perspective of autoethnographer, as discussed in Discussion Chapter. These findings suggest that Chinese hearing parents should gain knowledge about deaf identity and become aware of their deaf child's identity development. Chinese hearing parents need to consider their deaf child as a child first, a child with visual advantage second, then thirdly a child with a hearing impairment.

In summary, the parental involvement theory emerging from this PhD study could

substantially contribute to the understanding of parental involvement in the rearing of deaf children in China and to the field of inclusive education.

#### 7.2 A critique of the research

This section 'a critique of the research' is divided into two parts by discussing the strengths of the research design and then the limitations of methodology and methods.

#### 7.2.1 The strengths of the research design

Two methodologies of constructivist grounded theory and autoethnography were applied in the current research design. Constructivist grounded theory and autoethnography can act in a compatible way to gain deep insight into the data and continually reflect the interpretations. On the one hand, the main benefits of constructivist grounded theory are to constantly explore the multiple interpretations of data and seek meanings in a social process constructed by the participants and researchers. On the other hand, autoethnography helps researchers to connect their personal experiences with participants' world views that are located in a different context, in order to gain increased understanding of their stories.

To use this current study as an example, autoethnography allows me, as a deaf person growing up in a hearing family, to get involved in the world of Chinese hearing parents who raise a deaf child and connect my personal experience with those parents' stories. Constructivist grounded theory provides me with the flexible principles of concurrent data collection and analysis before constructing a theoretical framework (Charmaz, 2014; Charmaz, 2006).

It could be argued that if only constructivist grounded theory is applied to this current study, it may not enable the researcher to stay close to the data through gaining access to and getting involved in the field settings, which autoethnography advocates. Also, it could be equally claimed that if only autoethnography is applied to this current study, it may not enable the author to shape the systematic framework of theory that emerges from the data and codes, following the guideline of

constructivist grounded theory coding practices.

Therefore, constructivist grounded theory with autoethnographic reflection encourages me to open possible avenues in the continual process of data interpretation to uncover a theory based on a social and cultural understanding.

### 7.2.2 Limitations of methodology and methods

#### Methodology issues

Both grounded theory and autoethnography belong to the qualitative research methodology. Consequently the author could not avoid the issue of bias caused in the process of data collection and analysis.

Firstly, although the intensive interviews of constructivist grounded theory enable the author to access a deeper level of information, including emotional responses and unheard voices, the presence of the author and/or the author's self-conscious may result in bias to the responses (Creswell, 2014). Researchers should prepare for their interviews and check the interview guideline with a trusted person to seek feedback (Birks and Mills, 2011; Charmaz, 2014). The author discussed this issue with her supervisors and revised the interview questions if needed before conducting interviews with Chinese hearing parents. Additionally, in order to manage bias in the current research, the author used the method of theoretical sampling to guide the direction of subsequent data collection and used autoethnographic reflection to learn from possible mistakes from the initial stage of interviewing (Charmaz, 2014; Creswell, 2014; Birks and Mills, 2011).

Secondly, interpretation from a personal perspective may result in bias within the data analysis, even though grounded theory coding enables the author to stay close to the data at all times. Furthermore, both stages of initial coding and focused coding might increase bias, although constructivist grounded theory's systematic principles of coding practices would enable data interpretations to take the viewpoints of participants into account. Those biases may result from data interpretations at different stages of data collection and analysis, which are affected by the researchers'

different backgrounds, such as gender, culture, social class and so on (Creswell, 2014; Charmaz, 2014). In order to check the bias, the method of memo writing with autoethnographic reflection was applied to this current research to monitor the credibility of data analysis and to examine the different levels of data interpretation.

The current research was to explore and develop a theory of parental involvement and this theory has emerged from the data analysis of intensive interviews with a small group of Chinese hearing parents. However, this parental involvement theory may only suit Chinese hearing parents who support their deaf child to be involved in inclusive education and/or a hearing culture. Also, it may be assumed that the parental involvement theory could change by adding the potential variables of quantitative data, for example age and gender, family background and so on. Thus, in order to develop the rigour of parental involvement theory, it may be possible to consider a mixed methods research design to examine the usefulness of the model of parental involvement theory in a broader context.

#### Methods issues

The main purpose of the current research is to examine the Chinese hearing parents' perspectives of their involvement in supporting their deaf children to prepare for and be educated at mainstream schools in Beijing. According to the fact that the data were collected from intensive interviews with 10 Chinese hearing parents in Beijing, the theoretical framework from the analysis of data may not cover a wider range of unheard discourse from Chinese hearing parents of deaf children in other parts of China. However, Creswell (2014) argues that good qualitative research requires particularity instead of generalisability. In this study, the rich and thick description collected from 10 Chinese hearing parents with two rounds of interview, as well as autoethnographic reflections on the data interpretations, adds to the validity of the research. Consequently, the results of this PhD study can achieve the standard of particularity by combining constructivist grounded theory and autoethnography rather than meeting the boundaries of the research sample (Creswell, 2014; Charmaz, 2014).

#### 7.3 Recommendations for further research

The parental involvement theory in this study showed the different ways that parental involvement can help and support a deaf child's development in language and cognitive and social-emotional skills. This current research suggests that this theory could influence a child's deaf identity development. Since this PhD study was focused on a small number of Chinese hearing parents in Beijing, it would be extremely valuable to widen this exploration. Thus, this study will be fed back to different types of educators and professionals who work in inclusive education and deaf education, in order to widely apply this theory to other areas of China. Further research could utilize the same methods in different countries to develop a larger scale, international study. It would also be important to conduct additional studies in China, in different regions, to deepen the current study's findings on Chinese hearing parents' experiences of raising their deaf child. More broadly, research is also needed to determine parental involvement theory by conducting a cross-national study with a mixed methods approach, such as focus groups, questionnaires, observations and survey and so on.

Additionally, the evidence from this PhD study suggests that there are potential future research studies which need to be investigated, such as parental involvement in coaching deaf children, parental involvement in deaf children's readiness for inclusive education, and parental involvement in raising deaf children in the early years and so on.

## 7.4 Concluding remarks

In conclusion, a parental involvement theory, 'the effects of parental involvement, parental involvement strategies and the barriers to parental involvement', adding a concept of deaf identity, has been developed and emerged from the rich interview data with autoethnographic introspection. The theory of parental involvement could contribute to the theory and practice of inclusive education for deaf children. Furthermore, it is hoped that this theory of parental involvement will be to the benefit of parents of deaf children and educators in the field of inclusive education and deaf education in China.

**Appendices** 

 ${\bf Appendix} \ {\bf 1} \ {\bf Letter} \ to \ staff \ who \ will \ spread \ information \ for \ the \ participants$ 

(Chinese and English version)

Chinese Version: 宣传单

您好,

我是一名诺森比亚大学聋教育专业方向的博士学生贺熹蓉。此项研究目的是帮

助家长支持听力障碍儿童的随班就读的教育,并且促进中国融合教育的实践发

展。

我诚挚的邀请您帮忙宣传给有在北京随班就读经验的听力障碍儿童家长。如果

有家长感兴趣参加,请联系我并且我会解释此项研究的目的。

如果有家长有参加此项研究的意愿,我会和他们见面并确保在参加者信息单和

同意书所说的权利。同时,我会说明我在此项研究将要做什么,为什么要做此

项研究。另外,我会征求家长的录音许可,所得资讯保存在保险的地方并被保

密。

感谢您在此项研究中所付出的时间与努力。如果您有任何疑问,请及时联系我

(xirong.he@unn.ac.uk).

此致,

敬礼.

贺熹蓉

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**English Version:** Letter to staff who will spread information for the participants

To whom it may concern,

I am Xirong He, a PhD student studying deaf education in Northumbria University.

My research aims to help parents provide support to educate their deaf children in

mainstream schools, and to promote the practice of inclusive education in China.

I would like to ask you for a favor to provide the information of potential parents of

deaf children who have experience in mainstream schools in Beijing in China. If

parents intend to take part in my research, please contact me and explain my research

aims for them.

I will meet them to make sure their participants' human rights as shown in the

information sheet and consent form if parents are willing to take part in my research.

I will explain what I am to do and why I am doing this research. And I will ask

parents' permission to record what we talk and all the data will be kept safely and

privately.

Thank you for your time and effort in my research. If you have any questions, please

do not hesitate to contact me (xirong.he@unn.ac.uk).

Your sincerely,

Xirong He

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# **Appendix 2 Information sheet for participants**

(Chinese and English version)

Chinese Version: 参加者信息单

您好,您被邀请参加由诺森比亚大学博士学生贺熹蓉进行的此项研究。

此项研究的目的是什么?

此项研究目的是探索家长如何帮助教育听力障碍儿童在随班就读学习,并且促进中国融合教育的实践发展。

为什么我被邀请参加此项研究?

您有教育您孩子在随班就读的经验,没有选择特殊学校在读。您的经验非常宝贵,对此项研究有帮助。研究员(贺熹蓉)诚挚的邀请您参加此项研究是有助于理解有关的父母融入、父母支持的重要议题。

我在此项研究要做什么?

您将会被邀请参加与研究员贺熹蓉进行的个人访谈,个人访谈大概一个小时左 右不超过两个小时。同时,研究员(贺熹蓉)将要征求您的录音许可,所得资 讯会被保存在保险的地方并被保密。

另外,欢迎您介绍您认识的家长或朋友如果有意愿参与此项研究。

如果我不愿意参加此项研究怎么办?

如果您对您的参加觉得不自在,您可以在任何时间退出此项研究,无需给出解释理由。这不会给您带来任何麻烦。

如果我原来答应参加,后来改变主意怎么办?

如果您对您的参加有疑惑,您可以考虑退出,可能需要您给出解释理由。另外,您可以让我删除在此项研究中已经提供的个人相关的信息。

# 已搜集的资料怎样被处理?

此项研究所收集的资料会被研究员贺熹蓉保存在保险的地方并被保密。您的名字以及个人相关信息被匿名处理并保密保存,不会出现在任何印刷的材料文件上。为了让您的孩子更好的在随班就读学习,研究员(贺熹蓉)将会写出报告供您参考。

如果我想了解更多的信息,和谁联系?

主要联系人: 贺熹蓉

电邮: xirong.he@unn.ac.uk

手机: 00447942330126 (英国); 008613651073368 (中国)

您也可联系主要联系人的导师:

Professor John Swain, Northumbria University,

Email: john.swain@unn.ac.uk

Dr. Catherine Gibb, Northumbria Univsersity,

Email: cathereine.gibb@unn.ac.uk

**English Version: Information sheet for participants** 

You are being invited to take part in the research which is being conducted by Xirong

He, a PhD student in Northumbria University.

What is the study about?

My research aims to explore how parents provide support to educate their deaf

children in mainstream schools, and to promote the practice of inclusive education in

China.

Why have I been asked?

You have chosen to educate your child in a mainstream school rather than in a special

school and your experience are very useful and valuable for my research. So you are

in a good position to help me to understand the issues of parental support.

What am I being asked to do?

You will be asked to take part in interviews with me Xirong He. Each interview will

be carried out in one hour and no more than two hours. And I will ask your

permission to record what we will talk if you have them and all the data will be kept

safely and privately.

You will also be asked to introduce another potential parent from your friends or

colleagues who would be happy to take part in my research.

What happens if I do not want to participate?

You have the right to withdraw from the study at any time without reasons if you feel

not comfortable in taking part in my research. This will not affect your treatment in

any way.

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What would happen if I agree and then change my mind?

If you have any hesitations about your participation in this research, you could take

your time to think about it and then might provide further information, and you can

even ask me to destroy information during doing my research.

What will happen to the data that is gathered?

All the data will be kept safely and privately by the researcher Xirong He. Your name

and details will be kept confidentially and will not appear in any printed materials. I

will write about the research for parents, so that you can learn about this work, in

order to help your children to improve their abilities in mainstream schools.

Who do I contact if I want to ask more questions about the study?

The main contact for this study is Xirong He, Northumbria University,

Email: xirong.he@unn.ac.uk

Tel: 00447942330126 (UK); 008613651073368(China)

You can also contact:

Professor John Swain, Northumbria University,

Email: john.swain@unn.ac.uk

Dr. Catherine Gibb, Northumbria Univsersity,

Email: cathereine.gibb@unn.ac.uk

# **Appendix 3 Consent form**

# (Chinese and English version)

# Chinese Version: 同意书

我明白此项研究是由诺森比亚大学博士学生贺熹蓉进行的。我也知道所得资讯和个人相关的信息由贺熹蓉保存在保险的地方并被在此项研究中保密。

如果我同意,请在方框内打钩。

我已经阅读参加者信息单。□

我已经阅读并且明白此项研究的目的。□

我可以就此项研究提出疑问,并且得到满意的回答。 □

我同意我参加此项研究是自愿的。□

我明白我可以无条件、随时退出如果我改变主意,这不会给我带来任何麻烦。□

我同意访谈。□

我同意个人访谈和交流被录音。□

我知道我的名字以及个人信息被安全保管并保密,不会出现在任何印刷的材料 文件上。□

我明白贺熹蓉已经说明此项研究的重要性,并且提供有关的机构单位或工作人员的联系方式如果涉及到听力障碍儿童的安全与保护问题。□

我已经阅读并且明白我所担保的权利。□

| 参加者姓名:    |
|-----------|
| 参加者签名:    |
| 日期:年月日    |
|           |
| 非常感谢您的支持。 |
| 研究员姓名:    |
| 研究员签名:    |
| 日期:年月日    |

如果您对同意书满意并且同意参加此项研究,请您在下面的横线上签字。

# **English Version: Consent form**

Northumbria University. I understand all the data will be safely kept and privately copied by Xirong He in her research project. For participants: please tick boxes if you agree as below: I have read the information sheet before. □ I have read and understand the aims and objectives of the research.  $\Box$ I could ask any questions about the research and these have been answered to my I agree voluntarily to take part in this research. □ I know I can withdraw at any time if I change my mind and this will not affect my I agree to be interviewed. □ I am happy for my any comments to be tape-recorded. □ I understand that my name and details will be kept confidentially and will not appear in any printed materials. □ I understand that Xirong will explain the importance. If she is concerned about my children' safety or other child protection issues and contact the appropriate staff or authorities who know me well and help me.

I understand that the research is being conducted by Xirong He, a PhD student in

I have read and fully understand my guaranteed rights. □

| For participants: Again, if you are satisfied above consent form and agree to take part |
|---|
| in my research, please sign your name below.  |
| Print Name:   |
| Signed Name:  |
| Date  |
|   |
| Thank you very much for your support and time.  |
|   |
| Researcher's name:  |
| Signature: Date:  |

#### **Appendix 4 First-round Interview Questions**

#### **Informal questions:**

#### Brief background information

Before beginning the main part of interviews, I want to know Chinese hearing parents' background, including their education, age, working status, etc.

## Details of Children with hearing impairments

And then I will ask Chinese hearing parents about the details of their deaf children, including age, deafness diagnose, hearing loss level, equipments which currently aid hearing, etc.

#### **Formal questions:**

### Chinese hearing parents' views about deafness

I would like to ask Chinese hearing parents about their understanding the deafness, including their reaction to diagnose happened to their children, their experience to help their children, their attitude towards deafness, etc.

#### For example:

- (1) Tell me what happened about your child's deafness?
- (2) How did you feel when you first experienced your child's deafness?
- (3) Who, if anyone, influenced your reaction to deafness? If so, tell me about how he/she or they influenced you?
- (4) How would you see your child then? What happened next?
- (4) After deafness diagnosis, how did you deal with your child's deafness?
- (5) Tell me about your thoughts and feelings when you helped your child to handle deafness?
- (6) Who, if anyone, involved? What happened next? How were they involved?
- (7) What positive changes have occurred since you learnt to deal with deafness?
- (8) What negative changes have occurred since you learnt to deal with deafness?
- (9) Tell me what you learned to deal with those changes?

# Chinese hearing parents' views about educating their deaf children at mainstream schools

I would like to ask Chinese hearing parents about the information of educating their deaf children at mainstream schools, including why they choose mainstream schools, how they provide support for their children to be educated at mainstream schools, what kind of strategies could contribute to meet children' special needs, the advantages and disadvantages of mainstream schools, etc.

#### For example:

- (1) Tell me about how you chose languages for your deaf child?
- (2) Who, if anyone, influenced your choosing language? Tell me about how he/she or they influenced?
- (3) Could you describe a typical day or event when you were choosing language?
- (4) What happened next? What was it like? What did you think then?
- (5) Tell me about how you chose schools for your deaf child? What did you think then?
- (6) Who, if anyone, influenced your choosing schools? Tell me about how he/she or they influenced?
- (7) Could you describe a typical day or event when you were choosing schools?
- (8) What happened next? What was it like? What did you think then?
- (9) What positive changes have occurred since you have chosen language or schools?
- (10) What negative changes, if any, have occurred since you have chosen language or schools?
- (11) Tell me about your thoughts and feelings when you learnt to choose language or schools?
- (12) Tell me about what happened when your child was educated at mainstream schools?
- (13) Could describe a typical day or event when you supported your child at mainstream schools
- (14) What contribute to meet your child's special needs at mainstream schools?
- (15) Could you describe the most important lessons you learnt through experiencing in coaching your child at mainstream schools?

#### **Appendix 5 Second-round Interview Questions**

### **Informal questions if meeting new parents:**

#### Brief background information

Before beginning the main part of interviews, I want to know Chinese hearing parents' background, including their education, age, working status, etc.

#### Details of Children with hearing impairments

And then I will ask Chinese hearing parents about the details of their deaf children, including age, deafness diagnose, hearing loss level, equipments which currently aid hearing, etc.

# Formal questions (asking new questions if meeting Chinese hearing parents who took part in the first round interview):

### Chinese hearing parents' views about deafness

I would like to ask Chinese hearing parents about their understanding the deafness, including their reaction to diagnose happened to their children, their experience to help their children, their attitude towards deafness, etc.

# Chinese hearing parents' views about educating their deaf children at mainstream schools

I would like to ask Chinese hearing parents about the information of educating their deaf children at mainstream schools, including why they choose mainstream schools, how they provide support for their children to be educated at mainstream schools, what kind of strategies could contribute to meet children' special needs, the advantages and disadvantages of mainstream schools, etc.

#### New questions

I would like to ask Chinese hearing parents about their experience of supporting their deaf child to prepare for mainstream schools and learning at mainstream schools, their views of their child's characters, their experience of coaching their deaf child,

etc.

#### For example:

- (1) Could you describe the most important lessons you learned through experiencing of dealing with deafness? What helps you to manage deafness? What problems might you encounter? Who has been the most helpful to you during this time? How has he/she been helpful? Has any organization been helpful? What did staff help you with? How has he/she been helpful?
- (2) As you look back on your experience in raising your deaf child, are there any other events that stand out in your mind? Could you describe each one it? How did this event affect what happened? How did you respond to this event?
- (3) Could you describe a typical day or event when you were supporting your child to be ready for mainstream schools? Could you describe a typical day or event when your child was going to mainstream schools?
- (4) Could you describe a typical day or event when you were helping your deaf child at mainstream schools?
- (5) How would you describe your child in these two years [five years, eight years as appropriate]? Describe your child that you hope to be then. How would you compare your child you hope to be and your child you see as now?
- (6) What positive changes have occurred since your child was ready for or educated at mainstream schools?
- (7) What negative changes have occurred since your child was ready for or educated at mainstream schools?
- (8) What happened next? What was it like? What did you think then?
- (9) What helps you to educate your child at mainstream schools? What problems might you encounter?
- (10) Who has been the most helpful to you during this time? How has he/she been helpful?
- (11) Has any schools teachers and staff been helpful? What did they help you with? How has it been helpful?

### **Appendix 6 Back-Up Interview Questions**

### For example:

- (1) Is there anything that you might not have thought about before that occurred to you during this interview?
- (2) Is there anything else you think I should know to understand early intervention better?
- (3) Is there anything else you think I should know to understand language for deaf children better?
- (4) Is there anything else you think I should know to understand early education better?
- (5) Is there anything else you think I should know to understand inclusive education better?
- (6) Is there anything else you think I should know to understand learning environment for deaf children better?
- (7) Is there anything else you think I should know to understand parental involvement better?
- (8) Is there anything else you think I should know to understand the issues raised from the way of your raising children better?
- (9) Is there anything you would like to ask me?

# Appendix 7 The process of data collection and data analysis with the strategies of theoretical sampling and theoretical saturation

#### Phase 1 First-round interviews

- 1.1 First-round interviews with 5 parents (Parent Li, Wang, Zhang, Chen, Liu)
- 1.2 Interview with Parent Li and Parent Wang, and then analysis 2 interview data using initial coding and focused coding
- 1.3 Interviews with Parent Zhang, Parent Chen, Parent Liu, and then analysis 3 interview data using initial coding and focused coding

### Phase 2 Theoretical sampling and theoretical saturation

2.1 Theoretical sampling

Generally speaking, after analysis the new questions emerged from the interview data. So the second-round interviews questions includes the first-round interview questions and some new questions.

2.2 Theoretical saturation

Analysis results lead to next direction of interviews question. The question about parents' response to their child's deafness nearly reached to theoretical saturation. The question about parents' views of educating their deaf child was far away in the theoretical saturation.

#### Phase 3 Second-round interviews

- 3.1 Second-round interviews with another 3 parents (Parent Mei, Zhao, Song) and 1 couple of parents (Parent Xue) as well as the 5 parents who engaged in the first-round the interviews
- 3.2 Interview with Parent Mei and Parent Xue by asking the whole set of questions, and then analysis 2 interview data using initial coding and focused coding
- 3.3 Interviews with the 5 previous parents by asking the new questions, and then analysis 5 interview data using initial coding and focused coding, plus checking transcriptions with them

#### 3.4 theoretical saturation

The question about parents' response to their deaf child's deafness fully reached to theoretical saturation and I need to stop asking these questions. Instead, I need to ask more questions how parents educate their deaf child to mainstream schools

3.5 continuing second-round interviews with the rest 2 parents (Parent Zhao and Song) by asking the questions about their views of educating their deaf child at mainstream schools instead of the whole set of questions, and then analysis 2 interview data using initial coding and focused coding

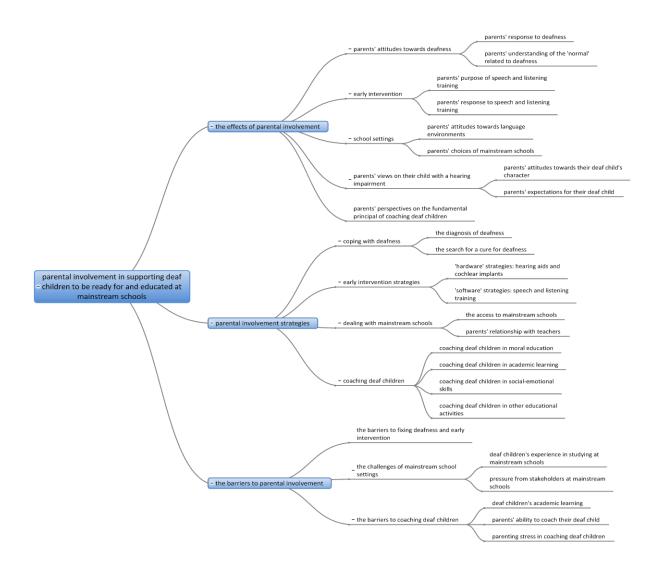
3.6 theoretical sampling and theoretical saturation

The questions about parents' views on deafness are not needed to ask because of theoretical saturation. Instead, the questions about parents' views on educating their deaf child are in the state of theoretical saturation.

#### Phase 4 back-up interviews

- 4.1 I did not ask the last 2 parents about their views about their child's deafness, so I was worried that I might miss information or different answers. Therefore, I decided to ask Parent Zhao and Parent Song about their views of their child's deafness. After interview with 2 parents, their answers are quite similar to the rest 8 parents regarding the questions about their views of their child's deafness.
- 4.2 I not only checked the transcription with 10 hearing parents, but also ask the questions to examine whether the data was in the theoretical saturation

# Appendix 8 A diagram of theoretical sorting based on coding and categories



# Appendix 9 Participant details

| Parent | Mum/  | Child's | Child's | Child's        | Year when   | Interview date  |
|--------|-------|---------|---------|----------------|-------------|-----------------|
| name   | Dad   | gender  | born    | mainstream     | a child     | (child's age at |
|        |       |         | year    | schools status | was         | time of         |
|        |       |         |         |                | enrolled at | interview)      |
|        |       |         |         |                | a primary   |                 |
|        |       |         |         |                | school      |                 |
| Li     | Mum   | Female  | 1986    | University     | 1993        | 2009, 2010      |
|        |       |         |         | (2005          |             | (24, 25)        |
|        |       |         |         | enrolment)     |             |                 |
| Wang   | Dad   | Female  | 2002    | Primary        | 2008        | 2009, 2010      |
|        |       |         |         | schools        |             | (7, 8)          |
| Zhang  | Mum   | Male    | 1982    | University     | 1989        | 2009, 2010      |
|        |       |         |         | (2001          |             | (27, 28)        |
|        |       |         |         | enrolment)     |             |                 |
| Chen   | Dad   | Female  | 2001    | Primary        | 2007        | 2010 (9)        |
|        |       |         |         | schools        |             |                 |
| Mei    | Mum   | Female  | 1998    | Primary        | 2005        | 2010 (12)       |
|        |       |         |         | schools        |             |                 |
| Xue    | Mum   | Male    | 1999    | Primary        | 2006        | 2010 (11)       |
|        | (Dad) |         |         | schools        |             |                 |
| Liu    | Mum   | Male    | 1992    | Middle high    | 1998        | 2009, 2010      |
|        |       |         |         | schools (2002  |             | (17, 18)        |
|        |       |         |         | enrolment)     |             |                 |
| Zhao   | Dad   | Female  | 2001    | Primary        | 2008        | 2010 (9)        |
|        |       |         |         | schools        |             |                 |
| Song   | Mum   | Male    | 2002    | Primary        | 2009        | 2010 (8)        |
|        |       |         |         | schools        |             |                 |

#### **Appendix 10 Personal story**

I was having uncontrollable high fever for over 10 days when I was 10 months old. The heavy sickness spread to inflammation of my lungs. My parents did not have an idea how to look after me and I was sent to hospital to receive an injection called 'Garamycin'. After an injection, my high fever stopped. However, my parents did not realize this injection was overdose and they also did not know the 'Garamycin' could affect the cell of human ears.

My parents did not realize I became deaf after the fever had stopped and they did not pay much attention to my ears. One day, the nursery staff called a group of baby to have lunch when I and my hearing peers were playing. My hearing peers reacted to the nursery staff and started to be ready for lunch. Only me was still playing. The staff called me again and again and asked me to have lunch. But I was still playing without response. The staff realized there must be a problem of my ear and told my mum when she picked me up to go home. Then, my parents brought me to Beijing Children's Hospital to check whether there was any problem of my ears, however, the instrument was simple to give a report that I might have great hearing loss. Later, my parents took me to Beijing TongRen Hospital to check with my ears. The instruments displayed I was a profoundly deaf baby with over 100dB. (I understand over 100dB is quite similar as the sound of airplane starting to fly into sky.)

I was diagnosed as a profoundly deaf baby until I was 1 year and 3 months old. My parents often thought I could speak at a later age and they also thought I had slow reaction before they were getting know deafness. They felt shock and disappointed when my deafness was confirmed in the hospital.

During the early childhood, I experienced a different life from hearing peers, I spent a large amount of time in hospitals and private clinics with my parents. My parents turned on their duties to look after me day by day. My dad decided to look after me at night and my mum decided to look after me at daytime. Lots of costs on medicine to cure my deafness often oversupply their both wages. They still continued to search any cure to my deafness and I experienced electronic anesthesia, Qigong, acupuncture. (When I get to know the fact that there is no possible to cure the sensorineural deafness at an undergraduate course at my university, I insist not on telling my parents about the truth because it would make them sad. Perhaps they knew the fact earlier than me and they might not believe that the truth. I remembered they stopped to find any cure to my deafness until I was 13 years old when I started to face heavy stress from study in the middle school and teachers usually gave lots of assignments every Friday, so I used weekends to complete my assignments.)

After I was diagnosed as a profoundly deaf baby in Beijing TongRen Hospital, my

parents heard that there was a kind of neurotrophy medicine from Japan to cure my deafness. And the doctors advised the effect of homebred neurotrophy was not better than that of the import and they recommended using the Japan product of neurotrophy. My dad asked his colleagues and one of his colleague told my dad his mother worked at another hospital. In this way, my dad could buy the import nutricentical from his mother's workplace. All import neurotrophy were cost by my parents.

The journey of neurotrophy started when I was 1.5 years old. Everyday I received the injection into the muscle of my hip until my hip was too stiff to be given the injection. When I had the last injection into the muscle, the liquid of the injection was out. Therefore, I was forced to have an injection into veins of arm, foot and even head in turn everyday. I had been given injection for around 2 years until I had antibodies to the injection of neurotrophy.

That is my first journey in curing my deafness. I exactly do not know how the neurotrphy's effect is because I was too young. Maybe it was helpful and maybe not.

My parents could afford to buy me a pair of hearing aids when I was 5 years old. I remembered this pair of hearing aids looks like small match boxes. And my mum sewed a pocket in the front of clothes for me, so I could find it easy to put the hearing aid boxes in that pocket. So I could play outside without worrying about boxes to be dropped out. However, I could not play in the rain or wet weather with hearing aids because this circumstance would affect my hearing aids when I started to use hearing aids. (I have been careful about my hearing aids until now and I know how to protect hearing aids from damage.) I also remembered my hearing aids changed to the lighter things behind my ears when I was 6 or 7 years old.

When my parents knew a method of Qigong from friends, my mother brought me to a quite big hall near Wu Ke Song in Beijing. Qigong was popular in our community and Beijing city. Lots of people started to learn and pass the information to each other, especially old people. It was said that Qigong can cure deafness. Qigong can be translated as energy or spirit kong fu. Qigong is a kind of Chinese exercise method, which uses breathing, physical and mental movement training to keep mind, body and spirit healthy and balance.

My mother and I learned the approximate method of Qigong in the hall and after workshop my mother bought a series of book and audio-tape no matter how much. The next day, my mother took me to nearest park called 'The Temple of Heaven' to start practice Qigong at daytime followed the book and practice again at home in the evening. Later, we accidentally found a group of people who practice Qigong and most of them are old people and a few are middle-age people. We started to involve this group to practise and the funniest is to obviously see I am the youngest member of them aged 6. And I looked like a very short old people except black hair. After

more than one year, my hearing loss did not improve, instead, my health was better and better. So, the efforts of curing my deafness were in vain. It was appeared that Qigong aims the old people, I think.

When my parents heard a method of acupuncture from newspaper advertise column, my dad drove a car to take me and my mom to visit a doctor. The clinic was located in Liu Li Qiao of Beijing and it was very far away from my house. My parents honestly begged the doctor to cure my deafness and look after me, when they found the doctor who can use acupuncture to cure deafness. They had eager feeling to hope my ears can be better no matter how hard, they insist to find any cure to deafness no matter how useful.

The journey to cure my deafness started again and I was in Year Four in a mainstream primary school. I often used weekend to go to hospital and sometimes I had to use the time of less important class on weekdays to receive the treatment of acupuncture over almost half day. I could not eat lots of food before starting each treatment of acupuncture. Furthermore, I have to drink traditional Chinese medicine after treatment and I was not suggested to eat ice cream during the period of acupuncture. It was said the ice cream would affect the effect of acupuncture. In other words, I must resist the desire to eat ice cream. Sometime, I was just licking with one lap of my tongue when I saw my classmates eating ice cream after school. It was so hard for me to resist the desire to ice cream in hot summer when I saw people eating ice cream in hot summer. And I was successfully to not eat ice cream for 2 years during the treatment and I was often hoping my deafness become better because I could eat ice cream if my ears could become normal.

During each treatment, my head and ear was full of 12 needles. Sometimes the needle was so deep in the muscle that it can blood, the doctor pulled out the needle and used cotton with ethyl alcohol to stop. After the blood stopped, the doctor re-do acupuncture and the pain was harsh again. When I felt this kind of pain each time, I had to clench my fists or my hands tightly catch my leg's muscle or knees. It would help me to avoid crying out during the treatment, perhaps this way helps me to reduce the feeling of pain. I never let out a yell.

After finishing each 3-hour course of the treatment, I could eat foods. Sometimes, I could endure hunger to receive 3 hours treatment in the hospital, even I could fall asleep. My dad sometimes drove me to the hospital to get a place of bed at a very early morning and my dad wanted me to lie on the bed to sleep well for 3 hours. I remembered there were only two beds in the clinic. If we arrived a bit late, the places of bed were occupied by others. We could not wait for another 3 hours to get the place of bed because it was also far away from my house. So I sit on the chair for 3 hours rather than waiting for a place of bed after 3 hours, when I was falling asleep on the chair, but I have to sit straight, if my head was a little bent, the 12 needles touched my pain. I had better not sleeping on the chair with 12 needles, but sometime

I was so tired that I could fall asleep again and again on the chair, although I could feel much pain on my head and ears. Sometimes, my dad had to work and I only took the bus over one hour to reach the hospital by myself.

Except that the experience of curing my deafness, I started to experience the hard time to practise in speech and listening when I was 6 years old. My parents heard the news from friends about the recruitment of the preschool programmes attached to the deaf school and this programme aimed to practise oral language for deaf children. They knew this news very late and they knew it was not possible for me to be recruited because of full place booked at that time. Otherwise I had to wait for another year to start to learning oral language, which means I would be 7 years old to learn speech. However, they just had a try and brought me to wait for the staff of school who were finishing work at school between 3-6pm. I was so young that I did not understand my parents why asked me to wait at the school gate. My dad eyes suddenly shined when he saw the old man came out from the office into playground. My dad asked me to quickly call him 'ye ye' ('ye ye' means grandpa in Chinese.) and then I did. Maybe my voice was attracted to the old man to come over to my dad and I saw my dad and that old man was talking. My dad and my mum honestly begged that man to give me a place to register at the preschool programme. Later, I was so lucky to be chosen as a member of the deaf school. It sounded like I broke the record at that deaf school. When I entered to the gate of deaf school on the first day, the old man standing at the gate smiled at me. I did not know who this old man was before. One day, my teachers recommended me to attend school activities on behalf of my school due to my outstanding performance in my class over 2 months. Then, I realised the old man was head teacher in my deaf school. My parents also did not know who the old man was at that time and they knew he must be a deaf school teacher.

During the period in deaf school, I experienced the happiest time with deaf peers and teachers of the deaf. I was arranged the first student to meet one-to-one tutor to practise speech in a small soundproof room out of my class at 9 o'clock. And I did not know why I was the first student to meet my tutor until I was arranged the last one to meet my tutor one day. On that day, I remembered I was not asked to meet tutor at 9 o'clock and my tutor asked me to see her at 11 o'clock (11.30am was lunch time). I was a bit anxious when I was waiting and I also attended the group class. Finally, I met my tutor and the tutor seriously asked me 'do you know why you are the last one?'. And then my tutor told me 'if you did not well practice with me, you would be the last one and you would not have enough time to learn new knowledge. Your friends are having lunch now and you would be late to have lunch.' I understood I was naughty and I did not listen to my tutor for a period before that day. After that day, I was working hard to practise with my tutor and I understood the first place was not easy to keep. In addition, my parents coached me at home night by night to strengthen the skill of speech which was taught at the deaf school on the same day, even they used the time on way to school/home to practise my oral language. When my parents sent me to school or picked me up to home, I was not excited because I had to practise speech with them. If my grandparents did, I was very happy because I did not need to practise and I could play for a short time. I often imagined 'turn to grandparents please' before go to school or go home, well, most of time my parents did more than my grandparents. So I knew my magic did not help. (When I am looking back to my childhood, I appreciate from the great effort from my parents. Without their strong faith, I am afraid I cannot speak Chinese clearly.)

It was not surprising to know that I received my parents' unusual oral language training method at home and practiced basic Chinese words day and night. I remembered my mum used chopsticks and mirror to aid my pronunciation, when I started to learn the pronunciation of the basic Chinese alphabets 'a' 'o' 'e' 'i' 'u' 'ü'. The pronunciation 'a' was the first letter to learn. My mum opened the mouth to look like a big circle to say 'a' while she put my one hand on her front neck and put my the other hand on my front neck. I imitated her mouth's shape to open widely and tried to pronounce 'a'. I could not control my tongue movement, so my mum used chopsticks to press my tongue to keep flat before I was ready to pronounce 'a'. My mum also asked me to use mirror to see my mouth and my tongue, in order to practise pronouncing 'a' many times everyday. (I think it was very tough task to practise pronunciation.)

My parents may not like me to do sign language because they may not aware of sign language at that time and they also grabbed any time whenever I was awake to remind me of practice speech, even whenever I was play outside. It was crazy and the practice in speech and listening was huge bitter task for me at that time. Sometimes I was so frustrated that I wanted to stop trying to speak. Sometimes I refused to practise and was ready to move on to something else. However, my parents often said to me 'you are not old enough to make that decision'.

After one year in deaf school, my parents encouraged me to enrol in a local mainstream school which was 15 minutes walk from my home. There was an exam of entrance to primary school for each student and it was a big challenge for me to face the important choice in my life, either mainstream schools or deaf schools. I remembered I was in a happy mood to meet the examiner and I was fine to answer some simple previous questions. When they asked me to count from 1 to 100, I tried my best to speak clearly number one by one and then I did not know why I started to cry. I remembered I insisted on counting to 100 when my tears were flowing on my face. After the exam finished, I cried to find my parents who stood outside the gate and I thought I failed the exam. My parents did not say a word and just hugged me in their arms. Fortunately, I passed the exam and my parents were excited to kiss me.

Before I started to be a student of mainstream school in 1991, one day, my parents brought me to a mainstream school to visit the head teachers. Head teachers have

concerns because they never met a disabled student even a deaf student and none of school teachers have experience of teaching the disabled students. They also afraid that they would have no capable of teaching a deaf student like me. My parents honestly begged them and tried to persuade them to accept me. One of three head teachers liked me so much and he agreed to have me in a mainstream school. However, they said I can be allowed to study at mainstream school one year and then decide whether I could continue studying at mainstream schools depends on my academic score. In other words, if my academic score passed at Year One, I can continue studying at mainstream schools; if my academic score did not meet the standard of Year One, I have to go back to deaf school. My parents decided to want me to pass the academic score at Year One in their heart and I can remember their faces and body languages are full of a strong decision.

On the first day of starting studying at the mainstream school, I had a happy feeling at early morning and I cried after school. What a two different feeling about mainstream school life at the first day. I came to school with a happy mood to see new teacher and classmates and everything was new for me. When I had a moral class, I remembered the teacher stood at platform speaking for 45 minutes without notes on the blackboard. I felt very disappointed when I saw my hearing peers nod to express they understand what that teacher said. I did not know how to follow the teachers next time. I wanted to cry but I tried to hold back my tears into my stomach. After school, I started to cry out on the way home. My mum asked me why I was crying and I could not express what happened at school by oral. I remembered I pointed at the textbook of moral and my ears with shaking my head, my mum suddenly understand what I meant. My mum asked me again, 'you do not understand, right?' and I did not understand what my mum asked me. I still pointed at textbooks and pointed at my ears, my mum asked me, 'I see, you cannot hear what teacher said. Right?' I probably understand the word 'hear' 'teacher' when I was young at that time. My mum pointed the textbook and told me, 'we can study together'.

I did not imagine I would face the challenge on the first day in a local mainstream school and I thought the life between deaf school and mainstream school is the same or similar. However, the mainstream school life seemed to go beyond my ability and my imagination when I experienced the first time of normal school life with hearing teachers and hearing peers. After one day in a mainstream school, I have a strong desire to become a hearing person one day and I also imagine I would be given a pair of ears with normal hearing under magic. The life of mainstream schools was much different from that of deaf school. I got to know I am the only deaf student in my school around 1000 students.

After six classes of the first day, I did not follow 6 different teachers of different lipreading. Some classes have board writing backed up and I could copy on the paper, whereas other classes have little board writing. Each day had 6 different classes. The second day added another 4 new classes, I still did not follow another 4 different

teachers with their different lipreading. Overall, I had to be familiar with over 10 different teachers and 45 hearing peers in my class in a short time. My parents realized this issue and my mum visited my class tutor to discuss the progress with my academic regularly. My teachers used the diary to record what taught in 6 subjects a day. My mum coached me at home according to the diary and she wrote the feedback of coaching me at home. Sometimes, my mum felt not capable of coaching me in some subjects and she would take time to visit teachers at school. She acted as a student of primary school and asked teachers how to teach me in different subjects. At school, I study with hearing peers, at home, I study with my parents. My mum is good at Chinese and my dad is good at Maths.

When I was Year One in a primary mainstream school, my parents encouraged me to attend the club of playing Ping Pang, called table tennis. I was the only one deaf student of the Ping Pang group. I remembered there were 15 students in a group to play with one coach. They had many different groups, it depended on age and development level. I enjoyed watching players' wonderful performances and I started to learn the skills with coaches step by step.

I remembered I started to practise sports when I was Year Three. I got two 'liang' (liang means 80-89% score) and it would affect me to achieve the criteria of the award called 'san hao xue sheng' ('san hao xue sheng' means students can achieve three distinction on academic, sports, morals together. The score of both academic and sports must be over 90% and morals would be judged over 95% votes by classmates and teachers. The district level of 'san hao xue sheng' is strictly assessed commencing in Year Four. The Beijing city level of 'san hao xue sheng' must achieved by getting three awards 'san hao xue sheng' in Year Four, Five and Six and voted by classmates and teachers. If students can get three continuing awards 'san hao xue sheng', the students can be potential to be directly selected by good middle school through a series of accessment. In other words, only less than 1% students who meet the above criteria might be chosen.) I could meet two distinction on academic and morals, only sports score was less than 90%. I thought I was tiny and short and I was not good at the kind of sports which needs power and height, for example, throw heavy balls, the high jump, whereas I was good at the kind of sports which needs fast, for example, running, skipping. For this reason, the average of my sports scores less than 90%. My parents worried about the sports score and they were concerned that I could not get the award 'san hao xue sheng' because of sports score that could pull me down in next three years. My parents decided to take a lead role in developing my skills in basic sports.

My dad was a football player before he worked at company and he knew how to teach me to love sports. Actually, sports was viewed as a bitter task for me, however, it was much less painful than speech practice. I remembered we chose the nearest park called the Temple of Heaven as the best of place for sports practice and we found some places were good to start practice in sports. For example, we could run a

circle in the middle of park and we could find stone steps to the gate of the temple called 'the Hall of Prayer for Good Harvest' to practise the skills of jumping. Through one year hard working, I finally got the 'you' on the sports score ('you' means 100%-90% score). Later, when I started studying at Year Five, I was so lucky to be chosen as a member of school sports team consisting of around 10 students who studied at Year Five and Six and this sports team would need professional practice to attend compete with other schools in same district area and even in city Beijing. I remembered we had to use the time after school to practise the professional skills in basic skills, running, jumping, throwing.

One day, my coaches decided to test each student of sports team to run the long distance around 3000 metres and this test never be done before. This test was challenge for us when I was in Year Five. I did not know whether I could accomplish this task before I had a try. The test started, each of us started to run faster than me, however, after half an hour, I slowly passed over one by one who run ahead me, some of them gave up running, my coach rode bike to encourage them to keep running. And then, I did not know where they were and I just kept running like Forest Gump. At last, only I finished the task by running all, no stopping and no walking. My head coach standing at the playground of my school to watch who got back firstly and he could not help praising me as the youngest member of the team to finish task and he never thought I could accomplish the long distance. Me too. When my coach got back to record each test results, he also praised me. I did not know how I could accomplish it because I never tried to run such a long distance. I just remembered my head and my clothes were full of sweat. From that task, my confidence in sports increased in spite of my tiny body.

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