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Santa Barbara

Perspectives of Parents of Children with Autism or Intellectual Disability on Inclusive  
Education in Urban China

A dissertation submitted in partial satisfaction of the  
requirements for the degree Doctor of Philosophy  
in Special Education

by

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By

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## ABSTRACT

### Perspectives of Parents of Children with Autism or Intellectual Disability on Inclusive Education in Urban China

by

Weiwei Chen

The dissertation study is focused on an investigation of the thought and attitudes on inclusive education and the Chinese approximation of inclusive education—the “Learning in Regular Classrooms” (LRC) by parents of children having autism or intellectual disability in urban China, as well as their perceptions of their children in terms of their disabilities, in reference to their typical peers. Sixteen qualitative interviews were conducted on parents of pre-school and school-aged children, from two metropolitan cities, Beijing and Chengdu in China. It was found that although most of the parents possessed concrete understanding of inclusive education, the poor implementation of LRC, as well as the unsupportive climate on disability in the outer society, constantly made them feel the painful gaps in practice. However, they unanimously expressed their determination to have their children mainstream in LRC, in comparison to the special educational schools, based on their ultimate goal for their children to enjoy an independent and honorable life in the future. In support of their aims at securing the LRC placement, the parents also listed a number of mental and pragmatic strategies to tackle the challenges confronting their children in LRC, especially the severe stigmatization brought about by one’s disability in China, from the school administrators, typical peers, teachers, and others important persons.

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## **Chapter 1**

### **Introduction**

Over the past several decades, along with a widespread denouncement of segregation of individuals with disabilities, inclusive education has been gradually gaining momentum worldwide (Mitchell, 2010). Although its emphasis on tolerance and appreciation for diversity has been largely recognized, inclusion has not been consistently translated into current educational practices (Hodkinson, 2012). In China, many special education researchers have expressed dissatisfaction of current exclusive practices of individuals with disabilities mainly through academic literature focusing primarily on data collected from the provision of resources for “Learning in Regular Classrooms” (LRC)—an educational enrollment in China featuring children with disabilities learning in the same classrooms with typical kids (Deng & Zhu, 2007). The negative opinion about LRC is also expressed in mass media reports covering the dire situation of school-aged children with disabilities, as well as and the perspectives of the children’s family members (Zhu, 2016). However, very rarely are parents’ opinions about the LRC investigated in a systematic way. An interesting situation in China is that there has long been a dual emphasis on both the LRC and publicly-run special education schools. Under these circumstances, it will be informative to learn the parents’ preference between the two distinctly different educational formats and inquire into the underlying reasons for it.

### **Background of the Study**

**“Inclusive education” in China.** Currently in China, there has been a controversially practiced educational institution titled the LRC, “Learning in Regular Classrooms” (or *Sui Ban Jiu Du* in Mandarin), which, similar to the widely recognized

practices of inclusive education, refers to allowing students with disabilities to learn in the same classrooms as their non-disabled. However, compared with an ideal state of inclusive education, which would be explicated in successive sections, the localized LRC is currently performing inadequately with a much lower level of supporting resources. The creation of the LRC was said to have stemmed in the 1980s when China severely lacked both financial resources and trained professionals in order to build and provide individualized educational settings for children with special needs in separate, segregated schools. Therefore, the students with special needs were placed within the general educational school with typically developing peers, and were offered little attention and assistances from the teachers. Yet presently, at a time when China's economy has soared for more than ten years, there are no noticeable changes made in the state policy in regards to the LRC. (Deng, 2001; Deng & Manset, 2000; McCabe, 2007; Peng, 2011; McLoughlin, Zhou, & Clark., 2005; Shang, Fisher, & Xie, 2009). At the same time, the government remains focused on promoting a dual system of including students with disability to learn in publicly operated segregated special education schools as well as in the regular classrooms (Liu, 1992; Zhao, 2013).

Ideally, inclusive education subscribes to a belief that runs counter to the discredited "medical" view of people with disabilities which sees them as "passive, being enquired, subject to charity only" (Hunt, 1998, p. 18) and one must recover from the disability in order to take part in schools and society. However, except for the stance of inclusion that has been set up in the principal of the LRC in China, the medical model is still the sole theory on which the government authorities rely to understand the lives of people with disabilities (Deng, 2001; Huang, Guo, & Bricout., 2009; Lang, 2009; Stein,



2010), similar to what was observed in many Western countries from World War II to the 1980's (Ferguson, 2001). What aggravates the difficult situation of people with disabilities, after the Cultural Revolution ended in 1977 in China, the capitalist market economy has swept almost each public sector of China. The consequent profit-driven, elite-oriented fashion resulted in the waning of both the traditional Confucian wisdom of “tenderness” and “charity” and the more recent socialist ideology that each person is equal on the basis of the fact that they all contribute to the construction of the socialist society have both waned from public awareness (Shek & Merrick, 2012).

While the LRC is struggling with many programmatic inadequacies and drawbacks, inclusive education as an emerging terminology disseminated from the Western countries is gaining significant attention from people in China, particularly within the academic and mass media circles (Deng & Zhu, 2007; Zhu, 2016), although its recognition among the stakeholders involved in special education remains unknown. Presently, national educational policies are increasingly using the term “inclusion” to express an attempt to improve various service and social outcomes of individuals with disabilities (Beijing Disabled Persons' Federation, 2014). Therefore, it is legitimate to anticipate that the concept of inclusive education will grow to be realized in social and educational settings more and more often.

**Inclusive education.** Over the past 30 years, including children with disabilities into general education has become a sweeping trend across countries (Mitchell, 2010). Partly, it has been developed into educational practices that open the opportunity for children with disabilities to go to the same neighborhood school as other children their age do. Just as importantly, the spirit of inclusion has been written into legal decrees that

each child with disabilities must be granted the right to be in the least restrictive educational setting in order to desegregate them from typically developing children (Yell, 2006). The building of inclusive schools that welcomes students with disabilities has gained speed, especially after the issuance of Salamanca Declaration in 1994, calling for practices ensuring that inclusion be the norm in education (UNESCO, 1994). This declaration formally recommended that governments should accept and promote the principle of inclusive education in their laws and policies. The Salamanca Declaration agreement made in the World Conference on Special Needs Education was likely reached in part after its participants witnessed firsthand the abject suffering of children with disabilities who had been stigmatized and neglected as a result of being excluded and ostracized from being legitimate members of their society in their current and future lives (Lang, 2009). In comparison, allowing children with disabilities the experience of actively participating in school life side-by-side with their general peers have been repeatedly shown to produce desirable academic and social results in them as well as their typical peers (Lindsay, 2007).

However, as inclusion has been widely implemented in schools in the Western countries and yielded frequent positive student outcomes, there have been many unsuccessful instances during the process (Mitchell, 2010; Mittler, 2005; Parementer, 2007; Ravaud & Stiker, 2001; Warnock, 2010). This phenomenon draws criticism from a number of people who feel “disillusioned” by inclusion (Hodkinson, 2012) despite their past support of this ideology. In this case, what is doubted is not “inclusion” as an aspiration that contends for the equal right of educational pursuit. It is, in fact, the suspicion of whether “inclusion” should be examined more as a pure value rather than as

working concepts defined by varied sets of meanings under different socio-cultural contexts (Norwich, 2008). Attractive as the terminology is, researchers start to realize that when put into real-life practice, inclusive education likely will be held up by barriers called “dilemma of difference”—that is, as long as there are differences between individuals, unfavorable results will show up at an attempt to merge these individuals into a group, whether their uniqueness gets addressed or ignored (Minow, 1985; Norwich, 2008). In fact, even though people with disabilities exist “in the environment, there are few signs of full integration of disabled people with the environment.” (Titchkosky 2003, p. 121)

**Parents’ perception of inclusive education and their school choices.** The increasing participation of parents and/or caregivers into their children’s school life has been highly lauded during the past two decades throughout Western countries (Swap, 1993; Edwards & Kutaka, 2015). For young children having special educational needs, their parents’ partnership with providers of school education and the investment of their unique thoughts are especially imperative. At the time when inclusive education started to be implemented in Western countries, large bodies of studies were conducted on parents’ perception and attitudes on inclusive schooling in which their children were involved (e.g., Cook & Swain, 2001; Erwin & Soodak, 1995; Turnbull & Winton, 1983). Findings indicated that inclusive education was neither a good or bad educational approach in the eyes of the parents. However, since school education is such a common approach to cultivate and train school-aged children to prepare for an independent life in society, most parents are forced to make a choice among various schools available to them (Bowe, Ball, & Gewirz, 1994; Godwin & Kemerer, 2002; Lewis, 2003).

Unfortunately, these choices could be particularly hard for parents whose children require special educational support (Heiman, 2000; MacMillan, Greshan, Fornes, 1996; Trainor, 2010).

Past research demonstrated that the logic of actions and perceptions of a certain group of people in terms of child's educational pursuit could be effectively examined by observing their expectations and accompanying values pertaining to the person as a learner (Eccles & Wigfield, 2002; McClelland, 1987; Murphy & Alexander, 2000, cited in Wigfield & Eccles 2000). As to the parents' perception of education in relation to their own child, it has been largely affirmed that parents act rationally, and that information exposed to and acquired by them, in addition to the values that the parents places on aspects related to their children as a learner play a powerful role in a parent's school preferences.

### **Statement of the Problem**

Apart from the fact that the concept of "ideal inclusion" is discussed in the fields of education, social psychology, and legal fields in a similar way, it is important to discuss inclusive education by reflecting on perspectives that are used by a certain group of people and the socio-cultural geography in which this study is situated (Amstrong & Barton, 2007; Parmenter, 2007). Inclusive educational practices exercised across nations and cultures to fulfill this ideal have fallen into a wide range of formats, and have faced a variety of challenges as reported by educational staff, parents and other family members, and even the students with disabilities themselves, as well as school educational authorities represented by the schools (Chang & McConkey, 2000; Collins & O'Mahony, 2001; Low, 2009; Lowe & McDoneel, 2008; McCabe, 2007; Norwich, 2008; Riddell,

1998; Zhao, 2013). The three separate groups of individuals (i.e. teachers, parents or family members, and school authorities) all actively consider the educational benefits for students with disabilities and invest their best efforts towards those educational benefits. However, each category of people may have different thoughts and actions compared to one another based on one's differing values and goals (Collins & O'Mahony, 2001; Low, 2009; Lowe & McDoneel, 2008). Therefore, a meta-analysis of the pros and cons of inclusive education will present a mixture of information sought from all stake-holders, which may or may not depict the overall shape of the educational practice in question, and will definitely fall short of capturing group-specific endeavors and concerns. Identifying these endeavors and concerns individually may be useful for the advocacy efforts of this group and may also contribute to the mutual understanding and further collaboration between groups of different interests.

In addition, research has indicated that inclusive education has been implemented differently and has carries distinctive implications for similar populations in different countries and areas (Deng & Zhu, 2006; Meyer, 2010; Norwich, 2008). This is especially the case within countries such as China, where inclusiveness and diversity are the core concern of neither schools or policy makers, and, on the other hand, secluded and separate special educational institutions are highly favored by educational authorities as the most suitable place of learning for children perceived to have impairments (Deng & Zhu, 2006; Deng & Manset, 2000; Li, 2010; Peng, 2011). Therefore, inclusive education must be carefully scrutinized under the lens of the interaction between group identities and geographical locations.

Along this line of thinking, it is of vital importance that the direct viewpoints of parents

of children with disabilities regarding their thoughts and opinions of inclusive education are thoroughly examined. No less important, the investigation should be done with the additional intention to reveal the perceived disability-related social, cultural, and educational status quo in the eyes of the parents in China. The latter is especially needed when past literature about parents' perception of their children's inclusive or segregated education is so varied (Cook & Swain, 2001; Erwin & Soodak, 1995; Grove & Fisher, 1999; Guralnick et al., 1995; Hanline & Halvorsen, 1989; Jenkinson, 1998; Kasari, Freeman, Bauminger, & Alkin., 1999; Larson & Lakin, 1991; Leyser & Kirk, 2004; Lowenbraum, Madge, & Affleck, 1990; Miller et al., 1992; O'Shea, O'Shea, & Algozzine, 1989; Reichart, Lynch, Anderson, Svobodny, Di Cola, & Mercury, 1989; Simpson & Myles, 1989; Turnbull & Winton, 1983). Although according to a few other studies (Ma & Tan, 2010; Nennet & Gallagher, 2013), parents generally demonstrated more enthusiasm and optimism about having their children studying in mainstream settings than the teaching staff, findings about their specific preferences of educational placements were mixed as indicated in the myriad of studies listed above. On one hand, many parents spoke positively about inclusive education; on the other, a few also expressed various degrees of concern, even solid preferences for segregated settings for their children. It is revealing that, overall, evidence ran thin that parents resolutely embraced a learning environment offering their children with disabilities the chance to study with general kids. However, deep underlying reasons were rarely looked into and can not be fully understood without closely examining the interaction between a parent's subjective judgment and the larger context, as is the focus of this study, between the minds of Chinese parents and the context of modern Chinese society.

Most preciously completed studies that focused only on Western countries, such as those cited above, understandably concentrated only on the past two to three decades, when interests in learning about the outcomes of mainstreaming children with special needs increased within these Western societies (especially within the United States), after the legal guarantee of children's equal and least restrictive educational rights (The Minnesota Governor's Council on Developmental Disabilities, 2007), and when the importance of parental participation in a child's education started to draw scholarly attention (Ferguson, 2001). In other words, these studies were mainly conducted in an early stage of inclusive education in the Western countries and may provide a reference point and rationale to look more closely into the burgeoning inclusive educational practices and the perspective of parents of children with special needs in China.

In contrast to the historical background of most of these Western studies, China is currently running a dual-track system in which the LRC ("Learning in Regular Classrooms") and segregated educational settings are promoted simultaneously by the government. Interesting though, public investment on segregated special education schools is shown to far exceed the one on the LRC (Peng, 2011). Therefore, when inquiring about the parents' view of the LRC, it is impossible to ignore their attitudes towards the highly advertised special education schools. Naturally, the dual stress on the two contrasting educational settings prompted me to investigate Chinese parental choices between the LRC and the segregated special schools further. Also, because of the much observed, negatively-based medical model perspective on individuals with disabilities in Chinese society, how parents' attitudes on inclusive education might be affected given possible impact of this prevalent negative assumption on their view of their children with

disabilities are also worth examining.

A parent's choice could be forced and difficult to make when not one of the options provided to a parent are perfect, and especially when the target population are children with disabilities (Heiman, 2000; MacMillan, Greshan, Fornes, 1996; Trainor, 2010). For this reason, I believed that it is valuable to make sense of the attitudes and choices by parents of children with disabilities living in China not only by a simple depiction of their preferences, but also by fully examining a parent's line of thinking of how they choose between the two, the LRC and the segregated school setting, as guardians, representatives, and advocates of their children with disabilities. Furthermore, I seek to further examine a parent's conceptualization of inclusive education, his perception of the current inclusive practices in China, and how much a parent believes that his child is actually included in real life, as a contextualized psychological background of their preferences of educational placement.

**Theoretical frameworks on motivation, expectation and values.** There currently are myriad of studies focusing on schooling-related choices based on major theories of motivation, expectancy and values on learning (Eccles & Wigfield, 2002; McClelland, 1987). The core of these theories is captured within the issue of disabilities in Reindal's (2008, 2009) relational model for examining the life quality of individuals with disabilities by examining the individual's capability to achieve certain life goals. Unfortunately, Reindal does not further theorize the model and apply it to schooling motivation. Moreover, to date no existent study has been completed on parental choices of placement based on either the general theories addressing schooling motivation and expectation or Reindal's relational model.



The motivational theories and Reindal's relational theory described above have opened a window into a glimpse of the considerations of parents when they must make a choice of a certain schooling setting that assumedly can foster more satisfactory learning for his child. As suggested by these theories, during a parent's process of choosing an educational format, parents may tend to gauge their children's abilities, their levels of needs, and the supports that can be obtained (either from the schooling institution or from other sources). At the same time, they may also compare subjectively their values attached to each learning task, for example, learning to make verbal requests, designated to be fulfilled. (Eccles & Wigfield, 2002; McClelland, 1987; Reindal, 2008, 2009)

***Dilemma of difference.*** When parents become the lead decision-makers in determining the appropriate educational setting for their children with disabilities in contemporary industrial societies where the issue of equal educational opportunities have increasingly been governed by national policies, parents often stumble on unforeseen barriers that are sharply noticed by researchers but far from being widely discussed. Among these difficulties, the biggest obstacle that those parents might face is that, under the current socio-economic culture of the industrialized society, parents of children with disabilities belong to those who are most keenly experiencing the pain from stigma incurred by a "dilemma" of "being different" (De Wolf, 1974; Goffman, 1977), a notion summarized from a number of policy researchers (Minow, 1985; Norwich, 2005, 2008). Whether the unique characteristics of their children with special needs are addressed or not in their educational settings, stigma and losses of opportunities inherently follow. These unfavorable outcomes are believed to derive from certain roots that can hardly be ignored. For one thing, the simple presence of "differences" (or more accurately,

“deviances” from the norm) is something that stigma is perceived to be tightly attached to across cultures.

At the same time, plural and even incompatible values and goals held juxtaposed within the person also makes it natural for the educational dilemmas to happen when related to various physical and cognitive impediments to school learning. Some researchers believe that the plural values are set up as a result of the dual influence of a private, personalized drive and the pressure received from a larger system (Cole, 2005; Stocker, 1990, as cited in Norwich, 2008).

As there is neither a well-supported inclusive education system in China nor a reportedly well-functioning special education school system, it is worthwhile to look into parent preferences within the dilemmatic framework and examine how this model of special-needs choice works under such a localized, Chinese socio-cultural and educational context. Expectancy-value model and the dilemma model were the two theoretical model around which the interview protocol was primarily developed, although parents interviewed for the study had considerable latitude to come up with information that deviate from the two theories; the protocol was semi-structured in order to accommodate free conversation.

Therefore, it is both meaningful and feasible to conduct a study on the perspectives of parents of children with disabilities in China to fill a missing piece of the puzzle depicting the full picture of parents’ opinions of education for their children with disabilities that neither well supported nor well modified in the classroom, that could very likely, as studies in other countries have suggested, cause a “dilemma” that troubles parents about school placements. It is also interesting to take a particular look on how

these parents' conceptualizations of inclusive education are, given both the traditional position about disability in China, and the continual influences of Western educational thoughts.

At the same time, it also pays to inspect the parental LRC-related preference in China, since so far little is known on this topic in the particular geographic area of China (Niu, Liu, & Tian, 2005)). Most studies in China focused on investigations in parental satisfaction at special education schools where their children were attending.

As expectations, values, and subjective appraisals and their relationship with larger socio-cultural influences have been shown to be the major lenses to inquire about the formation of human choices and, it is assumed in this study that Chinese parents' preferences of either setting is highly linked to their expectation on their children with disabilities as learners and as natural members of the school, and their subjective judgments of either their children or their environments. It is also assumed that some characteristics embedded in the current Chinese educational system, culture, and society are also related to the state of mind of these parents.

Within this context, it is important to know how parents with children with developmental disabilities in China understand inclusive education and how their current observation of the LRC practiced in Chinese educational system is different from the ideal model of inclusive education. Also, given the knowledge of the diverse attitudes about mainstreaming and segregated education from parents of children with disabilities in the Western countries, how their Chinese counterparts navigate "the dilemma of differences" is worth studying under the current education-related socio-culture in China. In addition, the negative social value of disability in China makes it interesting to look at

how Chinese parents position their children with developmental disabilities within the Chinese population of school children. These will be the goals of the present research.

### **Purpose of This Study**

As inclusive education gradually becomes a popular term of educational practice serving children with special needs, considerable research has been done, mainly to measure the quality of a certain localized inclusive implementation at schools through the questioning of the parents' feeling and perception of the effectiveness of this form of education. There are also a few literature examining parents' intention to place their children who were being educated within a restrictive setting to one less so. However, only limited research have explored the parents' attitudes towards inclusive education through a scrutiny in a dynamic state of mind of the parents by which they weigh and compare their perceived advantages and disadvantages of inclusive education.

As the behaviors of choosing is already a complicity in itself due to a multitude of causes, they are often further blurred by dilemmas that would most probably and interestingly arise in the process. The issue of dilemma perceived by individuals, as many researchers have pointed out, is tightly related to culture (Norwich, 2008). Therefore, it is wise to ask research questions that are contextualized by a particular socio-cultural environment, in this case, China, on its unique position as simultaneously having a conservative culture and the openness to world media and updated Western educational schemata. Hopefully, unique perspectives from the participants could be detected based on their educational and socio-cultural experiences specific to the Chinese society.

Also, adding these missing bits of information into the collective body of inclusive literature can help depict clearer dimensions underlying the profile of parents of children

with disabilities. During history there have been many inconsistent remarks by disability writers and researchers on this group of individuals, whose affiliations are hard to be determined. No less importantly, the study will serve to derive from the parents a bold view of the practices of inclusive education in current Chinese society.

Through the interviews with the parents, I aspire to answer several research questions:

- I. What is the present level of awareness and understanding of inclusive education among Chinese parents of children with developmental disabilities?
- II. How is the current “Learning in Regular Classrooms” (LRC) different from their conceptualization of ideal inclusive education? How are their children with disabilities currently included in their educational sites in China?
- III. Within a dual system offering each special-needs child the opportunities of either the LRC or learning in special education schools, which setting is preferred by the parents? How do the parents integrate their expectations and values of their children with special needs as a learner into their opinions of the current Chinese version of inclusive education, the LRC?
- IV. As students or future students in Chinese schools, how do children with developmental disabilities appear in their parents’ eyes?

### **Significance of the Study**

The research conducted in this paper will help reveal with greater scope and depth parents’ attitudes and perception of an educational setting that serves to include both children with developmental disabilities and their typical peers as students learning under

one roof. Besides exhibiting their comprehension of the emerging term “inclusive education”, parents will provide down-to-earth commentary about inclusiveness in China and their feelings about it. Their words will also shed light on their own position towards disability, both as a typically developing person and as a person who has a child with disabilities. Contemporary Chinese society and its educational system serves as background to this information.

As an insider to their education of their children with disabilities and also closest partner or even representative of their young child, a parent has a significant role in the education of children with special needs. In many countries, their right to decision-making in their children’s education has been written into law (Warnock, 2010; Yell, 2006). In contrast, those in China have not had the luxury so far. As part of the effort to help present parents’ voices, this study aims to take a close look at the opinions and judgments that these parents make when thinking of the ways that their children’s school education is provided, in the hope that this investigation will result in parents’ expectations of their children’s education being better met. Through this study, parents are portrayed in more detail, as an important member of the group that support the child with disabilities in pursuit of their various learning goals, even in a country that does not provide systematic support of parent rights.

This study will also serve to contribute to the body of global research on parents’ views on the school lives of children with disabilities. So far, ways that parents of children with special needs view and interact with educational institutions, such as daycare centers and public schools, have been examined in a case-by-case manner, restricted within a single organization or a limited area, and mainly focused on presenting

parents' consideration of the pros and cons of the educational program without further tapping into their internal debate on program choice. What is more, although there has been an aggregation of literature tackling the topics related to parents' attitudes towards inclusion and/or segregated education for their children with disabilities, only a few studies were found to directly focus on parents' subjective expectations and appraisal of their children's physical, social and educational environment (Ivey, 2004; Mutua, Miller, & Mwavita, 2002). Furthermore, none of these studies used both expectations and appraisals (and their interaction) as the integral threads to weave together a picture of the parents' perspective about inclusive education. Meanwhile, the existing research was conducted mostly in a socio-cultural and political context other than China. The unique features embedded in China's culture related to disability, education, and parenting may cast new light on understanding the perception of inclusive education implemented around the world from parents whose children have unique educational needs. In this sense, this study will also serve to provide more information to the inquiries in the thoughts, behaviors and actions of Chinese parents in response to the current educational provisions for their children with developmental disabilities in this country.

### **Some Issues of Methods, Assumptions, and Terminology Used in the Study**

Expecting complex messages from the targeted parents, especially when it comes to the process of building up ideas and expressing attitudes, I decided to investigate using in-depth qualitative interviews to record large volumes of information and allow ample space for description and explanations. Qualitative interviewing was conducted with parents who have children with disabilities in the two Chinese metropolitan cities of Beijing and Chengdu. The reason to solely focus on urban areas rather than rural ones is

the drastic economic and educational discrepancy between Chinese urban and rural areas (Lytle, Johnson, & Yang, 2005). Such differences may make the findings on the parents' expectations and schooling preferences hard to explain by merely referring to the socio-cultural characteristics of China.

Although convenience sampling was conducted as the major method of interviewee candidate selection, certain criteria were applied to the selection of interviewees in order to avoid the loss of transferability, an important feature of research that equals "generalizability" in quantitative studies. In other words, transferability refers to the feasibility of conducting future studies to replicate findings from the current one.

To be specific about the selection criteria, interviewees were restricted to parents only. Grandparents and other relatives in the children's family, even when they were the care-givers responsible for escorting children to school or to special half-day or full-day rehabilitation centers, or even accompanying them during both school time in these programs and time spent at home, were not chosen to be part of this interview study. Also, only those having children with developmental disabilities (i.e., autism and intellectual disability) were invited to take part, because they were expected to represent children facing both physical and social challenges which draw substantial concerns of the parents, in comparison to children who only had limited physical functioning. In order to elicit information that truthfully reflect situations of those children and how their parents' opinions on issues about their school lives might have been linked to their status quo, only mothers or fathers who were observed to be deeply involved in their children's lives were included for interviewing. This is because of an assumption that perception was formed out of keen experience with the relevant subject in question. Before each



interview formally started, warm and honest casual conversations took place between the interviewees and me, as an intentional effort to obtain information from parents in a way that mitigated worry of judgment from someone of authority.

Compared to eliciting responses with other research tools such as questionnaires, successful interviews demand more time and depends on ample trust from the interviewee. Therefore, the recruitment of willing participants takes more efforts. Additionally, my budget turned out to be only able to afford a short (three-day) stay in Shanghai, despite that it was a city where I had not had as much connection with parents of children with disabilities as in the other two cities—Beijing and Chengdu. Therefore, only one interview was completed in Shanghai, disproportionately fewer in comparison to the eight participants in Beijing and the other eight in Chengdu. Also, the child of the parent in Shanghai attended a segregated special school offering combined elementary to middle-school grades, different from all other cases. Therefore, Shanghai was eventually excluded from the geographical areas where interviews was analyzed and summarized. However, this does not impact the representativeness of the cases as speaking for parents in metropolitan cities in China.

Questions designed to be answered are just a few, but I was keenly aware of the diversity in the reactions that parents might make in response to them, based on many facets of the reality pertaining to what the child and the educational system was in their eyes. After all, this study itself is focused on subjective perspectives, perception and expectations that represent each of the interviewee's "reality." Beyond all this fluidity, I firmly held the assumption that parents of children with disabilities in China, like any other persons facing the inevitable challenge of making choices, make rational decisions

by weighing benefits and costs even in face of a major dilemma.

Due to the fact that inclusive education is still a novel term in China, the term “*Rong He Jiao Yu*” (inclusive education) brought up in the interview conversations by both the interviewer and the interviewees may possess more than one meaning, not restricted to inclusive education in its ideal and most acknowledged form, but also referred to the education that were witnessed by parents in China, the LRC (“Learning in Regular Classrooms”). At the same time, parents’ “attitudes” as stated in the title of the paper, encompasses not only positions and perspectives, but also behaviors or behavioral plans, as the latter was found to coalesce with parents’ opinions about the LRC.

## **Chapter 2**

### **Literature Review**

In this chapter, socio-cultural and educational characteristics in contemporary China, overview of inclusive education in the Western countries, expectations and values related to school-selection, and the scholarly works on the parental perspectives on their children's disabilities will be summarized. These previous studies will form an investigative and analytical framework for the present study.

#### **Socio-Cultural Characteristics in Education and Disability in Contemporary China**

Defined in Bryan's (2007) terms, "culture is commonly held characteristics such as attitudes, beliefs, values, customs and patterns of behavior possessed by a group of people, which have been learned and reinforced through a socialization process" (p. 8). In the field of research on inclusive education, there has been a widely agreed principle that related issues should be studied under specific cultural context (Amstrong and Barton, 2007; Alur, 2007; Chang, 2000; Lang, 2009; Liu, 1992; Marks, 1999), as "concepts cannot be translated across cultural and historical settings" (D'Alessio, 2007, p. 10), and culture-specific constructs such as linguistic products and ethical practices are proposed to be important subjects of study (Plaisance, 2007). Although many universal, inherent, psychologically rooted features were found by past research, a large majority of studies in education related to children with special needs distinguished their findings under the framework of the local culture (Chimedza, 2007; Lavia, 2007; Riddell, 1998). In this sense, the disability-targeted socio-culture of China, with all its well-studied uniqueness, should be set up as a stage for the displaying and explication of the thoughts and behaviors of the parents whose children are influenced by disabilities in this country.

**Parental rights lack of legal and political support.** Under the current educational and cultural context of China, the particular features of special-needs education can be largely seen both from the legal and organizational position of the children and their parents, as well as the public mindsets about disabilities. So far, China has been following a two-track system down the path of educating children with various disabilities. Although “Learning in Regular Classrooms” (LRC) has always been acknowledged as an important format of schooling for these kids, efforts to expand special schooling placements never ceased (Liu, 1992; Zhao, 2013). For example, the statistics of special education schools are paralleled side by side with those of general schools in *The Statistical Bulletin on China’s Development in Education in the Year 2014* released by Ministry of Education of China, showing a new total of 2000 special education schools in proximity to 201, 400 general elementary schools.

So far, according to the laws and regulations concerning special-needs children, opportunities to enjoy LRC are still worded as to be granted only to those children who are able enough to study in regular schools. Furthermore, criteria used to assess their ability have not been specified. Institutions are demanded by law to be held accountable for their failure to take in children with disabilities, but no particular punitive measures are stipulated for these misconducts. Overall, children’s rights to LRC as well as the quality of it were largely found hard to guarantee (Deng, 2001; Deng & Manset, 2000; McCabe, 2007; Peng, 2011; McLoughlin et al., 2005; Shang et al., 2009). As a country who has been deriving much of its efforts in the improvement of policies and practices from the initiative that the United Nation made to improve life quality of people with disabilities, so far it has not received any professional guide from UN in order to support

Chinese children with disabilities on their entry into schools (Meng, Han, & Cao, 2011).

Together with the children with disabilities receiving inadequate assurance in their educational opportunities, their parents are simply lack of mentioning in laws. Unlike the disability act in the United States where rights and responsibilities of parents and the due procedures that they can follow to safeguard their children's best interest are clearly defined (Yell, 2006), parents whose children have disabilities in China are simply off the page of Chinese legal books (McCabe, 2007; Pang, 2009; Wilde, 2001).

**Parents' duties in their children's lives.** Ironically, along the long history of China to its contemporary time, the responsibility of caring children with physical or mental disabilities have been resting with their family members, such that two-thirds of the disabled children and adults depend on relatives for survival (Fisher & Li, 2008; Stratford & Ng, 2000, cited in McLoughlin et al., 2005). Duties that the society imposed on families are many (Yang & Pearson, 2002). This facet of culture is reflected from lives of ordinary people in China to behaviors of the authorities of the society. For example, in the UN's committee meetings regarding the mission of fostering independent living for people with disabilities, at some point representatives from China started fighting with those from other countries, insisting that no one wanted these people to be taken away from their families, and interdependent household are the best place to care for them instead of living separately (Stein, 2010).

Chinese parents, as any Chinese family members, are willing to sacrifice for their family, in particular, for their children. McCabe (2007) reported the findings from a parent study in China, saying that this explained a startling remark from their parent participant that "It is only parents in China who truly understand how essential parent

involvement is” (p. 48). In China, parents of children with disabilities are the steering wheels of their child’s lives. However, they are also lonely fighters, devoid of support from policy and culture:

“Parents involvement in China does not mean being a member of a team. Rather, it means advocating for one’s child in the face of adversity, and often giving up one’s job and other life activities to become the child’s primary instructor. Parents do not have a choice of whether to participate; if they do not actively advocate for their children, and take measures to arrange their schedule to enable them to teach their children on their own, who else will step forward? Currently, there is no one else.” (p. 48).

In spite of the caring shown by Chinese parents, contradictorily, there are strong comments on how they view disability with discriminative eyes and try to conceal their children’s exceptionality (Yang & Wang, cited in Meyer 2010; Shang et al., 2011; Yang & Pearson, 2002). There is also observation that over 90% of children being abandoned by their parents had disabilities (Shang, et al., 2009), and that children with disabilities were the most difficult ones to be adopted by families in China (Fisher & Li, 2008). However, the major reasons of the parents’ avoidance of the label of “disabled” on their children have not been studied.

**Parents’ position in China’s education.** Besides the traditional positioning of parents as the sole care-taker of their child with disabilities, past studies placed them on a disadvantaged position on the hierarchy of power between parents and schools (Deng, 2001; Liu, 1992). In fact, this culturally inherited inequality penetrates most of the East Asia countries. For example, it was found that a large proportion of Asian parents felt that visiting schools means distrust and disrespect for the teachers (Swap, 1993). Equally, for fear of an assumed offence to the teachers, the parents withdrew from exposing their own ideas to the school. Thus parent-school interaction turns to be stagnant, and “mostly depend on norms rather than individual inclination.” (Swap, 1993, p. 27). Although

parents in China generally tend to embrace inclusive education more than the teachers (Li, 2010; Ma & Tan, 2010; Zhang, 2010), their enthusiasm might be concealed in front of the school and teachers for the parents may not feel confident and comfortable enough to discuss this issue with the other side.

While discouraged parent-school communication might serve as one of the major factors in the parents' feeling of helplessness in their children's education, some other reasons might co-occur. there are quite a few accounts from researchers who stated that national and local disability policies and perspectives taken by authorities in China are still predominantly "medical", which identify each of the individuals as a machine with failing functions await to be fixed (Deng, 2001; Huang et al., 2009; Lang, 2009; Stein, 2010). Although nothing similar has been mentioned regarding parents' attitudes towards their child, Kuan (2015) described the uncertainty that the parents general hold in their children's education in current Chinese society, where the highest goal of study is to press children to achieve academic excellence and economical success which demands high-level functioning even in their early school years. What was left unremarked from her study was the perspectives and positions of the parents of children with disabilities when they came to choose between various educational settings.

**Elitism as a classical Chinese educational philosophy.** For an extensive period of time, elitism has been holding fast as a dominant trend in Chinese culture of education. It took shape after Confucianism became the sweeping political and civil thought which widely underlay policies and practices of the high authorities of the nation. Based on this school of thinking, high-stake "imperial exams" were designed to be the only way to select all ranks of officials for the nation. At the same time, it preached on the heavenly

bestowed “fate” for each person (Fung et al., 2007; McLoughlin et al., 2005) which was connected to the loyalty and subversion to the Chinese emperor.

After the fall of the empire since the year 1840, “high quality” (p. 111) of people was even more stressed by Chinese social elites, with a particular anxiety over “weak” physical and mental states as a threat to their aspired revival of a powerful nation (Xun, 2010). This cultural thought later persevered through contemporary China, apart from the swift deviation attributed to Chairman Mao’s elevation of the value of physical labor and derogation of intellectual achievement (Deng, 2001; Liu, 1992; Stone, 1998) from 1950’s to 1970’s. Especially during the recent 25 years, the embracing of elitism reached a new height, beneath the disguise of “education for quality” (*Su Zhi Jiao Yu*) (Kuan, 2015), which promoted a conceptualization of students within the dichotomous framework of “having “quality”” and “not having “quality””, demarcated by whether one was equipped by his education to be “fully adapt to the global, knowledge- and information-based economy” (p. 37). Furthermore, “the established wisdom is that the limited Chinese educational resources should be reserved for those who can contribute to society by learning and not used by those who require assistance in basic activities of daily living” (Chen, 1996, as cited in McLoughlin, 2005, p. 278). At the same time, practical life skills are long believed to be something that should be taught at home by parents, therefore, as McLoughlin (2005) observed in the education in China, “leaving schools with the province of academics” (p. 278).

In contrast to a uniform emphasis on lives full of elitist academic and financial successes, lives with disabilities seem to have been receiving little attention, if not the attention that are spurred with curiosity and pity. In a good sense, Confucius guideline for



moral deeds called for the sympathy for people whose lives are infested with miseries (“*Ren*”) (Liu, 1996). In a bad sense, this principle, acting together with the long-operated social customs of gauging people by high-stake quantitative evaluations, leads to a charity perspective in people with disabilities (Fisher & Li, 2008; Peng, 2011). This perspective brings a meaning of derogation that people with disabilities are submissive to those who are functioning better in academic and economic achievements and thus considered the backbones of the society, as if they were useless idlers. What adds to people’s misperception are some myths lingering in Chinese culture that associate disability with karma, for example, from disrespect to the family ancestors (Yang & Pearson, 2002), lack of self-discipline and willpower, to the susceptibility to morbid thoughts (Liu, 1996).

**Exclusion of people with disabilities under collectivist culture.** Widely recorded exclusion of people with disabilities from mainstream educational institutions from elementary to higher educational schools co-existed with the well-known collectivist culture (Yang & Wang, as cited in Meyer, 2010) in the Chinese society. This culture directs its members to focus more on their social identity and value (Fung et al., 2007). Also, holding personal and societal unity acts as the underpinning force behind the call for integration much more than the equal rights concern that have mobilized the Western disability movements (Lewis, Lau, & Lo, 1997).

In another sense, a society with collectivist culture was found to be more prone to segregation of people with disabilities. In his efforts to explore into the lack of social attention to disability despite the benevolent moral teaching of Confucius, Meyer (2010) juxtaposed the two major cultural structures, and found that “in an individualistic culture

a person with a disability would thus be seen as someone to be integrated. In collectivist cultures, by contrast, the disabled person can more likely expect to be segregated from the larger community in subordination to the group.” (p. 3). To the writer, collectivist culture tends to segregate the societal members who deviate from the central ideology and popularly recognized bodily forms and behaviors.

Other researchers also remarked that people in China focus more on preserving a group-oriented identity and adopting publicly approved values (Fung et al., 2007). In this respect Cheng (1944) has pointed out that “The fundamental institution is the family. People trust in small, face-to-face communities, not abstract contractual relationships” (as cited in Meyer, 2011, p.14). The custom of keeping people with disabilities to his own family implies the pursuit of a conflict-free, shame-avoiding approaches of handling disability-related issues, which may lead to a concerted neglect of the pursuits of families and individuals with disabilities and, at the same time, an intension to deny special needs derived from the impairments of its members.

What have been explicated in the works of the above researchers’ jointly points to a schooling culture in China that has been brewed in a social culture that estranges those groups on social periphery and gauges the utmost value of a person by the collectively interested, elitist criteria. The same harsh standards are used to measure human normalcy as described by “*Quan*” (perfection) and “*Zheng*” (proper). As Stone (1998) exclaimed: “There was no room for excess, extremes, or deviation... Variation was cast in cosmological discourse as counter to the normative body. The fact that this occurred within a context which set the individual as a relational, family-centered being, and was otherwise known for a worldview premised on complementarity, flux and balance, does little to soften the exacting notions of normalcy.” (p. 92).

### **An Overview of Inclusive Education**

During the past half-century, a major reform of deinstitutionalization started to gain momentum, sweeping from northern Europe to the United State, and many other parts of the world. Although its mission was directed to open up the opportunity for people with disabilities to live in the closest approximation to the other people in the same community, it fostered an enthusiasm that aspired to boost the life quality of children with disabilities by ensuring them access to general schools originally serving typical children. As Mittler (2005) has pointed out, the impetus of inclusive education, which is an organic part of the inclusion movement, was launched by the simplest claiming of a full, dignified and decent life for young persons with disabilities. This movement was fueled by the Salamanca Conference of UNESCO in 1994, who issued a declaration (UNESCO, 1994) calling for all governments to adopt policies to offer “education for all” and “enrolling all children in regular schools, unless there are compelling reasons for doing otherwise”. Although across years this intriguing proposition witness highly positive impact on a number of countries committed themselves to inclusive education in fields of rhetoric, laws and policies, especially developing countries, there were disparate levels of translating these abstractions into practice (Mitchell, 2010; Mittler, 2005; Parementer, 2007). Reasons lying behind the gap between policy and practice are manifold, ranging from economical factors, awareness of teachers and parents, to institutional incentives (Mitchell, 2010; Plaisance, 2007).

The inadequacy in inclusive measures and services actually results in the excluding of the disadvantaged students even if they are allowed to study alongside their non-disabled peers. Therefore, despite the morality- and right-based believes that fueling the concept of inclusive education, a paradoxical phenomenon called “exclusion from the

inside” takes place under inclusive contexts (Plaisance, 2007, p. 49). This puzzling fact implies that the implementation of the ideal of “inclusive education” is, in reality, far from being satisfying for people related to this issue, be it the students, parents, professionals, administration, or researchers. In their eyes, “inclusion...seems not to always work” (Warnock, 2010, p 36), certain students risk to a bigger extent of the failure to participate into the mainstream (Potts, 1999), students with disabilities are simply marginalized than being embraced by the mainstream environments (Ravaud & Stiker, 2001), and in Hodkinson’s (2012) sharp conclusion, “(inclusion) was, and indeed is, a sincere deceit (p. 684). Full inclusion, which is generally perceived to be “meeting the needs of all children in a similar manner” (Campbell et al. 2002, as cited in Norwich, 2008, p.18), has been dismissed as unrealistic.

Because of this, for many people, inclusive education seems to have become a live example of ideological disillusionment. It was seen as just an “educational vogue” that are devoid of real meaning (Starczewska, 2013, p. 162). However, the impasse that has been chronically clung to the notion of inclusion provoked their thoughts one step forward to reexamine the conception of inclusion. As social psychologists, Jansen, Otten, van der Zee, and Jans (2014) proposed from their study that the concept of “inclusion” was a binary construct with two distinct parts: identity belongingness and individual uniqueness. With the two, inclusion sets the desirable stage on which the basic human needs of relatedness and autonomy can be satisfied under a group circumstance. Along this line, in the best form of inclusion, a group will extend its highest extent of willingness to embrace the individual as well as admitting his uniqueness. They also interpreted the most up-to-date definition of inclusion as that “it is the group that includes

the individual, rather than the individual who connects to the group” (p. 370). Their findings are instigating in a way that reminds people the dual dimensions of inclusion, and thus examines inclusive education from a broader angle that allows inspections on both how students with disabilities are taught to assimilate and how typical persons make efforts to adapt to the students with disabilities.

Consistent with their findings, many educational researchers provided arguments that generally perceive inclusive education of children with special needs as a multi-faceted notion. For example, Mitchell (2005) pointed out that some of the international consensus upon the components of inclusive education included the right of being educated in the regular and age-appropriate classrooms, and also concrete practices of both designing individually tailored curricula and pedagogies and facilitating the student’s access to aides and services. However, many others emphasized that legal rights and real practices are far from representing the conception of inclusive education to the fullest. In an incisive article of Lieberman (1996) debating on whether the isolating special education should be maintained for children with severe disabilities, he concluded with a sense of pity:

“The seeds of failure for full inclusion are in diversity... The day the standard for education becomes meeting the individual needs of all children, all children with disabilities can be in regular classrooms... But for now, we had better fight to preserve special education” (p. 26).

The one lacking in the current inclusive practices, according to him, are the welcoming stance about diversity and differences. Lieberman’s words well exemplify the wide-spread awareness of the link between inclusive education and the socio-cultures of different types of society. Although what he mainly related to in his article was the failure of accommodation on the part of the school, the lens that can be used to scrutinize the obstructions against inclusion is expanded into the realm of an outer system which interact

with the system of school performances—the whole society.

The same proposition was echoed by many other educators. Parmenter (2007) observed that despite the enormous improvement in the acknowledgement and promulgation of the rights of people with intellectual or other disabilities to be provided with daily life experience that are closest to the regular ways of community living, even in many high-income countries with rich resources, practices constantly took tolls from local culture that was incompatible to the inclusive ethics of valuing differences, fulfilling individual needs and caring for emotions and feeling of every member of the society. He further implied that this culture that are shared by the industrialized countries, which might be unfavorably related to the difficult situation that full inclusion was facing there, may have stemmed from the popular idea based on the long-held belief that only rationality in thinking and personal intellectual achievement mark one's most important contribution to the society. Consequently, he observed that people who have flaws in intelligence tend to lose full status as a person, hence being excluded from the typical human assembly. Likewise, a number of other researchers identified the market-driven economy and its affiliated drive for standards as the obstacles in the way of implementing full inclusion (Lavia, 2007; Norwich, 2008; Potts, 1999; Warnock, 2010). Effect of the larger ecological system was also mentioned by Mittler (2005) that the level of implementation of the campaigns that are targeting to the better understanding of marginalized groups has been found to be related not to the factors such as the resources available, but, for example, to the political will of the government.

Till now, in many countries, “formal exclusion” has not been constantly seen (Lipsky & Gartner, 1996). Nevertheless, other types of exclusions are often felt by people with

disabilities and unceasingly identified by researchers on disability rights. Ravaud and Stiker (2001), who used to theorize on the exclusion of the disability group, paradoxically equaled some certain forms of inclusion to exclusion, which might partly explain the invisibility of exclusion under some circumstances.

According to what they proposed, constraining the people with disabilities' presence and activities at the very center of a community, which they called "differentiated inclusion", was in fact "exclusion through segregation"; subordinating the disadvantaged group to the mainstream by offering them charity on them contributed to the disempowerment of these persons by "conditional inclusion" or "exclusion through assistance"; self-elected or alleged deviation from the norms constituted "inclusion through normalization" or "exclusion through marginalization" (p. 504-506). Their typology of exclusion as the translation of some forms of inclusion highlighted the detrimental effect of the absence of cultural-political or the spiritual ingredient from the legal and practical layers of inclusion— without a positive understanding of "being different", no matter to what extent the inclusion is implemented, segregation or inequality cannot avoid being introduced. Shereen (2002) illustrated Ravaud and Stiker's (2001) point on inclusion-induced exclusion by remarking that children in regular classes who could not be categorized into having "intellectual impairment" turned to be having "intellectual subordination" (p.4) to their academically successful peers, determined by their achievement scores based on normative subject examinations. It then obviously constituted "exclusion through marginalization", despite the fact that the low-achieving children in Shereen's study were physically present in the same classroom with their more test-competent peers.

The shared awareness of the risks of exclusion have triggered the calling from educational practitioners and researchers for a “reform of culture” ranging from local attitude and behavioral change regarding the school culture (Armstrong & Barton, 2007; Chimedza, 1996; Hodkinson, 2012; Potts, 1999; Stainback, Stainback & Ayres, 1996;) to the one entertaining a large-scaled, far-reaching sensitization of social consciousness towards underprivileged groups (D’Alessio, 2007; Lavia, 2007).

### **Parents’ Attitudes and Perceptions of Inclusive Education**

**Dissatisfied parents.** As O’Shea et al. (1989) mentioned, there has been constant disputes over whether regular schools have the capacity to take on extra responsibilities for providing adequate services to the children, facilitate their satisfactory progresses, and accommodate the diversity of students. Jenkinson (1998) further described the competitive assessment, philosophy of excellence, universal curriculum of regular schools as potentially preventing parents to easily consider inclusive classrooms as a reasonable choice to make for the education of their children.

**Parents’ general support of inclusion.** Many researchers pointed out that parents of children with disabilities are generally supportive of the philosophy of having kids with special needs study under the same setting as their typical peers, no matter whether their children are currently placed in preschool settings (Reichert, Lynch, Anderson, Svobodny, Di Cola, & Mercury, 1989), in resource rooms or self-contained programs full-time at elementary schools (Cook & Swain, 2001; Simpson & Myles, 1989), or already included (Grove and Fisher, 1999; Erwin & Soodak, 1995). Miller et al. (1992) used to do a direct comparison and found out that the ratings for the idea of inclusion was very high among parents whose children were either in segregated settings or in inclusive settings (n = 204).



**Parents' reservation in including their own children.** Leyser and Kirk (2004) found that parents whose children were learning with typical peers at regular schools showed a significantly lower level of optimistic perception of inclusion than their counterparts whose children studied in completely secluded settings. Jenkinson (1998) found that out of the 193 parents of children with disabilities in both settings, 33% children in the special education settings were those transferred from inclusive ones, in comparison to as low as 4% of the children who made a reverse transference from segregated learning to inclusive classrooms.

Consequently, research shows that many parents think that it is more beneficial to have their children continue studying at a segregated setting, even when given the autonomy of choosing between special education and inclusion. In Jenkinson's (1998) case, the majority of the 75 parents whose children were in exclusively special education settings preferred their children to stay in the very setting where they were. Likewise, Turnbull and Winton (1983) found in their interview study that in either group, over 50% of the mothers of special-needs preschoolers in specialized programs stated that their children's program was enough to satisfy both the child's needs as well as the parents' needs, so that it had no drawbacks.

**Parents' satisfaction with both settings.** Larson and Lakin's (1991) study on parents' level of satisfaction with their children's being institutionalized and deinstitutionalized revealed a trend that parents were overwhelmingly satisfied with their children's life within institution but also showed the same level of satisfaction after they moved out of institutions. Likewise, a survey done by Lowenbraum, Madge, and Affleck (1990) found that although 87.5% of parents rated their satisfaction with the inclusive

placement of their children as very satisfactory, 91.3% of them rated equally high on their children's past resource-room placement experience, too. Guralnick et al. (1995) found similar results, with mothers of preschool children showed complete satisfaction towards their present special education placement, but with 40% considering transferring to inclusive settings. The same "contradictory" percentages emerged from the studies done by Hanline and Halvorsen (1989) and Kasari et al. (1999). Except for these quantitative summaries of parents' attitudes and intentions, the interview study by Cook and Swain (2001) have shown that although those parents were at odds with the educational authority's decision to close their children's special education schools and to move them to regular schools, interviews show that almost all of the 65 parents embraced the thinking of replacing their children into an inclusive schooling system.

**The "adamant" parents.** Kasari et al. (1999) requested their parent participants to respond to the question of whether they have considered changing their children's placement. About 4% of parents in the autism group and 2% in the Down syndrome group insisted that inclusion is not beneficial at all for their children. Besides these researchers, Simpson and Myles (1989), in their process of examining what mainstreaming modifications were preferred by 53 parents of children with mild disabilities, reported that a small percentage of parents rated it impossible for them to allow their children to be mainstreamed, even if their recommended modifications were postulated to be all met. These findings suggest that instead of being willing to ponder upon the pros and cons of both type of educational settings in the first place and then make a choice between the two, some parents might simply abandon the idea of placing their children in inclusive classrooms without a thought.

## **The Dilemma Paradigm**

As having been mentioned in the previous section, being included, or not included, children with disabilities are at a high risk of being excluded. However, social, community or school ethics and the related governmental policy orientation in education regarding children with disabilities are both not easily malleable through time. Obstacles deeply rooted in these aspects prevent inclusive education from fully evolving from a loudly-acclaimed, well-intended moral discourse into an actual practice that results in the good of anyone involved. While over the years, numerous studies and articles have presented a hodgepodge of difficulties and problems permeated across all aspects of inclusive education, especially policy and practice within the range of state, community and school, little was suggested about the mechanisms underlying the long-disputed nature of this format of education. British educational philosopher and researcher Braham Norwich was among the few ones who worked to shed light on this issue. He used “dilemma” as a window to look through into the aspect of education where children with special needs are involved.

Along the history, special needs education, as Dyson (2001) once commented upon, was seen as neither “a story of uninterrupted progress, nor of a doomed struggle against overwhelming odds” (p. 25). Norwich (2008) drew on Dyson’s examination of the historical course of education for children with disabilities and attributed the above conclusion of Dyson’s to the limited resolution to the “dilemma of difference”. He pointed out that tensions from the dilemma have never been eradicated, although generation after generation, amendments were being added to policies and practices with this aim. In some sense, it makes an interesting observation paralleling to Murphy’s

(1987, as cited in Ravaude & Stiker, 2001) perplexed but inspiring exposition of lives of the disabled: “In all societies, disabled persons live in a state of social suspension. They are neither ill nor well, neither dead nor alive, neither really excluded nor really included in society” (p. 501). The embedded unsureness attached to the disabled lives as lives being “excluded” and “included” seemingly implies that there is always something imperfect, something unattended to, in the process of inclusion.

In Norwich’s term, “The basic dilemma is whether to recognize and respond or not to recognize and respond to differences, as either way there are some negative implications or risks associated with stigma, devaluation, rejection or denial of relevant and quality opportunities” (2008, p.1). He loaned this term from American legal researcher Martha Minow. In her study dated back to 30 years ago on the educational provisions for students who were English learners or students with disabilities, she remarked:

“Are the stigma and unequal treatment encountered by minority groups better remedied by separation or by integration of such groups with others? Either remedy risks reinforcing the stigma associated with assigned difference by either ignoring it or focusing on it. This double-edged risk is the ‘dilemma of difference’” (1985, p.1).

This well thought-out utilization of dilemma as a framework to interpret legal disputes over issues related to the mainstreaming of students with disabilities was highly meaningful for the understanding of ambiguity existent among various items of a statute, for example, the one lying between “least restrictive” placement and “appropriate education” that are simultaneously stipulated in the special education laws of the United States (Yell, 2006).

Although Minow brought out the term of “dilemma of difference” and traced it back to its conceptual assumption, she addressed the related phenomena from a

combination of points of view: of both the plaintiff and the defendant under the context of litigation. Her intention of investigation was not on the clarification of each stakeholder's view of the dilemma. Many study that compared and contrasted the education-related opinions of students with disabilities and the staff in their school found differentiated beliefs on the two parties (Collins & O'Mahony, 2001; Lowe & McDonnell, 2007). Although the findings were focused on the conceptual origins of the dilemmas—the perceived hindrances of inclusive education, they allude that it is a significant matter of research in the topics about the stakeholders' views of inclusion to make the inquiry on a group-specific manner rather than in totality.

Free from a similar attempt to investigate into the contention between different parties involved in special education with a reconciling manner, Norwich focused this framework on an individual group critically involved in the mainstreaming of students with disabilities—school educational authorities and the teaching staff, and he compared these conceptions across regions. In his study he examined the perceptions of “tensions” during their daily administrative work or professional performances, either in inclusive or special education settings. Consistent with what he presumed, in all the studied regions, dilemmas where the tensions were rooted were both pervasive and enduring, across a ten-year span from 1995-2005, although increasing efforts were put into educating children with disabilities in mainstream schools during that period. He also found that people encountered by tensions rigorously created ideas for the resolution of the dilemmas connected with these tensions.

While acknowledging the importance of creating effective solutions for issues continually emerging in the field of inclusive education, Norwich contended that:

“acknowledging and taking account of dilemmas provides a realistic and authentic approach to hope about an inclusive and humane education. It is a form of hope based on being creative about options, analyzing, clarifying and examining these options, finding ways of having it both ways as far as possible in a morally acceptable and decent way.” (p. 217)

In spite of its heartening nature, resolution of dilemmas in the education of children with disabilities seems to only rest upon slight modification of ready-made standards that are generally applied to typical children. As many other disability researchers who have proposed cultural change in order to eradicate exclusion and marginalization, Tomlinson (1982) proposed that the conflicts involved in the dilemma must be interpreted “in an evolutionary manner” (p.15). Besides, Fraser (as cited in Philips, 1997) insisted that approaches to address the “dilemmas of difference” have to distinguish between various types of differences, so that the dilemmas could be addressed “without (the assumption—Philips (1997)) in advance that one set of initiatives always takes priority over another” (p. 12). Points made by these researchers present new ways and methods to look into the difficulties that the dilemmas of inclusion bring to the various participants of education for children with disabilities.

Consistent with this line of thinking, Low (2009), in a series of research which sought to reconstruct the definition of “being normal”, or correspondingly, “being abnormal”, presented the findings on how a number of college student at Canada with disabilities chose to alternate between their identities of being disabled and of being not disabled, as a way to negotiate various physical environments present in their university. This study brought to the fore the individual’s actions of negotiating their identities between “able-bodied” and “disabled” in a given occasion as means to get around stigmatizing situations that they were constantly in. To put it simple, in the

mainstreaming environment of the university, they utilized certain tactics to conceal their disability at certain point when special supports were available, and made it visible at some other time when the inaccessibility of some environment that blocked their interaction with others. Detailed information was gathered about the behaviors of the students in face of the dilemmatic treatments that they received in their daily study settings. However, the value-laden mindsets behind their “negotiations” were not the research goal of the author.

Another researcher, De Wolfe (2014) looked into the activities and behaviors of parents of children with autism in a new depth in an ethnographic study. With this study she painted the profiles of these parents under the paradigm of “autism culture” (p. 8), which assumedly set aside the parents to belong to a discrete social group from the others in the world. From her point of observation, the parents “employ education as a tool for interacting with their world, for making and remaking the boundaries and spaces in which they engage with others” (p.17). The “insider’s view” that she took was inherent to the nature of ethnographic study that encourage empathy and localized perspective, and might also have been grounded upon the established findings of the “autism parents” bound to “autism culture” from a rich array of American disability studies (for example, Bérubé, 1996)), which may be tricky to be generalized to the socio-cultural context of China.

### **Choice and Expectation-Value Framework**

The issues presented above highlight the imperfection of inclusive education. This naturally drew attention to the thoughts and behaviors of stake-holders, particularly in response to their perception of the dilemma. For example, parents of children with special

needs, or persons with disabilities, are constantly confronted with the pressing responsibility to select certain sites to fulfill their educational needs. Each of the sites is usually corresponded with a certain formats of practice of inclusion/exclusion to which parents feel unsatisfactory for this or that reason. As Lieberman (1996) has emphasized in his persistent calling for the maintenance of special education, a fundamental ability to choose between options is essential for the realization of inclusive education.

Although in many societies, a reasonable range of service options that Lieberman proposed for the parents to choose are not available to choose from, many researchers (e.g. Norwich, 2008) agree that at least parents are free to choose between placing children at mainstream schools or special education institutions. Of course, among such limited options and given meager resources, as is often the case, their choices may not reflect real preferences but instead, forced picks (Marks, 1999), and may be rather ambivalent and painful due to the many dilemmas involved (Norwich, 2008). However, thoughts underlying these choices are valuable and should be investigated. This is critical given that parents are expected to be caretakers that make rational decisions based on their personal values which may be influenced by others' views and behaviors (Grove & Fisher, 1999; Palmer, Borthwick-Duffy, Widaman, & Best, 1998; Turnbull & Winton, 1983).

Among all the speculations in terms of what one might consider when an option is thought to surpass the others, several theories lend themselves to the motivation underlying these choices and preferences. As has been implied by these theories, the phrase "choice" is inherently associated with "motivation". McClelland (1987) defined choice as "people's conscious intents" and insists that "any general theory of



action...must take into account a person's motives, skills or adaptive traits, and cognitions or schemas". (p. 4). Murphy and Alexander (2000, cited in Wigfield & Eccles 2000) further pointed out the complexity of motivation by arguing that a variety of constructs of motivation have been utilized by a large number of theorists to explain how choice, persistence, and performance are formulated. Further, McClelland noted that the final action of any human being may be the result of several factors and may be more complicated than being influenced by a single motive. "One example of this has to do with an everyday behavior: eating. People likely do not eat simply because they are driven by hungry, but also because they have the skills and capabilities to eat, or because it is the appropriate time to eat." Therefore, McClelland (1987) held that something such as the "eating motive" may be misleading, as it entails a long list of underlying motives which lead to the final decision to eat.

Four "important motive systems" listed by McClelland (1987) are the *achievement motive*, the *avoidance motive*, the *power motive* and the *affiliative motives*. Two important theories which have been used to explain the achievement motives are Bandura's self-efficacy theory and the modern expectancy-value theory by Eccles and her colleagues. Eccles' expectancy-value theory regards choices as the product of the task-specific beliefs influencing expectancy for success and the values of these tasks. In fact, the expectancy in Eccles' theory is analogous to self-efficacy in Bandura's social cognitive theory (Eccles & Wigfield, 2002). However, in addition to the value of task success, Eccles included "task value" as one more dimension constructing the choice-based decision making. An illustration of this concept is that even if people answer the question "Can I/my child do this task?" positively, they do not necessarily choose to

work toward this task goal. Their eventual choice also depends on what values they assign to the pursuit of this task. In the context of parents' choices related to educational setting, it is understandable that although some parents are well aware that their children may possibly be recognized by their typical peers in an inclusive environment, they do not necessarily believe an inclusive setting will benefit their child as much as his being able to learn more "practical" skills with the teachers' individualized help in a special education setting. Apparently, this way of thinking may lead them to decide to choose a special education setting over an inclusive environment. Indeed, as past literature has shown, given the opportunity to choose an inclusive setting, many parents are making "hard choices".

Emphasis on the values and possibly value-encompassed expectation is a meaningful start to creating a useful way to investigate the questions regarding education-centered choices by parents of children with disabilities. Numerous studies have been carried out in order to explore the intensity of outside supports for the eventual purpose of understanding various aspects of life experiences of people with disabilities. As a natural complement to these efforts, Reindal's (2008, 2009) proposed her relational model serves as disability-oriented application of the general expectancy-value theory. According to her model, a concrete amount of available resources is a less reliable measure to gauge the recipients' feelings of satisfaction towards a related service. Instead, she places stress on the perception-oriented areas relevant to a dignified life outside of material objects, such as emotions, appraisal of practicalities, affiliation, control over one's own political and material environment, among other things. For her, this perspective that focuses on human volition and intentions guarantees a plausible

assessment of many issues focused on disability-related social justice, especially when it comes to “the integration of people with impairments into public space.” (2009, p. 160)

The work of the afore mentioned researchers all refer to their belief that values held by a person serve to delineate the path they take to reach a decision. It is not idiosyncratic at all to propose that the hoped-for educational attainments by parents of children with disabilities are closely bound to their deeply believed values. Landsman (2003), a mom of a girl with cerebral palsy as well as an ethnographer, described the mothers of children troubled by their impairments as “emplotting” (p. 1947) their children along a plot line that they drew for their children’s life paths and trying persistently and vibrantly, in their ceaseless efforts, to “(move) forward the child’s story toward the (hoped-for) conclusion” (p. 1956). In conclusion, the above described scholarly work all point to the worthiness of inquiring into human willingness and intentions which were reflected in the individual’s vital goals as the path to understand their choices.

Naturally, many major researchers traced the questions about human volition to the purposes of the society (Bourdieu, 1985; Bronfenbrenner, 1979). Likewise, a time-honored body of studies in disability pointed out that cultural-social forces are deeply inscribed into the appraisal of life experiences, decision-making, and life adjustments of people relevant to disabilities (Ferguson, 2001). Bourdieu (1985) translated it into a culturally reproductive pattern where cultural practices (“cultural capital”) beneficial for the gains of the dominant social class are exposed and insisted within the school. This was said to be due to a perceived position of the school which was a major place to “secure material and symbolic profits for the possessors of (the) cultural capital” (p. 84).

In turn, the cultural capital embodied by students of non-dominant classes are ignored and devalued, and the practice? of resistance to the dominant culture tends to be eradicated, which may also be reflected in personal values of the related individuals. Inspired by this theory of cultural reproduction at schools, Gao (2011) studied the college selection by high-school students and their families in China, and directly linked the operating mechanism of cultural-capital “habitus”, a term created by Bourdieu, to the “attitudes, expectations and aspirations” (p. 11) of the targeted groups in his study who were facing school choices.

The coexistence of the cultural capital passed down by the dominant group in a society and the class-specific or personal values within that society reveal an interesting picture of human volition. It implies that in the case of mainstreaming for children with disabilities, the school values, regarded by Bourdieu as conservative forces, interplays with family values, i.e., “class related tendency of students to enter further education, independent of their attainments” (Nash, 1990, p.438), in many decision-making process that the care-takers are going through. In other words, when choosing the children’s school location, there may be parent’ values which resemble school values that are consistent with dominant social and cultural codes, as well as their “group”-unique values that are sometimes inconsistent with the dominant ones. As a consequence of the existence of the latter values, there might be maintenance or adjustments made on the cultural or social capital (both of themselves’ or of the child’s) on the part of the parents, in response to the attempt of cultural reproduction by their preferred school settings. Therefore, Bourdieu’s theoretical explanation of human values and behaviors also provided an intriguing lens that allows parents’ intentions to be examined from the angle

of the “mainstream”/dominant culture as well as a culture of disability.

As the other aspect of the expectancy-system in the parents of children with special needs, “self-efficacy” or the estimated possibility of fulfilling the expectancy was studied by a few researchers. Their studies showed that what the parents regarded as important outcomes that they expected their children to achieve was not necessarily thought as achievable. Mutua et al. (2002) conducted a study on the relationship between parents’ expectations of what kinds of resources their children with disabilities needed to be provided in Kenya. Parents of 435 children were surveyed. The disabilities that the children had included physical disabilities, mild to severe intellectual disabilities, hearing or visual impairment, blindness, and autism. In this survey, parents were presented with eight material and human resources that are available in the community, and asked to rate their perceived necessity of obtaining these resources as well as their perceived likelihood of receiving them, on a five-point Likert scale. The findings showed that most of the parents had given congruent appraisal of “necessity” and “likelihood” to five of the eight community resources, namely, health, friends, religious affiliation, acceptance in the community, and a home in the community. On the other hand, important to be noticed, educational programs and employment/career services received discrepant appraisals. In particular, although parents emphasized greatly on their children’s education and strongly requested it to be provided to their children, they did not seem to be convinced that their children had any chances to achieve these services. In the following writing the author presented possible reasons, such as cultural barriers against the providing of the opportunity for the children with disability to learn, the high prices of education in Kenya, and the scarcity of availability of educational facilities and human resources

there. In other words, in any consideration of the education that parents desired to get for their children, there must have been at least two components.

The parents were all, on one hand, concerned about the significant implications that education could bring to the lives of their children, but on the other hand, were likely to consider, instead, some other more “realistic” means of education after they perceived how hard these educational resources were able to be applied to their children.

Similar results have been yielded from Ivey’s (2004) study on parents of children with autism. It looked into how parents perceive the importance and likelihood of issues related to their children. Among the 25 parents, 24 of them had their children studying in public school settings. Parents investigated were involved with their children’s classroom activities on a varied basis. During the study, parents were given 20 statements such as “my child with autism will be successful in school”, and then asked to rate the perceived importance of each statement as well as the likelihood of its happening. Results showed that among the 20 scenarios given, eight of them were found to be rated to a significantly different degree between “importance” and “likelihood”. These dubiously rated items included the educational outcomes that the children could: have support network of friends, have a secure financial future, be safe from physical harm, have highest education possible, have their own children, be happy and satisfied, be accepted in the community, and have time to play and watch games. Furthermore, the first five discrepancies were found to be significant. The study did not directly examine whether or not those parents’ attitudes towards having their children in public schools could have been influenced by their self-estimated gauging of the five learning outcomes of them. However, the research finding does again indicate how parents might be confident at

vastly different levels about how the current education of their children might fulfill their educational expectations for their children.

### **Geography of Parents of Children with Special Educational Needs—On the Land of Obscurity**

As Minow (2005) and Norwich (1985) both stressed, the key that makes a sizable amount of inclusive practices unproductive lies in the social nature of human differences—when the difference was counted in people’s mind, it caused unfavorable outcomes; when this different was disregarded by people, other unwanted outcomes occurred. Parents who are directly dedicated to the well-being of their children, who have encountered a tremendous amount of adversities in life as the closest partners of these children, are keenly involved with each happy or troublesome episode that the child has and inevitably most empathetic with the kid during many of his life’s ups-and-downs. They were the most earnest guardians and companies of their children, which placed them on the same powerless and fragile position as their under-privileged children. Goffman (1974) called the parents as belonging to the “wise” people related to the stigmatized child by sharing a stigmatized connection with him. In contrast, teachers and school authorities are constantly seen as those on a position of power in the system of education, and get absolute upper hand over the allies of parents and their children, either in gleaning of information, possessing of resources, or influence on a large variety of decision-making regarding the students’ education (Swap, 1999).

In academic studies their voices and concerns have been widely examined and valued, but mostly for the goal of promotion and quality-monitoring of special services offered to those children (Chimedza, 2007; Parrilla, 2007; Timmons, 2007). When

considering mainstreaming, the students and parents were both said to have a more positive feeling than the general education teachers (Bennet & Gallagher, 2013). And as many researchers already observed, there is always a gap between government policies and the family experience of children with disabilities (Shang et al., 2011). What brings about this discrepancy might be standard-driven teaching goals pursued by modern schools (Lerrivee & Cook, 1979) and the consequential anxiety of the teacher's over the possible disruption of a rigid management of the order in the classroom by children with disabilities (Avrimidis, Bayliss, & Burden, 2000).

However, in the realm of sociopolitical description of disability, instead of being viewed as their children's guardian angels, parents sometimes turn to be criticized as a group that coordinate with a social conspiracy that was designed to marginalize a group of social members who bare differences from the norm in order to maintain the dominant status of the ruling group for cultural or material advantages. Above all of the criticisms, parents tended to be most frequently mentioned as the "oppressors" (Reeve 2004, p. 91) of the child. They are viewed as holding the same medical interpretation of their child's disabilities as professional members around the child (Finkelstein 1998; Marks 1999; Williams 2001), who regard his impairments as a fixed property in him that made him an incomplete person, an "unfortunate" (Linton, 1998; Michalko, 2002) who can never share the world of normals.

The above-described dichotomous set of thoughts on the parents of children with disabilities to some degree reflects the contentious construction of disability-related identities in contemporary societies. For approximately 30 years, works involving perspectives on people with disabilities automatically accentuate their arguments on two



sides: those having disabilities as the judged and the accused, and those others as ones who judge and accuser. Usually, the first side, individuals with disabilities, were believed to view their own disability as being (at least partly) constructed by the barriers brought about by the outside world rather than a function of their own impairments, while the other side was generally viewed as possessing a contrasting, or “medical” understanding of the individuals’ impairments that are dismissed by disability scholars as degenerating, impersonal and dehumanizing.

Despite researchers such as Ferguson’s (2001) remark that not all families (probably limited mainly to families in the U.S.—the author) are passively subdued to the professionals’ decision-making regarding the institutional placement of their children, parents and families have been traditionally holding a very obscure, dubious image.

Kohrman (2003), within his article which cast a synopsis about his well-known ethnographic study on embodiment and subjectivity of disability in China, distinguished subjects of interests in disability study, again in a dichotomous manner, into “biocrats” which included “biomedical providers, researchers, and teachers” and what he would call “the afflicted” (p.102). Under this research setting, once more, parents seemed to fall through the crack of groups of stakeholders whose assumptions of the children’s disability identities substantially described by academic studies.

Among students with disabilities, Low (2009) observed that those students with disabilities, on one hand, speak on behalf of other students with disabilities, but on the other hand, distanced themselves from them, “making them “the ultimate “others” to themselves” (p. 248). This observation can be appropriately projected to parents of young students with disabilities, as a depiction of their ambivalent position perceived by the

outside world. Using Smith's (1999) metaphor of geographic cartography, "'The zone of maximum deformation' are inhabited by those described as foreigners by the privileged center" (p133)." These "foreigners", in Chiris Kliewer's use of the term,

"are people...who have physically infiltrated centered communities, such as regular education classrooms, but who have not yet been fully accepted in social and cultural terms—they have crossed borders to live in the land of Normal, but not been accepted as Normal by living and learning there." (p. 133)

Here, this type of persons is depicted as being largely unknown to the habitants of the "normal" and thus more central zone. Therefore, the projected images of parents against the background pictures of their children with disabilities became even more fluid—do their perception of their children make them belong to the center of the whole landscape, since themselves are members of the "normates" (Garland-Thomson, 2009; Michalko, 2002; Titchkosky, 2003), or do they stay at the fringe of the geographic areas as a partial result of their self-election to ally with their disadvantaged children as well as of being marginalized by the other normates? Or, there is a middle ground for those parents between the center and the periphery, through which they navigate to and fro, doubly influenced by the society that they grew up within as well as the current or even the prospective situation of their children with disabilities. Since one component of their image comes from what position they stand in viewing their children, this image of the parents and images of their children in the parents' minds can somewhat mutually-define each other.

Inspiring the readers on the mystifying identities of individuals closely associated with the identities of people with disabilities as they are, scholarly work cited in the previous paragraphs shed little light on where the parents of young learners with special educational needs may position their children and themselves under a particular

circumstance where they play the role of making choices between more inclusive or more segregated educational settings for their children. Under a Chinese context, there is also a severe absence of academic studies and autobiographies on these parents of children with disabilities.

## **Chapter 3**

### **Methodology**

This chapter will start from a brief summary of the methodologies used to investigate parental attitudes in the Western research. Later, detailed implementations of the chosen research methods in this study will be explained.

#### **Methodologies Used in the Literature**

Researchers have both used quantitative and qualitative methods to explore parents' attitudes related to inclusion. A few examples of research exemplifying quantitative studies are those done by Miller et al. (1992), Leyser and Kirk (2004), and Palmer et al., (1998). In common, they examined parents' attitudes towards the children's inclusion by having parents rate on certain variables presented in ready-made, reliable, and validated scales, and calculate the differences between participant groups or statistically describe the relationship between dependent and independent variables. As a result, their studies provided revealing findings about the level of acceptance of the parents regarding inclusion, and how certain demographic background commonly shared by them might have predicted their attitudes.

In comparison, some other studies done by Cook and Swain (2001), Jenkinson (1998), Kasari et al. (1999), Palmer, Fuller, Arora, and Nelson (2001) used qualitative research approaches. A common feature of these studies is that the researchers conspicuously assumed that there might be new information or a particular domain of information that had not been thoroughly known. As a result, their studies were aimed at detecting new areas that parents were concerned related to their children's education, finding out their perceived meanings of the disabilities of the children, or describing the

complex processes of how children were included. Obviously, the qualitative inquiry approaches could best fulfill these authors' academic goals. In this study, qualitative interviewing was similarly used as an appropriate approach to explore the current research topic.

## **Research Design**

**Qualitative interviewing.** Among all types of in-depth interviews, two of them can be of great use for the purpose of this project: ethnographic interviewing and phenomenological interviewing. The former asks the participants to describe their daily lives in their native society (Marshall & Rossman, 2006; Spradley, 1979) in order to “elicit insiders’ cultural knowledge” (Marshall & Rossman, 2006, p. 104). The latter, phenomenological interviewing is based on the assumption that people have their own subjective experiences in relation to certain events, and under their mental judgments there are a predetermined “structured essence to share the experiences” (Marshall & Rossman, 2006, p. 104). With this type of interviewing, common meanings of a concept or phenomenon can be extracted, but participant-unique ones can be maintained and even further explored, too. Since this study was aimed at both revealing the current inclusive practices as evidenced by the description from the parents of children in the relevant population and exploring the parents mental state in which preferences to schools were made, a combination of the two interviewing methods was used. However, no field observations were made in this study; it carried more features of an phenomenological interviews than ethnographical ones.

***Strengths of qualitative interviewing.*** In order to fulfill the above presented research purpose, qualitative interviewing was chosen as the most suitable methodology.

Sarah Tracy (2013) sees qualitative methods as the best instruments to examining what she called as “phronetic questions” that examining “morality and values”, which held the same assumptions as the ones of this study: “that perception comes from a specific (self-reflexive) subject position and that the social and historical roots of an issue precede individual motivations and actions.” (p.4) To conduct a study on a geographic location where few investigation has ever touched, using interviews to gather sufficient qualitative information about the constructs of the topic in this particular context bears its incomparable advantages.

Compared with the other forms of qualitative research, interviews can be a very powerful tool to learn complex reasons leading to certain events or practices, the procedures involved in them, and their meaningfulness to the person (Elliott, 2005; Krathwohl, 1998; Murphy, 1980). First, by making qualitative probing I felt more eligible to answer the question of “why do the parents possess a preference for a certain educational setting” or “why they do not uniformly prefer a certain educational setting”, for example, mainstreaming their children. In comparison, although some quasi-causal inferences made by quantitative methods might shed some lights on the relation between their choices and some external variables, the “thick description” that can only be achieved using qualitative methods would give the finding a strong sense of truth that struck a chord in the reader (Miles and Huberman, 1994; Tracy, 2013). This can be achieved by explicitly laying out the background at the time of the interview that helps the researcher “to decipher a twitch and tell it apart from a wink and from a parody of a wink—and they may interpret the meaning(s) of all these gestures and help predict whether we are likely to see the behavior again.” (Tracy 2013, p.4)

Further, the flexibility inherent in this methodology was also valuable regarding the pursuit by this study of fluid and malleable concepts such as “dilemma” and “navigation (of the children’s position on the map of human differences)”. This study was benefited tremendously by the opportunities that were allowed by the contingent, interest-driven nature of inquiring.

As this study was conducted on China, a country that was socio-culturally differentiated from the locations of most of the past literature on the relevant topic, a qualitative study would enable the data to be probed by grounding it in a localized context so that “the possibility for understanding latent, underlying, or nonobvious issues is strong” (Miles & Huberman, 1994, p.10), namely, “tacit knowledge” described as “the largely unarticulated, contextual understanding that is often manifested in nods, silences, humor, and naughty nuances” (Altheide & Johson, 1994, p.492, as cited in Tracy, 2013)”. Given that the Chinese mandarin is a “high context” language that does not strictly rely on its textual structures for meaning expression (Hall, 1976), being able to tactfully utilize this contextual message to decipher verbal data is of vital importance. This benefit is guaranteed in face-to-face interviewing.

***Weaknesses and resolutions.*** One thing needs to be clarified here is that some manifest weaknesses that are generally thought to infest the research design of the qualitative interviewing study can be overcome. In the current study, by comparing the inquest into the central topic as “a mechanical puzzle” (p. 68) which requires the finding of different, or even contradictory forces that might entangle to create the parents’ ideas in question, theories such as “dilemma of difference” and “value and expectancy” are chosen as the major framework for the interview questions. The choice of these foci

partly came from a philosophy that I was firmly holding, that the ones who are given less privileges by the society did not necessarily view their own situations and themselves as what the “others” did to them, and that they have their own set of values. Therefore, instead of trying to check out about everything that the parents know about the topic, the determined sphere of examination and the successive construction of interview questions were limited to a pragmatically operable extent.

Another weakness inherent to qualitative interviewing study is that it is beyond the researchers’ (especially when the number of researcher is limited) time and capacity to cover a broad array of topics due to the overwhelming workload resulted to the researcher (Silverman, 2000). In my case, not only, as what has been presented in the previous passage, the research was reasonably concentrated on a couple key conceptions such as “value” and “dilemma”, but the research topics were extended from purely “expectation-based” to cover a larger variety that is “reality-based”, for example, systematic description of educational and socio-cultural environments as well as the status quo of the social encountering of children with disabilities. This all naturally came as a corollary of the context-based expectancy-value framework used to lead the interview questions. In this way, the complexity of the social world was respected, in addition to pinpointing a research topic that was practically manageable.

However, it still seems not impossible that there might still be concerns that using the data collection method of interviewing, too many questions needed to be asked to elicit information for answering the four research questions, apparently quite detached from each other. Adding to the number, one more research question was later added onto the list based on the post-hoc finding of the parents’ enthusiasm to create “preconditions”



for their children to obtain opportunities of being enrolled in mainstream elementary schools. To address this potential risk, the questions were designed purposefully that answers for questions 2 and question 4, about how the children with disabilities got included in China and how parents categorize their children in terms of normality and ability, can be naturally identified from their answers to questions 1 and 3, about the parents' idealized conception of inclusive education and their position on school setting choices. It was foreseeable that the parents were going to relate their opinions of question 1, their "dream inclusion" to their real experiences with their children's education and lives. They would also reveal their understanding of their children's place amid typical peers when they expounded their considerations under their preference for a certain setting. Therefore, the workload involved in the interviewing, especially time consumed by the interview processes and the following transcription and analysis, was put under effective control.

Another potential pitfall comes from the fact that I did not, like any other qualitative interviewer, start the research with an empty mind. There had been accumulated observations, thoughts and opinions that preexisted when the topic of this study was picked, refined, and used to steer the question constructing, the interview conducting, and the understanding of the pool of data. It equals to saying that during the entire process of the research, from the beginning to the end, I have my own strong, personal values and commitment to the topic she wanted to address (Richards, 2005).

I was in my thirties, a native Chinese mandarin speaker, grew up in Chinese mainland, went across all essential stages of education in China—from preschool, through elementary school, middle school, college, to the graduate study for my first

graduate degree. Somehow, with a thrust to know and better able to “help” people with disabilities, after several years being teaching as a lecturer in English in an elite university in Beijing, I decided to pull off to Europe. There I got my second Master’s in clinical linguistics, and meanwhile, course-required visits paid to a small autism clinic in Joensuu, Finland aroused my interest in more directly involved in the lives of children with disabilities. I immediately plunged into the teaching of young children with autism in an autism training center back in Beijing.

What I kept noticing when working in the center was how parents were eager to see their children improve in a flying speed, whatever the children’s condition was. Most of them could not wait to test their kids at anytime watching for signs of improvement, for example, hastily right after I finished one session with the kid and walked him out to meet the parents. Although the teachers in that center followed a self-developed curriculum whose contents were guided by items in the ABLLS scale aiming at building up basic skills, parents demanded the child to be taught to the level on which they could learn academic contents and make verbal communication as effectively as their same-aged peers. It brought great pressure for all teachers, and left an impression to them that the parents were not “realistic” at all. Every teacher understood that the parents put the pressure on them out of an enthusiasm in their children’s later mainstreaming and their fear of the children being rejected by “normal schools”. However, dedicating most of my time teaching, the reason of this enthusiasm and the equivalent opposition to the idea of sending them to special education schools were left undisclosed.

After teaching for two years, I moved to the United States to do doctoral work with the decision “to learn the best interventions in this world” for children with autism.

However, in no more than a year, inspired by courses of disability rights, theories of disability and families, together with a qualitative study she participated in on families and individuals from the perspective of person-centered thinking (PCT), my mindset about disability started to turn from a majority-driven, positivist fashion that viewing being disabled under a plot of tragedy and ceaseless and compelling efforts to move back to normal. This ideological turn led her interest to detour from interventional techniques to the subjective appraisal of disability-related issues. My neutral, constructionist view of disability was reinforced after my niece, Morning Sun, was born as an infant with Down's syndrome in the second year into her studying in the doctoral program. My interaction with Morning Sun's mom and dad, close observations of especially their acts, thoughts and feelings later became a major rationale to conduct the current research.

There was one dramatic occurrence in life—giving birth and raising my first child—that hammered home some brand new, live realization of two “matters of course” in my mind. The baby was had when I was kicking off the interviews in China. They gave rise to two new attitudes, the first was the power of parental autonomy, with both its negative and positive implications, and the second was the existence of indispensable and generic life expectation in the parents for their children. The second state of mind was also evidenced in the qualitative research findings of Landsman (2008). The possession of these attitudes, especially the first one, played an important role to prompt me to venture into a description and analysis of “actions from the parents” during the research, a topic novel to the initial design. Eventually, I amalgamated them as a proposed dimension underlying the parents' options.

All the above mentioned life paths and encounters of mine constitute the “bias” that

I could have had during the qualitative research in question, as this genre of this type of study is the one that relies on the researcher's immersion into the context in which the topic-related phenomena takes place, which will further enable them to be able to interpret what they observe and then make "second-order interpretation" of what is going on (Miles & Huberman, 1994; Tracy, 2013). Although the immersion undoubtedly results in some bias, identification and reflection on them help to bring clarification to the results of the academic scrutiny.

In the eyes of ethnographers, bias is often both a burden and a wisdom (Richards, 2005; Tracy, 2013). It does have an impact of subjective judgment as in any case of research where conclusions "as objective as possible" are highly sought after. However, bias is a necessary condition of any ethnographic project that are aspiring to be informative. In the case of this study, the points of view regarding Chinese parents and lives with disability were viewed with a positive light and deemed as contributing to the reader's understanding of the particular research scene. Since "the mind and body of a qualitative researcher literally serve as research instruments" (Tracy, 2013, p.3), allowing readers the chance to examine the research findings controlled of the bias in my mind would serve the purpose for devising a non-misleading (if not undistorted) study.

***"Validity" and "reliability."*** Given the unique characteristics of qualitative study, mechanisms using measurement systems other than the post-test or inference ones are used to ensure the quality of the interview study. Generally, for these types of studies, researchers tend to talk less about the "conventional positivist paradigm" examining the "truth value," - namely internal validity, external validity, reliability, and objectivity - than other academic methodologies. Instead, many of them attend to credibility,

transferability, dependability, and confirmability (King et al., 2005; Lincoln & Guba, 1985; Marshall & Rossman, 2006).

“Credibility” aims to demonstrate that the data generated exactly explain the subject matter of the study (Marshall and Rossman, 2006). To strengthen the credibility of this study, two strategies were taken. First, in the “research design” section, self-reflection proposed by Richards (2005) and Tracy (2013) was conducted and documented to examine many presuppositions that I had about the topics related to Chinese parents, being a student in China, and leading a life with disabilities in China. During the interviews and data analysis, caution was taken to avoid having any firm preoccupation before getting to the stage of interpreting the messages conveyed through the parents’ answers, for example, by being careful not to ask leading questions. Expectations or hypotheses about the answers should be reduced to a minimal amount.

Secondly, dynamics within the interactions between the interviewees and me were discussed to make sure that the words and other expressions of meanings were interpreted as faithfully as possible. Thirdly, computer-assisted recording using an up-to-date digital recorder and the data analysis program, NVivo were used to ensure that the themes and patterns do exist across interviewees rather than just “in favorable examples” (Silverman, 2000, p. 187).

“Transferability” examines whether research is reasonably constructed upon well-established previous research (Marshall & Rossman, 2006). However, there has been very rare documentation about how interviews were conducted on parents of children with disabilities, and even less in the Chinese context. Therefore, the interview project included ample documentation on how the designing of questions and the

implementation of the interview were guided by previous research theories and methods. In this way, future researchers who are conducting similar qualitative research using the same theoretical frameworks can decide whether this case can be applied to their new research settings, indicating strong “transferability” for their planned studies (Lincoln & Guba, 1985).

“Transferability,” in a different definition refers to an accomplishment of a qualitative interview research “when readers intuitively believe that research findings correspond to something significant in their own world” (Tracy, 2013, p. 238). In the present study, I chose to ask research questions that elicit answers that educational professionals, policy-makers, persons with disabilities and their concerned relatives, and researchers in inclusive education and disability rights may feel resonates with their own situation. In the Results section, select quotes from the answers are displayed so that themes are richly presented and lively with details.

“Dependability” describes the extent to which the interviewing conditions or the study design has been changed. In a situation as fluid as a face-to-face interview, changes are actually encouraged to happen (Krathwohl, 1998). In response to these circumstances, in the “Data Analysis” section of the present chapter, changes made in the process and their rationales were fully recorded.

“Confirmability” is regarded by Marshall and Rossman (2006) as reflecting the question of whether the findings of this research can be confirmed by others. Lincoln and Guba (1985) suggest that the subjective, interpretive characteristics of qualitative studies should be made known to the readers so as to add to the strength of the findings. Another recommended way to ensure confirmability is to co-build the interpretation of the data by

the interviewee and interviewer together (Kvale, 1996; Smythe & Murray, 2006; Tracy, 2013). The member-checking, or “member reflection” where the researcher presents his interpretation and findings to the participant for their verification and modification is one example (Atkinson, 2002; Kvale, 1996, Tracy, 2013).

In conclusion, to mitigate the randomness and subjectivity inherent to interview research, and in order to gain a sense of academic rigidity, many details involved in the design of the study, interview questions, interview processes and data analysis should be logged. Questions and findings should be thoroughly discussed with other researchers, and even with the informants. Some researchers also suggest that the researcher should constantly question himself as to what other methods can be used, and why the currently used one is most beneficial to use (Marshall & Rossman, 2006; Tagg, 1985).

**Question designing. *Ethnographic and phenomenological questions.*** There have been a set of mature typology regarding ethnographic questions. Two “knowledge questions” (Patton, 2002, p. 350). According to Spradley (1979), two major types of questions are widely utilized in ethnographic data collection. One of them is the descriptive question (Spradley, 1979, p. 60), or experience and behavior questions (Patton, 2002, p348). These are aimed at gleaning samples of the language that the consultant usually uses on a certain topic. This type of question recurs as the topics move on to add new vocabulary to the repertoire. An example for the proposed study was, “Could you describe what a typical school day is like for your child?” The second question type is called structural question (p. 60). This way of presenting questions helps to “discover information about domains.” According to Spradley (1979), they examine the way by which the informant organizes his knowledge on a certain area. For example,

“What are difficulties that your children have at schools or the special education schools?” Besides, to exhaust the list generated by the informants, questions such as, “Can you think of any other difficulties?” can be asked. The third type of ethnographical question is a contrast question (p. 60), based on Spradley’s (1979) thought that meaning is defined through the semantic contrast implicit in any language. In this study no such question was asked, based on the research needs.

In order to collect data for phenomenological research interest in the presently discussed topic on parental attitudes, other questions were designed to elicit some more subjective information. One type of question is on the interviewee’s beliefs and values, such as, “Just now I heard you talk about several educational outcomes that you are hoping that your child can achieve in an inclusive/special education setting. Among them, what are those that you most expect that he is able to achieve, and why?”

***Co-construction of the questions.*** Werner & Schoepfle (1987) admitted that when exploring an unfamiliar culture, it is not uncommon for an interviewer to present a question that is culturally inappropriate. The amendment in this case was to work out a new question together with the interviewee. Werner & Schoepfle also insisted that under this situation, the interviewee should be granted enough freedom to instruct the interviewer. In the designing stage of this study, I decided that very likely, and most naturally, the parent informants would have a better sense of what the questions could be used to discover, and whether these questions were sufficient to address the most relevant aspects of their attitudes of their children’s education. In the case of disability studies, it makes much sense, since parents, as the closest participants in the children’s lives, and the potential beneficiaries of this study, are widely regarded as having a more



authoritative voice than the interviewer in deciding an appropriate question.

In this study, the first three pilot interviews with parents taught the me to reconstruct her research questions in the later sessions. Additionally, there were some parents who suggested a new framework of thinking and hence new wording of the question. One of them corrected my question, “What particular improvement of him makes you feel most relieved?” saying, “There is no such particular improvement in him that can relieve me. I will feel soothed and relieved only when there are an accepting environments all over the society, not just when he is changed into a better form.” Due to her unique background as a parent leader, the other parents were still asked the unmodified question. However, the implication that her answer suggested added to the awareness of mine that there could be multiple perspectives that parents might use to comprehend this question, especially for those who view their children as equal to others in terms of their social status and educational rights.

***Creating novel questions.*** As widely recognized among qualitative researchers, besides the pre-determined (“grandtour”) questions that must be in place before the interview begins, there are also other questions that can only be formed based on what has been answered (for example, Patton, (2002)). As the interviewing process unfolded, I came up with certain questions that were not present in the interview guide merely because certain responses from my interviewees elicited unforeseen perspectives that interestingly contributed to the research goal.

In the interview, one of the parents brought out a novel idea: “[I’m planning to] enroll him in the LRC in a neighborhood school first, for one year. If it does not work out, I’ll then transfer him to TH Inclusive School.” This was very different from many

other parents in the same city, who referred to TH school as their most preferred destination. Therefore, the second question quickly followed up to point out this singularity, “Why *Sui Ban Jiu Du* (LRC) first, and the inclusive school second?” Although the conversation then temporarily segued to her reasoning of this choice rather than continuing on her description of why learning in the mainstream would benefit her son, it produced important information about the role of parent advocacy that distinguished parents’ preferences for placement. There are many other examples during the interview. Contingent and inadvertent as they appeared, these mini-tour questions were mindfully incorporated into the interview to gather relevant messages, despite the miscellaneous ways that parents answered these questions.

***Limited grand-tour question complimented with rich mini-tour questions.***

Instead of crafting an involved set of questions regarding an extended array of refined topics, the interview protocol was designed to be just a guide that served to guide the parents’ thoughts on a bigger topic. In other words, the interview protocol was made up of merely grand-tour questions.

The first reason for this rests on my intention to be open to the variety of reasons that parents choose to talk about. In China’s culture, there was very likely a set of cultural power dynamics between disadvantaged parents of (potential) students with disabilities and the interviewer, who was regarded as an “expert” by parents, evidenced by the fact that many of them used part of the interviewing time to consult me about the training and services of their children. Therefore, I had to try not to, by any means, give any “hint” that would put pressure on them to talk in an allegedly desirable direction for my sake, different from what Patton (2002) suggested. This would both limit the width of the

topics to be probed and the parents' autonomy as advocates for their children and their own lives.

The second reason lies in the nature of the perception-focused investigation of this research. I believed that there was a ringing of truth in Patton's (2002) observation of the difficulty for interviewees to put together the reasons for a certain course. However, since what I wanted to know was more about the course of thinking ("What is your opinion...." "Why do you think...") than course of action ("Why did you do..."), especially with the thoughts involved in their mental inclination, it was foreseen that their answers would be confined to contents related to values or other subjective appraisals and judgment rather than a wildly spread-out description of every antecedent prior to the interested course of action.

For the above reasons, the interview protocol was constructed to be open to flexible follow-up questions to address the details and explore possible new patterns of information. It indicates a moderately unstructured fashion of questioning, which was used by other researchers conducting under similar research. For example, McCabe (2007) utilized "semi-structured protocols augmented with multiple informal conversations" in their qualitative study on parent advocacy for children with autism in China. Their "interviews were guided by general questions but shaped to some extent by the focus of the interviewees" (p. 41). Likewise, in designing the interview strategies, I also strived to strike a balance between unrestricted openness in the request for responses that bring about straying conversations and hard-to-transfer findings and rigid questioning that incur only bullet points (Krathwohl, 1998; Patton, 2002; Pawar, 2004).

***Sequence of the questions.*** Question sequencing was given consideration, too.

According to qualitative researchers, the speculated functions for each question can only be fully played out when they are arranged in an optimal sequence in an appropriate amount.

What researchers share in their opinions was that “easy” (Murphy, 1980, p. 158) questions should be asked first, then “sensitive, threatening” (Pawar, 2004, p. 34; Patton, 2002, p. 352) or “tough” (Murphy, 1980) questions should follow. What is worth noting is that these “difficult” topics seemed to have been defined by researchers in a case-by-case manner. For example, Patton (2002) regarded opinion and feeling questions to be potentially demanding and required participants to be mentally activated in their memories of past experiences before answering them. In the case of the current interview on parental attitudes of inclusion of children with disabilities, strong emotions can be anticipated in parents’ recollections of past experiences with their kids. It might then pose disruption in their answering of later questions.

However, since many parents already had some conversation or consultation with me before the interview, and since in most cases they immediately started talking about their children’s situation after asking several questions to get themselves acquainted with the research project, they were presumably well adjusted to answer certain emotionally disturbing questions. Therefore, these questions, such as, “How did you and your family find out about his differences at the very beginning?” came naturally after the parents’ description of their current situation, as the first question to break the ice, and served to transition the parents’ attention to more focused topics on differences and inclusion. Although the parents took this question extremely well, many of the other questions that were more “sensitive” and “threatening” in the original questions list were dropped in

almost all interviews, for fear of further elevating parents' discomfort, and, most importantly, for the sake of time.

***Wording of the questions.*** Not only the content of the questions, but also the linguistic characteristics of the question were said to have an impact on the quality of information elicited. It is recommended by Patton (2002) that special terms commonly used by the informants in their own daily lives should be picked up and used in the later questions to increase the clarity of the questions. This advice was faithfully followed in many cases during the interviewing, and was found also to have clarified the answers in turn, and even worked the extra effect of building up more rapport with the interviewees. Below is an excerpt of one interview:

“*I have never once thought* like, he should go to that type of place [special education schools].”

“*Why have you never once thought* like that?”

“Because I don't think my child has *reached that level* that I must send him to the special schools.”

“Then to *what level if he reaches* will you be willing to do this?”

“The students who go to the special education schools have lower functioning levels...”

Additionally, Elliott (2005) proposed that the interviewer try his best to compose the questions by using simple, everyday language rather than “sociological language” (p. 29). He quoted Chase's conclusion in regard to one of their interview studies, that the pedantically worded questions “...invite reports. They do not invite the other to take responsibility for the import of her response because the weight of the question lies in the

sociological ideas” (p. 29). During the interview study, I talked with parents from each city in their native tongue, Southwest Mandarin, believing that it helped the ideas to come out most naturally when being questioned with a dialect in which he commonly discussed the related issue with others. Also, questions were formed in a colloquial way to reduce the interviewees’ feeling that he had to say something academically desirable and meaningful. The message passed to the parents was, “I just want to know what you think about it.”

### **Participant Selection**

**Inclusive and exclusive criteria.** The study was specifically targeted to parents in Chinese urban areas, each of whom had at least one child medically identified as having developmental disabilities. Children who were physically disabled or hard of hearing or seeing were not be included, due to their drastically different needs for support in their school lives. There is no specific age range required for the children, but a certain degree of variety was required among their ages. Besides, participants’ parents were both in favor and disfavor of the inclusive education of their children.

Participants did not include the ones from Chinese rural areas. This is because of the consideration of the vast differentiation in the educational systems between urban and rural areas in this country (Lytle, Johnson, & Yang, 2013). These are two educational systems which differ in many aspects, such as teaching content, educational expectations, school facilities, qualification of the teachers, individualized support, and even the conventional forms of education for children with disabilities. Given the restricted time frame to complete a doctoral dissertation, a new variable such as this might have introduced an enormous amount of new information would have complicated the

analytical work to an unmanageable degree.

**Recruitment of participants.** I received the human subject research training at University of California, Santa Barbara in March 2012. After that, I submitted my research protocol to the Human Subject Committee of the university and was certified to apply this protocol to my targeted participants in June 2012.

After arriving in China, I recruited 16 participants in the cities of Beijing and Chengdu (See Table 2.) The recruitment was completed by using two types of contact people in the first of two cities, Beijing. The first type of contact people were principals of child rehabilitation centers. They gathered a meeting in which parents could come and consult with me in education-related problems. During the meeting, flyers about the research were handed to each parent, including the details of the study, the intent of the research, its major topic, rights of the parents, measures taken for privacy protection, and contact information. Those who were willing to do the interview left their contact information to me for further scheduling. Two parents were identified in this way. Another contact person was a friend of mine who was a veteran teacher of children with autism. She checked around the agency where she worked and asked other parents who she knew for interested parents and then presented them the research flyers. Parents who decided to participate in the interview enrolled themselves with my friend. She then worked with me to find the best times for interviewing. Six parents enrolled themselves in this way.

In another city, Chengdu, two approaches were used, namely, contact people and snow balling. The first one was through contact people. One of the contact people was a principal of a newly-built, state-owned, government-promoted elementary school that

was acclaimed to be the first inclusive school in Chengdu. He counted on his teachers to identify potential participants and gave them the flyer to inform the interested parents. One parent went to the teacher for the enrollment. The other contact person introduced me to a parent group on Down Syndrome, and invited two of their leaders to participate. Another parent in this group agreed to take part in the interview after hearing about the research from me at an event hosted by the parent group. Still another contact person contacted and persuaded a parent to join the study by using social media. After being interviewed, these parents started passing around the news about the study and invited another three parents to be the participants.

### **Data Analysis**

The analysis of interview data, according to Kvale (1996), is not a discrete stage happening only after the interview is completed and transcription finished. According to him, it “permeates an entire interview inquiry” (p. 205). On many occasions, the “probes” previously discussed are used to clarify the points made by the informant along the interview can only be properly executed when the interviewer has carefully listened to and pondered the information that he has on hand. It implies that if the interviewer is also the analyst of the data, this process starts far before the end of the data collection. Some highlights from this “step-one” data analysis will be presented in the section about the “preliminary investigations.”

**Contextualization.** After the interview and transcription was done, the researcher’s attention was primarily spent on doing systematic analysis of the data information. In this stage, a general caution is that the words recorded from an interview gain their meaning from the context. For this reason, Poland (2002) suggested that a broad “macrocontext”



(p. 635), namely the historical and social location of the interview does matter to the meaning of the text. Also, it is reasonable to assume that an isolated sentence or phrase uttered by the informant can hint at the meaning from its previous and succeeding contexts, according to Linde's (1993) observation that narratives are "robustly resistant to interruption" (p. 26) and almost always able to be resumed at any given time. Besides, Kvale (1996) emphasized on the effect that the interviewer has on the responses by the interviewee, and how dialogue is developed along a track steered by both sides. The perspectives from all three researchers well remind the analyst how information retrieved from an interview should be reviewed as a socially constructed, interaction based, and contextually framed product.

One example of this contextualization was reflected in my efforts to translate a major code—"gen de shang" from Chinese to English. This code appeared in quite a few parents' responses about their expectation for their children. Literally, it was generally suggested to be translated to "catch up", meaning "reach a certain level that allows someone to cope successfully" or "keep up", meaning "move on without interruption." Eventually, however, translation of this Chinese phrase was decided as "be more or less equivalent with other children in the class." This was partly due to the fact that many parents immediately followed this phrase by stating reasons for why it was important for their children not to fall behind their peers too conspicuously in their grades. Another reason for this translation was the my constant consideration of the theme, which parents were well-aware of at the time of their interview: the hope for their child to be accepted by the teachers of the general education classroom as a student not drastically different from others.

**Analysis with conscious “openness.”** As this study strives to obtain a phenomenological understanding of attitudes from Chinese parents, it makes the “information categorization” started as early as even before the question-forming stage (Marshall & Rossman, 2006) so that hypotheses can be developed prior to questioning. This is also called “content analysis” (e.g. Lieblich, Tuval-Mashiach, & Zilber, 1998; Mostyn, 1985). However, the topic of this study touched upon a relatively unfamiliar scope of educational, social, and cultural practices in relation to children with disabilities for Western readers of literature, including myself, only to a different degree. Therefore, the post-interview data analysis did not simply include filling up the pre-formed categories with classified information gathered from the interviews (Lieblich et al., 1998), such as “choices between LRC and special schools,” “awareness of the dilemma,” and “expectations for their children.”

For example, certain actions were repeatedly stressed by the parents as an indispensable condition to escort their children during their mainstream learning for the best educational result. Besides elaborating on how their expectation of their children solidified their dreams for a mainstream learning environment, most of them listed some characteristics of their children which were perceived to be evidence that mainstreaming worked best on them. For this set of information, the category, “perceived suitability for mainstreaming” was created (see p. 100).

Of course, being conscious while holding this openness also means that I, instead of pretending that myself was free of all presumptions of any kind, took a stance of acknowledging the important point of departure of my research endeavor—my past observation that most of the parents were eager to see their children learning in a

“normal” setting with “normal” kids around them. However, holding this presumption neither prevented myself from being curious about their reasons for thinking in this way, nor from being sensitive about the alternative ideas that some parents brought forth.

**Iterative analysis.** Iterative analysis was innovatively created by Sarah Tracy (2013) as a midway between heavily grounded ethnographic analysis and more theory- and knowledge-driven, systematic phenomenological analysis. As Tracy suggests, this approach can be applied in a wide range of qualitative interviewing research and is characterized by its “problem-based” and “pragmatic” orientation (p. 184). After the interview, the data was placed by case in chronological order (Tracy, 2013) to display a trajectory of data collection and comprehension during the interviewing process. It bears great meaning in the case of this study, since the first couple of interviews, described later in this chapter, illuminated the later path of question probing and response analyses.

After the “primary-cycle coding” or making the “first-level codes” (Tracy, 2013), also known as “open coding” as in grounded theory (Strauss & Corbin, 1998) which was used to “condense the meanings of the original interviewing text” (Kvale, 1996), a more in-depth, theory-forming “secondary-cycle coding” was performed. To serve the purpose of this study that explored into the construction of the minds of the parents on their preferences of school settings, simple hierarchical coding (Tracy, 2013) (or “axial coding” (Strauss & Corbin, 1998)) was not enough. “Analytic codes” which were comprised of novel synthesis of theories were detected and created as the analytical processes rolled on.

For example, during the initial process of immersion into the text and the primary-cycle coding, it was gradually revealed to me that most of the parents tended to not only

cite their own expectation of the children's learning outcomes, but also referred to the positive characteristics that they observed in their children as another support to their preference of a particular setting. Under this circumstance, "prospective conjecture" (Tracy, 2013) was used to include the effect of the parents' gauging of their children's levels of abilities with the interpretation of their thinking, their expectations, and the affiliated values. In other words, a "secondary-cycle" code, "Perceived suitability of their children for the mainstreaming schooling" was created.

"Theoretical sampling" (Tracy, 2013) was also conducted when it became clear to me after the first several interviews that "parents' actions," differed from the originally conjectured "parents' reasoning and feeling" as the major foci of inquiry to attend to. Therefore, I deliberately incorporated the action questions into the protocol, and later gleaned meaning and subthemes from the responses which form part of the major theme, "Parents coming to terms with the drawbacks of LRC (see p. 104)."

Hierarchies of the information categories were displayed using NVivo, a digital, time-efficient version of the "conceptually clustered matrix" recommended by Miles and Huberman (1994, p. 128). I also kept an analytic memo where creative ideas about primary- and secondary-cycle coding were jotted down during analysis.

### **Learning from Preliminary "Investigations"**

There have been several initial observations of the targeted parent population from my contact with parents at the early stage of the interviewing, that occurred to me as inspiring for my later interviews and investigation into the collected data. In fact, the reason that the word "investigations" were marked with quotation marks was that none of the related findings were the consequence of intended exploration but of accidental

findings from the first three interviews. I still label them as “investigation” because in qualitative studies, despite the lack of refined investigating instruments such as well-supported research approaches, “the mind and body of a qualitative researcher literally serve as research instruments—absorbing, sifting through, and interpreting the world through observation, participation, and interviewing” (Tracy, 2013, p.3). After making careful reflection on data collected from this “pilot study,” I gained some precious understanding in a few topic-related issues, and subsequently made some important adjustments in my mental construction of the identity of the participants, on both the interview questions and the exact manner of applying these questions.

**Self-selection of the parents.** One of these observations happened during the days when I was recruiting participants. There were two parents who turned me down or the request from a contact person for the interview. They presented extremely similar reasons for their declination—their children were “normal” in both of their opinions. Therefore, they both disqualified themselves when requested to take the interview. “It’s hard for me to accept [that I will speak as the mom of a child with problems],” said one to my contact person. Meanwhile, my cousin, herself one of my diligent contact people, and who had a young daughter with Down Syndrome, said to me in confusion, “[If I must be interviewed] my answer will be just one sentence long. My daughter will definitely go to general elementary schools. She is normal!” Each time I alluded to her that she would be an ideal informant for the study, she dismissed my attempt hastily by saying that there was nothing more that she could offer except for that message, which she had repeated not only in the case of the interview study, but also in many family events in the presence of many other family members.

These parents who automatically excluded themselves from a disability-related study brought into my attention the existence of a group who are in a die-hard position regarding their children's "normal" social identity, and therefore contrast directly with the parents who had no skepticism of their own status as being a parent of children with certain unique, mostly challenging conditions that required some particular investigation in order to address/combat it, such as this study. Therefore, I was reminded by this occurrence during the recruitment that my originally targeted population, namely all parents in China whose children have developmental disabilities, has probably been limited to one subtype due to the self-selecting nature of the respondents to this study.

**“Dilemma”—Letting them say it.** The second finding was pretty positive in the sense that it provided a powerful verification to the question designing which intentionally did not include the word “dilemma” in any questions used in the interviews. At the time of question development, what inspired me not to make the word “dilemma” explicit to the interviewees was a result of my literature review that there was a certain fraction of the group of parents whose opinion on inclusive education were never apparently impacted by any recognition of “dilemma.” The same observation was held true for Norwich (2008) when constructing his research on the professionals’ perception of inclusion. According to him, there was “a small minority” (p. 65) of the participants across the three countries included in his study who claimed that it was hard for them to sense a certain dilemma that the researchers presented to them.

Thus it appeared to me that it was less wise to invoke the idea of “dilemma” in the cognitive process of the parents than to allow them the freedom to choose whether to express and elaborate it or not. This idea came from the inspiration from one interview

that I did in the United States. At the end of the interview on the family life of a woman who has a son with autism in the United States, I randomly asked her a closing question: “Do you think that your life is normal?” Suddenly it instigated an emotional speech from her where she vehemently explained how abnormal her life was, which carried a contrasting tone to the one exhibited in her former description of her life path in care-taking her son.

Her story being completely “rewritten” by the simple emergence of a question made me extremely conscious of the presentation of this type of terminology that is emotional. Emotional because the knowledge of oneself in a dilemmatic or abnormal situation are very likely to bring instant feelings of frustration or shame to the person. The terminology was also subjective and volatile in nature (with the slimmest sense of determination to ignore the difficulties caused by one of the two options entailed in the dilemma, the parents would in turn dismiss it as a dilemma, and vice versa). Lastly, the terminology was easily influenced by the context of the conversation (“I am facing someone studying inclusion in the United States and she is now talking about dilemmas in it. Then I am probably facing it, too.”).

What was found in the pilot study further confirmed the feasibility of hiding “dilemma” from the grand-tour questions. During the first few interviews, it seemed that two out of three parents showed no hesitation choosing mainstreaming, and the third spoke about the word “*Jiu Jie*” (divided) to express his painful situation. It meant that parents all tended to give out targeted information about the interested topic of “dilemma” even when no particular questions were asked about it. Therefore, the absence of the question was maintained throughout the later interviews.

**Coding and recoding while questioning.** After the first two interviews were done, the question, “What are your expectations about the learning results of your children in an inclusive classroom?” was asked, which was based on the concept of task-focused values and expectations in the expectancy-value theory by Eccles and Wigfield (2002). However, from their answers I found that the parents generally tended to relate the expectations more to the future life prospects of their children than to how their children really learned in the classroom, when they were weighing the usefulness of various learning settings. This was not part of my current research interest, but I decided to tailor my questioning to this phenomenon, make the question less restricted and only ask, “What are your expectations for your child in his education?” Many parents’ responses to this question tended to revolve around what they generally hoped for the benefit of the children’s future development, instead of specification of the immediate gains that their children should make in the classroom. Therefore, the “pre-categorization” / “precoding” that was associated with this question changed as the interviewing process proceeded, from a more tightly defined one to a less strict one. No less important, the saliency of the parents’ expectation of their children’s future performance level was later coded as “Absorbance with children’s future lives” as one critical observation aligned with the theorization of the parents’ centrality in the mainstream placement.

**Withdrawal of “significance” questions.** It was not hard to see through the capturing of the last two modifications that I made after my first two or three interviewees, that eventually the interview protocol evolved to be a less restrictive one that involved a stronger parents-led and conversational tone. Another pilot-based observation that made the question probing increasingly more free as the interviewing



project unfolded was my discarding of questions when asking the parents how significant (either significantly good or significantly bad) a witnessed or foreseen learning situation was for their children. The fact was that parents appeared to be utterly perplexed by this question. This was probably due to the fact that, even in the first couple interviews, there was a strong sign that the information involved in their answers went “saturated” very early on, in other words, parents could seldom present new and interesting information for this. There was an intriguing scene that evidenced the necessity to get rid of this question.

“[At the special education schools] in the recess, after going to the restrooms, they have to come back and sit at their desks, doing nothing but sitting still. Sitting until the 10 minutes or a bit more of recess comes to an end, the bell rings and they start the next session.”

“What bad do you think it might bring to your son’s future development?”

“...[silent for five seconds] what do you think? [with a wry smile]”

“... [smiling back in an admitting way]”

“Hasn’t a human being been made into a robot?... Even if he learns something, he’s a person without a normal life in that school.”

Although the parent might agree about the significance nature of the topics that they chose to bring up, he treated the answer as too self-evident, too commonly-known to be worthy of uttering. Realizing this, I rarely brought up this question in the interviews to come, or rather, replaced the formal, intimidating, interviewer-oriented wording of the question to some other utterance that was more intimate, informant-centered: “Did you see why you are particularly happy about this small progress?” Or simply a repetition of

what the interviewee described: “Yes you must have been so happy”, waiting for him to further elaborate on it if he deemed it necessary and interesting.

Using this method, the parents were much more motivated to continue talking about their outlooks for their children’s future. This also eased the pain of information saturation, although did not completely solve it. In fact, the persistence of a limited set of messages despite my attempt to elicit more from them highlighted the obsession in the Chinese parents about a prospect of being able to assimilate into the normal world, which became a major subtheme under the theme “Perceived advantages of studying in general schools” (see p. 95) as a result of the later data analysis.

## **Chapter 4**

### **Results**

The following findings from the present study are gleaned from the information obtained from the qualitative interviews of 16 Chinese parents in correspondence with the research questions: (a) Chinese parents' present level of awareness and understanding of inclusive education; (b) parents' experiences of current LRC practice in China to include children with disabilities, compared with their perception of true inclusive education; (c) parents' preferences of education placement decision for their children with disabilities and their relations to their expectations and values on their decisions; and (d) parents' view of their children with developmental disabilities as learners in Chinese school systems. These findings are presented based on the 13 themes and their subthemes sorted out from the interviews. In this chapter altogether there are 13 sections representing the 13 themes. Some subthemes are presented together, integrated under a single headline, with bracketed notes specifying which subthemes the headline covers.

#### **Parents' Knowledge of Inclusive Education**

"Inclusive education" (IE) seemed to have become a trendy jargon that was known by most of the parents except for two of them, either through being shared by other parents, or passed across from other popular media such as internet or government-affiliated charity events. Despite the diversified sources from which the parents' knowledge of inclusive education was convened, it appeared that the IE had become a concerted conception in the minds of the parents.

According to the parents, inclusive education was a format of education that could satisfy everything that they dreamed about the education of their children. First of all,

learning occurred in an inclusive environment was blessed with an open and warm atmosphere (most parents). Also, under the spirit of inclusion, other people related to the school, such as the staff, typical children and their parents were all willing to commit themselves to understanding and embracing the child as well as their family members (15 parents). Next, education conducted for inclusive purposes meant the one integrating specialized education as a necessary part (15 parents). By this means, it set up various accessible activities for both typical children and children with special needs. Thirdly, part of the teachers and staff were equipped with the knowledge and skills to guarantee properly targeted instructions of the children in order to foster continuous progresses in them (6 parents). The teachers were also good at facilitating benign relationship between the child with special needs and their peers (4 parents). (See subthemes in Theme 1, Table 1)

Therefore, not only “in terms of the total atmosphere, it is a very good one”, but inclusive education became materialized into a set of resources. It showed that parents deemed inclusive education doable as long as proper conditions arose. Also, parents had a prevailing yet revolutionary perspective that equalized on children with disabilities as an ordinary learner and a typical person. As Mo's dad expressed, instead of “shaping kids through cookie cutters so that they represent only one form”, inclusive education that they thought about was “mixing children with different forms together, and assisting kids to adapt themselves to those with other forms [for example, with disabilities].” Under this spirit, inclusive education implied that everyone involved in this educational undertaking enjoyed adequate exchanges of ideas and feelings which formed considerable empathy and mutual understanding of each other.

## **Chinese Educational System Falling Short to Meet the Needs of Children, Disabled and Typical alike**

Except for stating inclusive education as their much craved form of education, most of the parents alluded that there was stark disparity between the currently implemented practice of the LRC and inclusive education in its ideal form (See Theme 2, Table 1).

**No real inclusive education but LRC.** The majority of the parents pointed out that the LRC that they witnessed or experienced was not inclusive at all. They particularly emphasized the helpless situation of children with disabilities in this setting.

**Not much choices for children with disabilities.** Many parents stated that besides the LRC and special education schools which both were much flawed educational formats, there were no other choices existing for them to choose.

**Public education failing to accommodate differences.** Nine parents brought up this theme. They tended to view the Chinese public education as unsuccessfully meeting the education needs of both typical children and disabled ones. ***Failure to teach typical students.*** The general public schools in China, according to the parents, were both unable to address their children's educational needs and fell short of providing high quality education to truly benefit the development of typical students. "On one side, you think public schools can be good to him, but in fact they are not able to do what you want them to." Many of them tended to feel that the goals of the education were elite-oriented, its contents of pedagogy too demanding, and worst of all, enrollment rules of the educational system and concrete routines of most of the schools were not flexible. What the parents saw in their experience was that a larger group of students other than their children with disabilities failed to obtain proper public school education and were poorly

accommodated. Therefore, it was not that “this educational institution takes care of that part of the children but not yours”, but “only the highly intelligent ones are thought as “qualified persons”, no others are.” To them, under this fanatic elitist philosophy, the consequences from a student’s spending time in a Chinese public school would very likely end up in learning pedantic knowledge that had nothing to do with real life living and thinking skills.

***Failure to teach students with disabilities.*** According to parents’ opinions, a public educational system that was functionally limited in its services to children with diversities, and its way of teaching and learning naturally governed by its heavy inclination to prepare student to meet standards of paper-pencil tests, had resulted in pathetic learning outcomes for children with disabilities. It tended to be regarded by some as “a failure” that only provided the students ostensible benefits that did not do authentic good to their future life. “Ninety-nine percent of the things [I learned at school] are useless...the school did not teach us how we can socialize better, that is, what are the right manners to get along with people, or what are the strategies to use in handling daily businesses in life...Nothing!”

**Other failures of present public education in China.** Parents also mentioned a number of other pitfalls in the current Chinese educational system (See subtheme 4, in Theme 2, Table 1).

Therefore, on one hand, parents complained about how there was a lack of suitable institutions that are willing to admit students with disabilities and a shortage of well-designed programs that could sufficiently meet their children’s educational goals. On the other hand, the educational prospect of typical children was not optimistic either.

### **Dire Performances of the Children in Their Daily Mainstream Lives**

In general, parents' observation and estimation of the classroom performances of their children with disabilities was very low (See Theme 3, Table 1). When parents examined how their children fit into the mainstream learning environment, they sensitively delineated their children from the others in terms of academic achievements (All parents). In study, children with disabilities were seen as generally short of interest to know about the matters that they were supposed to do or to participate in any learning activities (16 parents). Also, many children seemed to have difficulty following the relevant scenarios in other respects, such as performing daily routines and sitting through class sessions together with their typical peers (5 parents).

In terms of social interaction, seven parents mentioned their children's difficulties to build relationship with peers whom these children had positive feelings about, and 5 parents described that their children's improper behaviors and occasional bursts of emotions seemed to keep their typical peers away rather than drawing them near. One parent, whose child was stayed in the mainstream school for the longest time than others, also reported that his classmates tended to isolate him as they ascended grades as they had to spend time coping with tougher study and tests. No wonder one parent said: "Among many things, one thing that I see is that he surely cannot catch up." (See Subthemes 5-7 in Theme 3, Table 1)

### **Exclusion of Children with Disabilities by Schools**

Schools were regarded as not willing to consider the educational needs of children with disabilities. Lack of enthusiasm in the part of the general schools and daycares were mentioned by 10 Parents.

**Declining entry using various methods.** Most parents mentioned that it was a prevailing practice for general public schools to disregard parents' attempts to have their children with disabilities enrolled. Among cases mentioned by all the parents, only one was admitted unconditionally by his neighborhood school whose principal vowed to run the school with a spirit of fairness and equality, besides another child who were taken in by an inclusive school. Most of the other students shared stories of being turned away, either by the excuses such as "our school has limited resources and now fully enrolled already" or by some "entrance screenings" that held standards too high for their children to meet. The entrance screenings were mentioned by four parents, and was said to be solely comprised by test items used to gauge the school readiness of typical children. One mentioned that the daycares he knew only agreed to take in "healthy" kids (See subthemes 1-3, in Theme 4, Table 1).

**Priority in take in children whose parents had personal connections with the school.** One useful way to get around the in-taking taboos of the schools for children with disabilities was through personal relation (5 parents). Some parents had already solved their children's problem in entering by doing it, or were planning to check around in the hope of building up such connections. "Now I wish that his dad could end up figuring out a connection to get to know, like, a principal or what. That'll change everything." Unfortunately, according to the parents' report, even if children finally found their way into the mainstream setting, quite a few experienced frustrating suggestions from the side of the school administrators or teachers that they should be transferred to special education schools. Besides, there were cases showing that while remaining in the mainstream setting, inflexible school rules prevented some personalized cares and



assistances that the students with special needs heavily needed.

**Inflexible school rules.** According to four parents whose children were in the LRC settings, schools did not have any intension to take into consideration of the situations of the disabled students and modify schools' rules, which resulted in compromised benefits for the children, and especially made impact on the students' affection for taking classes with typical children.

The institutional rejection of children with disabilities was stunningly popular, and the intake of children was not fairly conducted. Apparently, most of the schools and daycares did not regard enrolling students with disabilities a serious business, and also did not take the education of these children as their responsibilities.

#### **Exclusion of Children with Disabilities by Teachers**

Besides the general education institutions, nearly all parents mentioned or told stories about lack of proper care and instructions for children with disabilities from the teachers. The teachers' class management as well as pedagogical practices in the LRC situations were generally described by parents as unadjusted and ineffective.

**Ineffective teaching.** Parents were all pessimistic at how much the teachers could help their children making equivalent achievements as other students. Among them, nine parents listed teachers' persistence in applying the same set of teaching approaches, gauging the learning outcome of the students with the same standards, and setting the same goals for everyone. Modifications in instruction, if did happen, as in the cases described by four parents, who mainly dwelled on non-academic spheres. (See subthemes 1-3, Theme 5, Table 1)

**Harsh treatments of students.** Besides, the teachers tended to treat all students

harshly for disobeying, with or without disabilities, and were lack of motivation to change their disciplinary rules, according to eight parents. The extreme power imbalance between teachers and children was aggravated by the teachers' lack of knowledge about the children's disability-related difficulties.

**Not knowing the kids with disabilities and uninterested in teaching them.**

Many parents attributed the teachers' failure in teaching the children with disabilities to their lack of knowledge about the children's unique characteristics and lack of motivation to help these kids make progress.

**Superior position over parents.** Also, teachers were holding an authoritarian, patriarchal position in their relationship with parents, with an expectation that parents were responsible to work out the obstacles in their children's academic learning.

Therefore, students with disabilities and their parents were subject to great pressure.

Nearly all parents alluded to their nervousness over being "asked to meet" with the teachers. Almost none of them, except for two of them who described launching certain "explanations" to the teachers about the conditions of their children, mentioned requesting a meeting with the teachers. Gestures reportedly taken by the parents were mostly "confessing" or "honestly admitting" child-related situations to the teachers and the school staff.

Similar as what the parents remarked on school exclusion, teachers were also said to be in a position of not taking the teaching of the students with disabilities as a serious responsibility as well as failing to adapt their teaching to meet the special needs of these children. As K's mom said: "In *sui ban jiu du* (the LRC), once the student doesn't require the teacher to make efforts [to raise his test scores for the class and school evaluation

purposes], there's no pressure on the teacher. Then for him, there won't be any attention from the teacher...The special skills and experiences are really important...[without them] even if you put your kid in a mainstream daycare, and the teacher treat him with a tolerant heart...there might be no hazards caused on him, but there is also no progresses in him. ” The teachers' inability to make the kids “successful in academics” was a major regret that the parents saw in mainstream education.

### **Exclusion from Others around the Children with Disabilities**

It seemed a most frequent experience for children with disabilities to not only receive unfavorable treatments at their mainstreaming at school or daycare, but also facing unfriendly eyes and behaviors at other points of life. “There are too many [of these instances]. They happen everywhere.” Apparently, children who exhibited their impairments and related difficulties at their daily school lives were not welcome by peers and some parents of typical students (see subthemes 1-3, Theme 6, Table 1). Besides, even random persons around who happened to notice some uniqueness of their children tended to treat the children and the parents rudely (see subtheme 5, Theme 6, Table 1). In the parents' eyes, even one group of the professionals that were meant to closely serve the children, the pediatricians, tended to actively suggest to them that the child is valueless for the family and should be given up than treating him (see subtheme 4, Theme 6, Table 1). Four parents ran into this situation themselves, and one of them, who was the leader of a parent group for children with Down's syndrome, talked about this as a very prevalent occurrence.

According to J's mom, in multiple times during her son's (4 years old) medical experiences, pediatricians repeatedly told her to withdraw the treatments. One of them

also try to persuade her to “give him up” in some ways even when he was a newborn:

“When is was determined [that he had Down’s syndrome], the doctor’s attitude was, like we should just given up... “Oh, this type of kids, you don’t need to care much about.”...Then one day it turned out that he has congenital heart desease...this time it was not that doctor. He barely said anything to us, he just said: “Hm this kid”, something like “not worth that money to bring him up.” He said: “You are still so young. Give birth to another child! Won’t that be better?””

Across the whole society, intolerance of differences seemed to be intense. It was not hard to see that both those persons who were supposed to be close partners of the disabled children at school and their families, such as typical peers and their parents, and those who were more distal to them, such as passers-by, held deeply-rooted negative attitudes to the children with disabilities. Besides, the eugenic position assumed by such a great number of pediatricians were alarming. Despite of it, an optimistic note was that many parents seemed to have disconserted opinion from these pediatricians.

### **Parents’ Firm Preference for LRC at General Education Schools**

Almost all parents displayed a determination to support their children to learn in a typical environment like other kids. An exception was the parent of a child, who had spent long years of contented time exclusively in the special educational settings that the parent ran. Although she was open with the idea of her son continuing receiving education in her own institution, she still deemed it best for him to study in a government-operated inclusive schools. Instead of the enthusiasm for a mainstreaming learning environment like the LRC one, these parents displayed a uniform avoidance of sending their children to special education schools. Like many of them said: ““I don’t

think what they teach in special education schools fit the needs of children with autism... Why, because they are different, they have to be locked up at home? They have to be secluded in special institutions? They deserve the same colorful lives as others. ””

(See Theme 7, Table 1)

### **Perceived Advantages of Studying in General Schools**

**Adding a major normal experience to the disabled students’ lives.** Parents unanimously stressed that a typical schooling environment was an important setting to add to the child’s mainstream experience, even if the child did not learn as much as expected. As what Ja’s mom repeatedly stressed: “I definitely want him to receive the bigger (typical) atmosphere, no matter how many painful efforts it takes us to guarantee this for him. How many academic stuff he can learn from here [a special day class within a typical school using an adapted curriculum]?... It used to not seem not a right place for him. However, now I feel we are not willing to give up this school.”

**Inculcating about how to share a normal world with others.** Parents also emphasized on what learning in such an environment could naturally bring to their children (15 parents). What was important for the children, according to the parents, lay in their hope that it would help the children develop knowledge about what the normal world looked like, what was common human interactions like, and no less important, a feeling of being accepted from other people and joy from the acceptance. (See subthemes 2-4 in Theme 8, Table 1)

**The magic power of learning with typical peers.** All parents, except for R’s mom whose child have spent a long time in special education settings, whether their children were currently studying in a general education classroom or not yet, expressed their

optimism in what could be “naturally” introduced into their children’s minds and behaviors either by their mingling with or even merely sitting among their typical peers.

Whenever they

discussed how they regarded mainstreaming as an advantageous place to be, they started by mentioning the typical peers. “Typical daycare has its plus. What plus? It is the children that they have there.”

Not only a school life with typical peers seemed to reduce the extent of planned intervention for the children with disabilities, but more efficiency was regarded to be brought into their learning of either academic knowledge, everyday routines, or communicational skills, through the children’s interacting with peers. Overall, the existence of peers constituted the strongest reason for parents to put preference on the LRC. Even if those whose children were encountering great difficulty in being conscious of the explicit meaning and connotation of “being together”, the parents still regarded it beneficial if only they could minimally take the normal world in, for example, by “looking at what the others are doing”, or even just took away some vague feelings from the “atmosphere” of being surrounded by typical peers. “I only hope that he, by studying in the inclusive classroom, can get a feeling of the happiness of those (normal) kids around him, that also passes over to him so that he can start a very crude type of sharing their joy and happiness. Just a little bit of consciousness of it is enough.” (See subthemes 5-7, in Theme 8, Table 1)

**Bringing long-lasting friendship between disabled and typical children.** Among the points made by the parents in support of their preference for desegregated learning settings, “progresses” in their social knowledge and skills were not the only highlighted

themes. For example, most parents stressed how studying in a typical public school environment would enable the children to develop friendship. In fact, the “friendship” or “friendly contacts” that they described came in broadly diversified forms depending on their kids’ ability levels. However, they all saw it as a valuable experience that the children would enjoy. To a few of them, habit and ability to make friends does not only provide the children with instant benefits such as the opportunities to learn personal communication skills, or obtain a feeling of personal happiness, but served somehow as a precursor of friendship with other persons in the future.

The social benefits that were assumed to be gleaned from the LRC enrollment held unsurpassable significance in the parents’ minds. By stressing the vital importance of mingling with typical peers, the parents not only think highly of the immediate advantages of the LRC, but also how this relationship and its benign results on their children’s lives can be projected into the future, when they grow up and must live by themselves.

### **Hopes Seen by the Parents in LRC**

Parents mentioned various positive observations that they made in their children’s mainstream experiences, from daycares, schools, to daily lives which helped to preserve their hopes for their children’s educational benefits in the LRC learning. These observations were excitingly described by the parents despite their complaining about the LRC and its larger setting—public education in China as a whole, the gap between China’s general public education and real inclusion, and the exclusive gestures that children with disabilities and their families encountered from all parties in the school and the society. A number of the cases mentioned by parents could not compare with those

negative points that parents laid out about the LRC.

**Heartened by children's signs of adaptation and the improved reactions from teachers.** Apart from many adverse experiences that had been touched upon by the parents, four children who were learning in the LRC seemed to have shown signs of progress and more or less tuned in to the mainstream environment. Small as the progresses were, parents were seemingly heartened by their changes (See subtheme 1, Theme 9, Table 1).

**Seeing teachers and peers make efforts to make their children feel accepted.** At the same time, according to some parents, some teachers and typical students displayed caring and helpful stances to their children. Also, the teachers and peers became more adapted to their presence too, and modified their attitudes or goals to work with them (See subthemes 2-7, Theme 9, Table 1). Unfortunately, this was only reported by three parents, with one of the children enrolled in an inclusive school and one in a school whose administrators firmly held extremely open and radical state of mind in educational philosophies. The school of the third child was quite accepting from the very beginning, too. One of the parents said:

“At the very beginning the teachers required him to perform like the normal kids, such as do the same homework...they wanted to lift his scores to the same as the others...after having failed in a lot efforts, (they asked us to move him to special education school)...but he cried and cried in special education school, so I had to call the head teacher although it was so embarrassing. But after that call, attitudes of all of them toward my son started to change.”

**Various assistances from parents of other disabled children.** Among all the



supports and helps mentioned, what were universally recognized by the parents were those from other parents whose children were encountering similar problems. Except for their enthusiastic assistances in many practical aspects of the children's lives, "older parents" (*da jia zhang*) passed down to the "younger" parents treasurable mentalities and attitudes in face of all the challenges. These young parents either took shelter against stress or received valuable advice in many aspects related to choice of programs or ways to instruct their children. This feeling of being well-advised seemed to be part of the reason why many parents sounded confident in talking about their planning for their children's education. (see subthemes 10-12, Theme 9, Table 1)

**Sporadic good wills from typical parents.** In addition, there were also nine parents who mentioned that some members in their communities and some parents of their children's typical peers had displayed impartial, caring attitudes toward their children. The number of cases mentioned were again small in number. Especially, the support coming from typical parents were again restricted to schools which respected the philosophy of inclusion and diversity. For example, in the case where typical parents advocated for L to come back to the general school, the majority of the parents belonged to faculty and staff from a renowned university. "Many of them used to be visiting scholars in America, Europe and Japan," as said by the parent interviewed (See subthemes 8 &9, in Theme 9, Table 1).

**Family members united to pursue the common goals for the children.** Except for one parent who was divorced, almost all other parents (14 of them) explicitly described the concord supports from their family members, mostly from their spouse, as jointly assisting in the caring and decision-making for their kids. Some mentioned the

above conclusion implicitly.

**Understanding that “Inclusive education is just on its “initial stage” and starting to receive more attention from the government”.** Despite parents’ listing the shortcomings thought to be harassing the current public education system in China, seven parents from the same group presented their opinions that the education administered for students with special needs was just at its beginning stage of development, which conveyed a sense of understanding and good-will. “The government is doing better” said by one parents echoes the opinions of many others.

In summary, parents were hopeful and saw the possibility that their children could receive the optimal benefits by learning in the LRC. Mostly parents were encouraged by experiencing supports from others, frequent and prevalent as those from their own families and parent groups, or just incidental and occasional as from teachers, peers, and other parents. However, they could not help talking about them when expressing their enthusiasm in an LRC placement for their children. Apart from many criticisms about the government-administered educational policies and practices, many of them believed the government’s attempt to change the current situation was for better.

### **Perceived Suitability of Their Children for the Mainstreaming Schooling**

Along with supports seen in people around their children, parents also presented numerous other evidence to support their ideas, either based on the intrinsic nature of their children, or out of humanitarian argument.

**Having higher ability levels than those fitting for the special schools.** Parents unanimously expressed their claims that their children had stronger abilities than those in special schools. Usually this claim came as the first sentence when they were asked why

they disregard special schools as a better placement.

**Minimal abilities to make progresses, in academics and social skills.** (See subthemes 2-5, Theme 10, Table 1) The children with disabilities were described as possessing pro-academic qualifications such as having certain verbal expression ability (14 parents), as what is most exemplary of the parents' appraisals of their kids, "at least he speaks." Parents were also inclined to point out that their children were making progresses in their learning in mainstream settings. Some parents tended to also highlight how their children took initiative to learn things of their likings, or carried interest in making contact with similar-aged children. No matter how insubstantial the characters ("at least he speaks"), how insignificant the progresses ("no matter how small the progress is"), or how vague their motivated attempts could be ("I feel that slowly, he is willing to interact, although I cannot say for sure because interaction is not a simple stuff."), the parents firmly resorted to these as a solid evidence that their children fit mainstream school life better.

**Children were possible late-bloomers.** Even if some parents acknowledged that their children were temporarily not living up to the learning codes and expectations that general public schools had, they dismissed this fact as not being an indicator of possible school failure in the future, contrary to popular educational viewpoints (5 parents). By referring to their own personal properties and learning experience, the parents took the current unfavorable state of schooling of their children as possibly trivial and transient.

A dad who was a professor in a major institute of technology explained this view of his on his son's study in a general public school: "As to the scores both of us never check with him. Why don't we do it? Not quite because he is a special kid, but my own

childhood experience was exactly the same. My parents' job was to maintain the irrigation system across villages, so they often walked to far-away places along those pipes, not home for many days in a row. They just left me at their office building since it was close to the school at downtown...For the whole Grade 3 I was there alone, there was just myself. For the homework I literally did nothing, nothing, and I only learned those that interested myself, totally put away stuff I didn't like. Because of this experience, personally, I think, on certain things, when you are not at the right stage to do, it doesn't matter if you did a bad job. When time comes that you turn to like it, probably you will do a better job than anyone. So...for the kid we have right now...seeing he's interested, we give him some instructions, not interested, we just leave him alone."

**Possessing pleasant personality.** What is more, six parents reported their children as possessing certain properties that generically make them easy-going with others, usually by being meek or delightful in personality. For these parents, they preferred that their children enjoy their time in the LRC, where exclusion might be mitigated by certain degree of friendliness from the others that was guaranteed by this favorable character of their children.

**Having worthy lives as any other kids.** (See subthemes 8-11, Theme 10, Table 1)

Besides concrete abilities, as many as 12 parents presented their belief that their children's lives were as precious as others, and they should be treated equally, and receive help from others like any child was entitled to. Only five of them used the term "rights" to express this idea, but the same conviction of equality between typical and disabled children was echoing among them.

Overall, students with disabilities were generally viewed by their parents as being able to

fare well in the LRC among their typical companies. They tended to emphasize that their children were very likely to complete minimal goals of academic and social development goals set for the class. These qualities of their children seemed to add more confidence in them that the LRC would be the most suitable placement. Importantly, the awareness of the ultimate value of life for their children reinforced their affirmation on their children's ability to enjoy the LRC.

### **Perceived Disadvantages of Going to Special Education Schools**

Fifteen parents, except for R's mom who was able to provide her autistic son a warm and helpful special institution run by her own, firmly declared their denial of segregated special schools as their preferred setting. Based on all the unfavorable characteristics that the parents derived their negative ideas from, K's mom's remark summarized the parents' points that "(In special education schools,) benefits are definitely smaller than the negative stuff that he encountered". Most of the parents stated that "from the very beginning" they "never ever thought of sending" their children to special schools.

**Disabled Peers as Bad Role Models.** Peer influence seemed to be the biggest factors underlying their general disfavor for special education schools, instead of teaching qualities and school facilities and resources. In parents' eyes (15 of them), disabled peers were not able to become supportive partners for their children either when learning in the classroom or during other extracurricular activities. From them there were fewer desired behaviors than undesirable behaviors and habits to be learned. Worse, these behaviors would be picked up by their children in a rapid way. Therefore, receiving education in special schools would not only deprive their children of precious opportunities to make

critically important progresses learning social and interpersonal skills but deteriorate the current set of skills present in their children (See subthemes 3 & 4, in Theme 11, Table 1).

**Depriving of Future Chance to Transit to the Normal World.** Attending a special school was also viewed as a hindrance to the child with regard to learning about the everyday world that most of the other students were familiar with (8 parents). Besides, the children had fun and found enjoyment in their interaction with typical surroundings that would not be possible at a special school. As a result, the parents were afraid that their children's future would be impacted in that they would never know what the normal world is, let alone gaining skills to successfully function with typically developing children. One parent linked the role of mainstream schools to the child's future life: "(In the general daycare) he doesn't necessarily directly participate, but he should see them through his eyes. Even some normal kids are reticent, but he knows this world through seeing and understanding that's happening around him...He cannot just know by imagining... Like when he's at the door of a supermarket, he knows it's a market where you need to get what you want by paying for them, based on his past experience with other supermarket...Even if he cannot make meaningful contact with it, it's after all a normal environment, right?... Credits he gets from the school should serve his life. When we adults leave them some day you want to see him independent...In this daycare for just one and a half years he made so much progress in his social abilities...you don't give him that environment then he can't reach this level."

**Special schools as dumping grounds instead of educational institutions.** Special schools, for the great majority of parents, meant qualitatively different places from the

general school. Three parents even regarded enrolling their children in special education schools as “giving them up” and being irresponsible as parents. During the interview, special education schools were simply left out of the parents’ consideration as anything else that was irrelevant to their children’s education. As D’s dad said: “That one (the special school) ...how can anybody call that one a school?” Another parent compared it to a mental hospital where “you are going to be mad if you stay there long enough.”

Therefore, special schools, due to its perceived nature of segregation and a monotonous body of disabled students in the school, was regarded by parents as both depriving their children of opportunities to learn social skills, and of a future to “get back” to the normal world after they graduated as young adults. The idea of letting their children spend long years in a special school was horrifying for many of them.

### **Parents Coming to Terms with the Drawbacks of LRC**

**Feeling at ease with the disabled children’s academic failure.** Almost all parents declared themselves not mindful of their children’s lagging behind typical students in the LRC classrooms, except for two who hardly took their children as disabled. At the same time, many of them criticized that Chinese public education was a failure (see Theme 2, Table 1) and were conscious of the widespread opinions of Chinese parents in general that this education needed a reform. Along with this dismiss of the legitimacy of the current mainstream educational goals and practices, two parents who were respective leaders of parent groups for children with autism and those with Down’s syndrome stated that both of them were also feeling at odds with the deeply-rooted homogeneity in the value judgment in China. For all those parents, it seemed meaningless to put so much stress on the academic success under the heavily denounced Chinese general education system (See

subthemes 1-4, in Theme 12, Table 1).

**Thinking and doing differently from typical Chinese practitioners.** Five parents alluded or explicitly mentioned that they have already taken school-designated learning tasks apart and expected their children to get them one by one. Partly reflecting this strategy, many parents (7 of them) expressed that they would allow their kids to take their time in the process of learning. Also, for some of them (6 of them), it took certain time to wait for the interest and strengths of the children to surface. Like a parents said, “as long as he is making progress, each day—they could be super small ones, I’m happy enough.” As an evidence in practice, 10 parents claimed that they would not put stress on their children to, for example, speed up their learning. For them, all these impatience and anxiety that were closely tied to the practices of traditional Chinese teaching practices would merely backfire. Under the same thought, many parents (8 of them) presented their idea to let their children start elementary schooling at an age later than the average. Their opinion was that this done enabled their children to get better prepared, physically or cognitively, to be introduced into mainstream school life. For them, “one or two years older than their peers students are nothing.” (See subthemes 5-9, in Theme 12, Table 1)

**Running “night schools”.** Except for R’s mom who comfortably entrusted her son to the teachers in her own daycare and could easily convey her guidance to them to fulfill her educational expectations for him, Ji’s mom whose son was being accompanied 24 hours a day by an experienced babysitter and tutor, and L and Y’s moms, most of the parents (12 of them) instructed or would instruct their children at home after their day at school. The content of this extra teaching focused on various aspects—academics, life skills, behaviors, and interest in interacting with others. Besides, there was another



undertaking consistently practiced by many parents: doing their children's school-assigned homework for them in an eagerness for their children to remain at the current public schools.

**Feeling bullying generally acceptable.** All parents pointed out their great fear in terms of their children's lives in the mainstream as one—being bullied, but most of them expressed different degrees of ease on this issue, bearing more or less tolerance for bullying. First of all, some of them whose children had autism did not regard their children to be able to inflict hurt in feelings or self-esteem by incidences like this, since their children were regarded by them as not capable of understanding the social messages involved in it. Secondly, for more parents, the experience of being mistreated by people around was a useful skill in their early lives, to prepare them for similar frustrations that they might encounter in their adult lives. Being bullied then become a positive training in the eyes of the parents. There were five parents who described the specific bullying that they truly fear. Those included bullying that was too frequent or violent which would make their children reluctant to go to school, or those acutely focused on their children's disabilities. Generally, bullying and mistreatment were seen as an inherent part of the normal world. "Every child got bullied. You are not Obama." (See subthemes 11-14, in Theme 12, Table 1)

**Communication with the institutions and teachers based on understanding.** Quite a few of the parents (6 of them) showed understanding of the schools and teachers' difficult situation. For example, one of the major reasons the teachers had an inability to accommodate students with disabilities was that they were already assuming a heavy burden when teaching to typical kids in their classes and adding children with disabilities

who need more time and care from the teacher would mean that none of the children, both typically developing and children with disabilities, would not receive the attention and time needed to learn in a classroom. Therefore, parents did not demand much on the teachers' modification of their instructions to meet their children's unique needs. Instead, they just stressed their hope that teachers needed to be the foremost role model for typical classmates of the students with disabilities in treating them friendly and fairly. These particular points of emphasis might have been a result from the parents' awareness that it was easier, and probably less time- and energy- demanding for the teachers to display attitudes than have to spend time doing the real pedagogical adaptation.

**Communicating with the institutions and teachers respectfully.** In communication with teachers and schools, many parents took a humble position. Quite a couple parents let the school principals or teachers know about their children's diagnoses from the very beginning, during the in-take process. Although many of them were assured of the compulsory education policy and its proposed rights for the children with disabilities, they chose to disclose about their children with a tone of submission instead of assertion.

The parents also tried to express their messages to the teachers and staff in non-propelling ways. Besides the conventional exchanges of ideas between parent and teacher, they made attempts to try to optimize the results by either constantly presenting gifts to the teachers or trying to find out some liaison person who knew both sides. They regarded these ways as making their requests easier to be accepted by the other side. However, this was a rather painful strategy. They claimed that they "had to use uncustomary ways to reach" their goals of influencing the educational staff. Therefore, it

seemed to be something “unstated” on the part of the parents, due to certain mentality of “guilt” that it might unfairly occupy the teachers’ time and energy that could have been spared for other kids, as each one of them mentioned about the large class sizes in elementary schools and the corresponding heavy workload on the teachers.

**Picking non-traditional, more accommodating schools to do LRC.** Although special schools generally fell out of the parents’ preference, public elementary schools were not the only choice for most parents. In fact, they were shooting for a miscellaneous range of schools as well. For example, more than half of the parents in Chengdu intended to work their ways into a newly constructed, government-sponsored pilot inclusive school. Others said that they would consider non-public institutions such as non-governmental residential schools, schools run by religious practitioners, non-governmental schools for the children of immigration workers, international schools, and home schooling. Another option was to arrange for the child to immigrate to the United States.

What constituted their thoughts was the assumption that teachers at these alternative school settings were likely to be more willing to invest into the fostering of a tolerant and helpful atmosphere. Based on this mindset some parents came up with Plan B if their children were not able to enter the school of their first choice, that they would seek a “bad” (or underachieving) school for them instead of a “good” (or outstanding) one, which worked better to allow the children to learn in their own paces and manners, stressed them less, and did not push them as much in many other areas such as rule-obeying and motivated participation into group activities, just as they held looser requirements for their typical students. R’s mom, who was pretty confident that her

autism center could be the last resort for his son's school-aged education, showing their "pickiness" without hesitation: "Real inclusive school—yes. The LRC—no."

**If LRC fails their children, making whatever sacrifice to make up.** Two parents expressed their willingness to be their children's closet partner in the children's later lives if they turned out not ready for independent living after graduating from general schools. Both of them described their plans to "travel around (the country) and labor for work" with their children as migrant workers. Many other parents alluded to the same idea of taking care of their children in their lives whenever there was the need.

**Flexibility in mind.** On the topic of where to send their children, parents concerted with each other that it must be a "school", rather than staying at home. For many of them (7 parents) the uppermost choice was a mainstreaming environment, but they tended to possess a flexible mindset in regard to all possible negative outcomes that their desired learning settings might have on their children. They were willing to switch their children to some other settings, including special education schools, especially when they displayed downright unhappiness during staying at mainstream schools. They did not deny that finding a right place to learn for their children was a process of trial-and-error. In summary, "walking the way and watching the way" (*zou yi bu kan yi bu*) became the most used phrase by them when they talked about their expectations and the possibilities that they could be fulfilled.

**Red-lines.** However, quite a few parents stated that their choice would rest upon the manifest low spirit or reluctance to go to the school. Also, they uniformly displayed non-intolerance to the discriminations from school authorities and teachers, represented by a lack of any concern about the school lives of the child with special needs or even

antagonistic views against the child as potential threat to the good of the school or the class. Some parents also claimed that they would not want their kids to be a public laughing stock in the class, or being poked fun onto, or mentally or physically abused by several classmates together. The latter two situations, in conjunction, were disdained by many parents as “non-acceptance” or “bad larger environment” that parents regarded as both hampering effective study as well as causing harms to either physical or psychological being of their children. When any of these bottom lines was offended, parents were highly likely to move their children with disabilities out of the mainstream settings and into another school, with or without supports for their children.

In conclusion, although aware of all the drawbacks that the LRC had, parents had been fully prepared to fight their way and escort their children in the mainstreaming that the LRC was assumed to provide to them. To enable their children to be accepted by the general classroom as a suitable learner, parents were willing to spend much of their own time to assist. Their efforts not only focused on securing social acceptance for the kids, but also placed on academic assistances. Additionally, they conducted and planned for concrete actions, as well as, mentally reconstructed certain popularly held “facts” in order to solidify their conviction that the LRC would work for their children, despite all its flaws.

### **Expectations for Their Children**

Parents laid out many expectations for their children. In fact, parents did not differentiate between the expectations for their children to fulfill and the expectations that requesting efforts and assistances from others (including themselves). Neither did they differentiate between what their immediate goals and the future ones. This note of patience

was found in many parents' remarks, for example: "I'm happy as long as he is turning better, even to the least degree."

**Exhibiting and developing their unique strengths.** In learning, parents generally (12 of them) expected their children to be exposed to a broad range of learning opportunities. Regardless of how far their children would go in these realm of knowledge and skills, many parents thought highly of assuming all kinds of possibilities for their children in the first place. In turn, many of them also craved to see their children, especially when nurtured in a content-rich learning environment, could finally exhibited their strength and interest and thus learn efficiently through their advancement. One parent expressed his hope that his son's "strong skill" would be discovered: "In his education, we expect him to have a strong skill. Whatever skill he is found to be at school, we'll follow up and arrange more training on it." Two parents also mentioned the importance that the children's strength would orient them in their further educational planning for their children.

Parents also placed the development of communicative skills in the core of their concerns. Notably, there were not many parents mentioning their particular desire for their children to understand others, either through verbal expression or other forms of interactive communications (See subthemes 1 & 2, in Theme 13, Table 1).

**Behaving properly in public.** Proper behaviors in public was unanimously viewed as one of the most important goals for their children. On this point parents' thoughts fell into two categories. Regardless of the children's linguistic, social and behavioral levels, parents of younger ones mostly focused their requirements on emotional stability and simple verbal skills such as asking questions so that others could bring them helps

needed. In comparison, mainly those older parents tended to suggest that their hopes for their children to exhibit appropriate behaviors rested upon an underlying emphasis of being accepted by the others, including not being bullied, either at present or in the future. These tasks required higher attentional level, more advanced social judgment, and more complicated steps of cognitive and physical actions to accomplish. This parent's emphasis that a disabled person is responsible for not making others feel weird was echoed by quite a few others:

“I think his behaviors appear gross to those who don't know him... You are already disabled, so at least you don't appear loathsome.”

**Communicative abilities and appropriate social interactions.** All parents placed the development of communicative skills in the core of their concerns, although their required goals differ in degrees. Especially, among parents of children with autism, some parents merely wished their children to understand and use languages more (2 parents). A bigger group of other parents emphasized on their willingness to see their children being more motivated to approach others in a relationship (“initiation” or “*zhu dong xing*”) (6 parents). For all parents whose children had autism, advancement in the level of communication seemed to be a major indicator and usher of other progresses that would benefit their present and future.

Another big expectation that the parents had was that their children could get along with others. The parents who were much aware of their children's impairment in interpersonal relations rarely talked about their dreams of them getting along well with others as adults, but displayed a down-to-earth attitude to this topic which coveted the improvement in some basic affective and behavior elements essential to success in

interaction with other people. However, they also talked much about their wish for a future where at least they would know how to ask for help from the others, and may even bring them more benefits:

“For example, store keepers asks him: “what would you have, little guy?” He knows to answer, very simply, “noodle”. This means a lot to him in the future...whatever he needs, if he can express with language...clear and flowing, things can be easier for him at any given time. This is self-caring. I hope he can be independent. In the future, if he, for example, not living in his home (with us), many things he can make them work by himself...he can find a job, like a very simple one, like a gate guard. (With language skills) he can definitely do it. Like if this car cannot come in, he can just point to it and ask it to turn around...then he can provide himself with some money in this way...”. For some parents who were deeply involved in the close supervision of their children with severe autism, hence companies of them most of the time during the day, improvement on some crucial skills that might seem trivial to others was seen precious enough to enable these parents to enjoy some relief from the stress of unceasingly watching for their children’s improper behaviors and preparing to intervene. (See subthemes 3-6, Theme 13, Table 1)

**Ability to deeply and positively involve themselves with others.** The expectation for good relationship with others was supplemented by some parents’ wishes for their children's good long-term interpersonal outcomes that their children were able to construct to maintain warm relationship with others when they grew up. They sometimes mentioned it as “friendship”. Most of the children of these parents either had some disorders other than autism, or did not perceived by the parents to belong to core type of



autism. M2's parents clearly expressed it:

“If he can eventually build good relationship with others around them (*gao hao guan xi*), can hang out together with them without problem, we think this is the best scenario... If he can approach others and share with them, they come together as companions to each other...the parents will feel so relieved. if this doesn't happen, no matter how much money and other stuff you have prepared for him [before you die], you feel very hollow.”

**Being embraced by the society.** In sharp contrast, a few parents, especially those whose children were diagnosed with severe autism, clearly pointed out that they had little concern about their children's friendship with others when they became adults. On the contrary, as they were well aware of the permanent impact that the disability would have on their children, they stated their expectation for the *society* to warmly accept them (4 parents). One of them said: “The final goal is for the others to learn to somewhat accept him, and respectfully allow him to enjoy his own life, within the same society, under one sky...if they realize this, then no matter where he goes, there's inclusive education...like the X Center for Children with Autism, it's in an urban village, so the farmers in that village never make a fuss about those kids, they are used to them. They won't stare at one of them if he makes some strange noise and then come to ask you why. This way you feel light-hearted because you don't need to always explain. They all think: “This is normal! Autistic children do this. ” You feel relieved. This is what I hope our surroundings can be—people know children having autism is like children having a cold, they are just sick. In them there isn't some serious problem, so no one will stare at them. That's all. ...but talking about whether he may or may not have friends, may or may not, like us, establish

normal relationship with others as social companions to each other—I do not expect. Because this is exactly what their autism means, autism is a lack of this ability from birth.”

**“Becoming independent” (zi li).** Fulfilling one’s daily living needs was another much desired skill that parents were hoping for their children. Disparity appeared again between parents. This concept included their expected ability to address their basic living needs, as well their ability to independently make effective and acceptable communication with others. Those with children heavily impacted by autism (4 of them) emphasized basic communicative skills and self-care skills as the priorities to be worked on their children. However, other parents emphasized on more complex tasks that involved a larger set of fundamental skills and knowledge and higher level of executive management.

Despite of this difference, many parents dreamed bigger, on their children working for a job when they grew up, in conjunction with the above-mentioned expectation for basic self-caring. For parents who regarded themselves as low- or medium- income families, working for a paid job seemed to be the only way in which the child could survive in the future. However, for parents who were financially sufficient, working a job was still expected as a critical component of life that engaged the child into some persistent devotion to a beneficial and favorite activity, and served as an introduction of the child into a society of reciprocity in order to earn their feelings of belonging. As one of them said: “To have or not have a job won’t matter much to his material life...with the financial efforts made by we as parents...But what does a job mean? It means you are being integrated into the society, that is, you are needed by others, and you need them

too, in reciprocity.” (See subthemes 11-13, in Theme 13, Table 1)

**Higher-level living needs: a happy, enriched life experience.** Living a life with joyful mood mattered greatly for the parents (14 of them). For some of them it became a criterion deeply engrained in their minds and was used to evaluate and choose educational programs, in an attempt to prevent their children from feeling hurt and upset either at present or in the future. One thing that the parents viewed as leading to the production of genuine happiness was the skills required for the children to complete their favorite tasks. One of the parent even pointed out that she preferred inclusive schools only for the many activities thrown up at the school that allegedly would make her son happy. Importantly, a few children with autism (4 of them) did not receive expectations like this from their parents. They were the same parents of children with severe autism who did not put as much hope in a reciprocal, mutually beneficial relationship with others as those whose children were regarded as less socially impaired.

Another component of a happy life, particularly stated by parents of children who were not deemed to have core autism, was again revolving around the theme of friendship. “It would be the best if he can make good relationship with others around him, get quite close to them, and have fun together.” (See subthemes 16-18, in Theme 13, Table 1)

**Making progresses, even in academics.** Most of the parents (13 parents) were dreaming that their children would keep exceeding their current learning achievements in their school subject learning, despite their clear consciousness of a wide gap existent between them and their typical peers. They were conscious that it was far from being easy to be achieved, but like TX’s mom said, “this is of course what I least estimated, so if he all of a sudden get everything the teachers teach, I’ll definitely get a blast of

happiness. Because he can move upward is what I most wish.”

At least, they were looking forward to a positive progression of learning that showed even the least possibility to make the child “catch up with the class” which put both the child and his class on a better position in terms of points-based grades. A small fraction of parents had obviously higher expectations, all were fathers, based on the reflection of their own trajectories of learning as a student who, from some point in life, suddenly became fully motivated to study. They spoke about their anticipation to see their children follow their examples. They were waiting for the time when their children got the full drive to study (See subthemes 14 &15, in Theme 13, Table 1).

**Biggest dreams.** Among all of the coveted education and life outcomes that had been nominated, most of the parents agreed that they most desired the improvement in their children’s ability to communicate, although, again, parents of young children with severe autism expressed a narrower goal on merely spoken language while other parents mentioned a broader scale of communication-related areas. The next biggest one was that their children could get along well with people around them.

**Most soothing goal achievements.** Likewise, most of the parents thought that if their children improved in their ability to interact with others, it would make them greatly satisfied and feel all their past efforts and endurance of hardship paid off. For two parents who both believe that children with disabilities were the same as other children, what would make them feel best was seeing their children being placed by the outer world on an equal foot with the typical children, and viewed by other members of the society as someone to be accepted and treasured.

As in the case of the the biggest wishes, the parents presented a highly diversified

picture about the development of their children that would make them feel best.

However, like what parents mentioned as their biggest wish, to live independently in the future and to integrate into the mainstream society were always the two major themes.

As a summary of the parents' expectations, they placed diversified hopes on various aspects of the life of their children, ranging from the most-described hope for the development of ability to complete proper interactions, to the least concerned academic achievement. Furthermore, many of these expectations carried disparate contents based on their children's differential characteristics and ability levels. However, related to but beyond all the above mentioned intricacy, parents clearly expressed their willing that the children could live independently in the future, which included independent caring for themselves, as well as independent communication with others. Many parents expressed the relief that the independence of their children could bring to them, when they saw that the child was capable of taking care of himself and living as an independent member of the society. For them, independence meant that the child would no longer have a compulsory need to live on anyone else's pity and generosity. Some parents further specified that it was really meaningful to them in that it signified their children's return to the world of normal people. Regardless, for all of the parents, it was the most important milestone in their children's lives that they could imagine. Also, in the interviews, they expressed a commonly shared anxiety and unsettlement on the chances of achieving it: "...Sometimes, when he can't do as what I want him to, I'll be like: "Oh! What shall I do!" And I dare not go ahead thinking about his future, dare not think what will happen after we [parents] get old."

Another of their major hopes was that their children could integrate themselves into

the normal society, both in the present and in the future, the sooner the better. They also regarded the happiness of their children as highly important to them.

## Chapter 5

### Discussion

This chapter will cast some further thoughts into the answers gleaned to answer the four research question. Then implications of the current study and its limitation will be discussed.

#### Summary of the Findings

**Dreams of inclusive education dimmed by harsh reality.** The findings show that most of the parents of children with disabilities in the two urban cities of China have come across and have been struck by the image of “good inclusive education,” created by what they have heard from sources of information on disabilities, including other Chinese parents or experts from other countries where inclusive education is better supported and safeguarded. Comparing parents’ knowledge and expectation of true inclusive education with what they heard and witnessed happening in the local schools, one can understand their disappointment. Their discontent with the LRC practices extends to the companion groups of the special-needs students at the general public elementary schools, including the schools themselves.

**Unanimous preference for LRC and their underlying expectations for their children.** Parents’ practical attitudes towards their children’s school placement were marked by an overriding preference for the LRC, accompanied with a firm rejection of enrolling them in special education schools. It becomes a cross-disability and cross-age theme (See Figure 1). For the parents, the general education learning environment meant an ideal place to foster social learning including skills such as verbal communication, practical knowledge about the executions of daily tasks, and the routines of everyday

world, although the expectations of the level of complexity of these skills differed due to the children's versatile temperaments and cognitive and motor abilities. In comparison, special education schools generally fell out of favor, for their perceived failure in bringing about these desired outcomes, and also the detrimental effect the special education school experience has on their children. The special education schooling experience implied not only bad role modeling, but also a loss of childhood fun.

Weighing on parents' minds in their choice between the LRC and special education schools are the future independent living quality and social inclusion of their children. For this reason, parents focused on settings that they think would likely provide relevant learning opportunities that fulfill these goals. For the future, in interpersonal relationships, they hoped their children could adopt good behaviors and communication skills and be able to gain others' favor and acknowledgement. In terms of personal life, they expected their children to be self-sufficient by caring for themselves on a daily basis, directly communicating with typical persons for help, working at a job, enjoying life—in other words, to be able to get by on their own.

In comparison, parents showed little worry about their observation that their children did not make as much progress in academics as their typical classmates at school. Even if they were sometimes emotional about the academic lag, they did not seem to be deeply bothered. In the eyes of many of them, public general education was an utter failure, a system that set unhelpful goals for students and largely lacked ways to make learning easier except for pushing students with frequent tests and punishments. They thought it was unrealistic to see their children doing well under the circumstances that so many typical kids were struggling to adapt themselves to this education. Also, keeping their children's



cognitive impairment in mind, they were hardly daunted in the face of their own prediction that their children would not achieve at the same academic level as their peers. Therefore, the parents ignored the authority-designated learning goals in the general schools as much as possible, and at the same time, focusing their hope on a bit-by-bit progression in their children's achievements, with enough patience to wait for them to accelerate after the accumulation of the basics.

As the parents talked about their placement preference, they all expressed their belief that their children possessed certain "qualifications" to learn in a typical school. Put together, they represented an approximation of the conventionally conceptualized "school-readiness," such as cognitive ability, emotional and behavioral regulation, and social skills (Blair, 2002; Raver, 2003), although many of the qualities were just mentioned in a vague, peripheral way.

Besides, all parents stressed in different ways that their children's life are as valuable and respectable as other children, although those who used the wording "equal rights" were only limited to a few parents who were well informed about this language and were active members of parent groups.

Many of those whose children already experienced mainstream education also added that their children did want to go to school everyday. In fact, quite a number of parents mentioned that they feared bullying only because they are terrified of its lethal effect on their children's motivation to go to school.

Although parents were calm about a foreseeable, bleak future of academic achievements in their children, they persistently held onto the remote aspiration of what their children might eventually achieve. Many of them blueprinted similar learning

trajectories for their children: being exposed to any learning opportunity, academic and social alike; exhibiting unique strength and interest in learning; and then eventually focusing and blooming in things that they were motivated to learn. As for the imagined consequences of learning, most of them said they would be truly delighted to see average or close-to average performances. This burning aspiration is apparent in several parents, especially those who showed greater adherence to higher standards than others and directly equated “sending children to special schools” to “abandoning them.” For example, L’s mom would rather give up the championship in Special Olympics that he could very likely gain if he stayed at his past special school, to trade for the opportunity to enroll in the LRC at a general school, although she stated that the championship was what she would feel proudest about than anything else. Besides that, these dreams for a lasting spot in the LRC were also partly fueled by quite a few of parents’ wish that the early learning experience could be copied by their children so that they eventually excel after initial struggles.

In the perspective of Chinese parents, as the mainstreaming status prepares the students with chances to learn most of the much-craved skills and knowledge, as well as socializing opportunities—both of which were perceived as making key contribution to the long-term quality of life for the children—the segregated learning setting became a location that had nothing good to offer. Just as important, the disadvantages observed by the parents in both settings turned out to have unequal consequences on the parents’ attitudes, in that their perceptions about the potential disadvantages inherent in mainstreaming settings transformed to having less serious consequences. Also, they have put, or plan to put, in a lot of their own efforts to help fend off these disadvantages. In other words, what is lacking in separated settings were seen as irrevocably noxious to the children’s future pursuit of

life goals, while the seemingly adverse responses to the children from the mainstream settings were regarded as negligible, primarily educational or at least not leading to further and future disadvantages to the receiver of these educational services. Therefore, learning in the general education classrooms paints a distinctly favorable picture in parents' minds.

### **Key Issues about Chinese Parents' Conceptions of IE and LRC**

**Consistency with up-to-date Western conception of IE—a practicality- and rights-driven view.** Most of the parents showed considerable understanding and meditating of the name of a somewhat similar educational form to the LRC ("Learning in Regular Classrooms")—inclusive education (translated into Chinese as "*rong he jiao yu*", meaning "amalgamated education" or "*quan na jiao yu*", meaning "all-accepting education"). This alone is not something to be excited about, under the current context of urban China as a hub of borrowed educational terms and conceptions precipitated by fast development of technology, especially from the internet, and the mushrooming programs and groups that were dedicated to providing miscellaneous supports for persons with disabilities and their parents. However, what has been brought into attention was the fact that many parents, especially those who regularly attend parent trainings, have put together a description of "inclusive education" in their minds that reflects many of the essential precepts of this educational paradigm that have been discussed in the cumulative literature published in countries where, unlike China, there have been decades-long discussion and debates about educational equity and its much subsumed topic about the education received by students with disabilities.

***Inclusion involves all.*** First of all, parents seem to be fully aware that "inclusive education is not only about the children with disabilities," one of the themes stated in

UNESCO's (2003) *The Open File on Inclusive Education*. Instead of simply stating the inclusion-implied opportunity that their children could use the general educational classroom as their major site of studying, other aspects that they emphasized point to expectations for the other stake-holders to be involved, particularly teachers, peers, and families of the peers. This finding agrees with many researchers' suggestion that it is crucial to obtain support from staff and typical students in order to make inclusion successful (Mitchell, 2005).

***Inclusion means appreciating differences.*** Secondly, the “open and warm atmosphere” that parents envisioned tends to coincide with another key product of an ideal inclusive education in which “integration is to be valued; it is not an experiment to be tested” (Ferguson & Asch, 1989, p. 124). Under this situation, differences were respected and “made conscious, deliberate use of resources for learning” (Barth, 2005, p. 514). In other words, every participant of this educational format (particularly those who are not children with special needs) holds a welcoming stance towards differences, diversity, and variety as something of practical benefit that is worth celebrating.

***Inclusion demands individualization.*** Thirdly, parents brought in the ingredient of “specialization” into their “dream education” although they were well aware that an important characteristic of the education format in question was its ability to synchronize the teaching and learning for all the students in the same classroom. Except for securing a spot inside the mainstream classroom, they firmly demanded academic progress as an outcomes of inclusive education and expressed hope for teachers to know well and to work closely with their children to meet their individualized needs. Similar points of view exist in almost all inclusion-related decrees or scholarly writings explicating the

component of inclusive education where there are clear statements on the significance of the specialized support from teaching professionals (for example, Lipsky & Gartner, 2005).

It is by moving forward to the third point, the concrete approaches that they imagined the teaching staff would adopt and put into practice, that the parents in this study displayed a tendency to regard inclusive education also as a set of principles and a guide for behaviors. It shows that they viewed inclusive education not as a sheer lofty pipe dream but a realistic goal that can be implemented whenever there is the chance. This means that the parents do not conceptualize inclusion as a “pure value, that accepts no degrees, conditions or limits” which will, therefore, reach “a conceptual dead end” (Norwich, 2008, p. 19).

***Inclusion is a right.*** At the same time, those parents approached the concept of inclusive education from a perspective of human rights. The ideal inclusive education in their eyes also means denouncement of an exclusive focus on the weaknesses of children with disabilities, and an insistence that all children in the class are viewed equally as human beings, each with certain properties of his own.

The findings are consistent with early Western literature on the parents’ general lack of satisfaction at the meagerly-supported, under-resourced mainstreaming settings (Guralnick et al., 1995; Hanline & Halvorsen, 1989; Jenkinson, 1998; Kasari et al., 1999; Larson & Lakin, 1991; Leyser & Kirk, 2004; Lowenbraum et al., 1990; Miller et al., 1992; O’Shea et al., 1989; Turnbull & Winton, 1983). However, despite all of the negative perspectives on the LRC, parents did not lose heart on the prospect of real inclusion happening some day, contrary to the pessimistic claims about inclusion among

some Western researchers within the recent several years (Hodkinson, 2012; Starczewska, 2013; Warnock, 2010). The parents in China touched upon the conceptualization of inclusion without doubting its operability. Furthermore, many of them invested hope in the improvement in China's current special-needs educational system that will be brought by the country's "future development."

**Uniqueness in Chinese parents' framework of inclusion. *More emphasis on self-efforts than governmental responsibility.*** I found that none of the parents referred to the outcomes of inclusive education as being associated with decision-making on the level of the state or the schools. It is discordant with many published conceptualizations of inclusive education, which usually indicate intense involvement of and the investment from public agencies and school authorities (Andreasen, 2014; Lipsky & Gartner, 2005). An example of this is the *Salamanca Statement* proclaiming that:

"Every child...must be given the opportunity to achieve and maintain an acceptable level of learning...Those with special educational needs must have access to regular schools which should accommodate them...Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities...and achieving education for all..."  
(UNESCO, 1994)

Despite the exclusively rights-based perspective of the *Salamanca Statement*, similar content resounds in the literature on inclusive education. No matter what detail with which they were expounded, they uniformly connote the idea that educational authorities should become pioneers to campaign for the school access of children with disabilities, since real inclusive education is generally viewed as reformed schooling, especially regarding the development of an atmosphere of appreciation for diversity and the redesign of curriculum and teaching systems that can benefit all students (D' Alessio,

2007).

In this sense, Chinese parents seem to put forth fewer demands on the government and schools for the achievement of inclusive education, unlike what is described in the Western literature (for example, Wilde, 2001). Especially, since Chinese society has long witnessed a centralized educational climate that had been moderated by the government, it is quite unexpected that the role of the central government and schools were not heeded by parents. Instead, their answers concentrated on some other externalized foci that would also be harmful to ignore. For example, the parents tended to stress what the teachers and the peers can do to guarantee successful inclusion of children with disabilities. Many of them highlighted teachers guiding typical students by moralizing tolerance and assistance to their peers with disabilities as critical to creating an accepting atmosphere.

Consistent with what has been described above, a child of one of the parents experienced fluctuations in his general education class's acceptance of him, and together with his parent brought forth their opinion of inclusive education as not only that which is happening inside the classroom, but also outside, where parents who were seeking empathy and support for their children should launch high-quality communication with the parents of typical children in order to establish rapport, and in turn, to prompt their willingness to "educate" their typical children on their attitudes and behaviors towards their disabled classmates.

What is worth immediate noting is these parents' internalization of their responsibility to construct a favorable inclusive environment for their children. This particular role that parents of children thought they should assume is an unusual one,

since parents of children with disabilities have been largely regarded by other researchers as recipients of benevolent actions in an inclusive environment instead of as people who should work hard to obtain goodwill from others. While seemingly odd at first, their understanding is actually in agreement with socio-cultural characteristics particular to the Chinese society that have been repeatedly noted by scholars. In China, the responsibility of caring for children with disabilities rests mostly with the family, not outer society (Fisher & Li, 2008; Stratford & Ng, 2000, cited in Mcloughlin et al., 2005). Likely, parents customarily transferred their traditional primary role of their children's education to the contemporary schooling context.

***Awe for authority.*** The absence of parents' prescription for the role of the state and school authorities was very explicit during several interviews or, to be accurate, before interview sessions formally started. After the parents read the *Parent Consent Form*, I routinely checked with them to make sure they had no unaddressed concerns about the upcoming interviews. Then some parents would suddenly proclaim: "[I wish you understand] my support for your project doesn't mean that I'm gonna speak bad about my country [government]. I have no complaint about the country. I am satisfied with what it does [for us]. [And if it did not do things right, it's understandable because] it has its own hardships to overcome." This reinforced what Chinese disability scholar Deng Meng (2001) identified as being deeply ingrained in Chinese people's habitus, making them refrain from deliberate commentary on authorities. According to Deng, this influential force comprises "Confucianism" that taught people to "respect authority, ...accept their status within society." Furthermore, "coincidentally, the centralization of imperial power" that has commanded the classical dynasties "for centuries" welded the modern state



together with a sense of “collectivism and loyalty to the Communist party” (and its government) due to the socialist ideology that governs contemporary China (p.10). With this mindset, it is plausible that parents tended to avoid mentioning the responsibility of policy-makers in their opinion of inclusive education. Also, besides the power that the central authority holds over parents, the lack of equal communication between them may make governmental policy-making too far-fetched a variable for parents to understand and to partake in for the interest of inclusive education.

***Collectivist relationships.*** The conceptualization of relationships in “collectivist” societies such as China may also speak to why parents expressed the importance of making active contact and negotiations with parents of their children’s typical classmates; they proposed this “inclusive” relationship as a critical component of the wholesome experience of inclusive education. Studies show that in collectivist societies, people invested more in proximal relationships that are circumscribed within the institution of a community than abstract contractual relations. Therefore, they “mitigate against seeking redress for problems in the public sphere” and do not think contractual relation between individuals or with public institutions to be constructive at all (Meyer, 2010, p. 14). To add to this, Sonnader and Claesson (1997) also suggested that it was important for professionals in China to make sure that parents of children with intellectual disabilities shared common values and attitudes with people around them because it would have an impact on the parents’ attitudes on and reactions to the settings where their children received services. Concordance with others, mainly reflected in united minds and attitudes, constitutes the core of harmonious relationship. If governments and schools are not the ones to construct it, then the parents themselves will secure it.

Therefore, in the case of this study, under the simultaneous impact of these discussed factors, Chinese parents tend to emphasize the relationship among their children, typical children and their parents, and themselves, more so than any other relationship involved in inclusive education, as these individuals are probably thought to belong to the same group compared to teachers and schools, who are higher in the educational hierarchy. Compared with the unpredictability that they saw in the line of actions taken by the government, obviously the inclusive scenario that parents see as most favorable is the one where all the previously mentioned parties can maintain a constant exchange of thoughts and interactions, and in turn form a favorable school habitat that provides protection and nurturing to their children.

In summary, the finding that parents were generally reserved about the accountability of the central and local governments and central and local educational authorities in the implementation of inclusive education provides further evidence to other researchers' remarks about the rights that are relevant to parents in a society like China. Firstly, the absence of discussion on government and school management may derive from parents' lack of opportunity to converse about them along with the needs of their children, as parents are not bestowed such a legal right, as being observed by quite a few China researchers (McCabe, 2007; Pang, 2009; Wilde, 2001). Secondly, there is an overwhelming respect for authority, for those in the roles of management in China (Deng, 2001; Liu, 1992; Swap, 1993). Also, the parents' tendency to expect themselves to be the ones to negotiate a welcoming gesture from others around their children firmly illustrates the vital roles that Chinese families traditionally play to attend to the various demands of their disabled children (Fisher & Li, 2008; McCabe, 2007; Stein, 2010; Stratford & Ng,

2000, cited in McLoughlin et al., 2005; Yang & Pearson, 2002).

**An exclusion-dominated social and educational environment in China.** From the point of view of the 16 parent participants, their children with developmental disabilities are undergoing severe exclusion in their educational experience in China. They widely agreed that school was the foremost arena to exercise effective education, in order to avoid serious individual and social divisions in society and to guarantee the equal rights for children with disabilities (Armstrong & Barton, 2007). Although historically, public schools across countries placed restrictions on the “qualifications” with which children are selected, and unfortunately, those with disabilities have been refused enrollment in various ways, from an earlier time when legislation about inclusive education came into effect in most Western countries, formal exclusion has been progressively removed. The critical concern has shifted towards the safeguarding of authentic opportunities in mainstream schools to maximize the educational interests of students having special needs. (Lipsky & Gartner, 2005). However, in contrast to the generally smooth school entry in the Western countries, Chinese parents alluded to a stunning issue existing in the educational equality of their children with disabilities.

***Exclusion by segregation or marginalization.*** Children’s situation in China bluntly differed with their counterparts in the aforementioned countries, in that the outward denial of school entry still remains a standard practice of public schools. The attitudes of the school may partly come from years the central educational authority’s investment of major resources into “constructing special education schools.” For example, it is described as a much-hailed ambition that in the future, each Chinese town would have at least one special education school. This was stated under the rationale to provide high-

quality training and assistance to the children with disabilities so that they would grow up to be independent human beings in the future.

This partly explains why under this dual-system in China, general schools could claim that children with disabilities must attend special schools; they also describe themselves as “limited in resources” (compared with those in the special schools). Along this line, when teachers were aware that a child had disability, they would make very little attempt to teach the child with a mindset that the child did not belong to the class, or would try to persuade the parents to transfer the child to a special school. This is a case that vividly exemplifies Ravaud and Stiker’s (2001) systematic review of the states of exclusion and inclusion. Here, as the public schools and their teachers’ “ideality” has been “infiltrated by government writings” (Hodkinson, 2012, p. 684) that they received from official state policy promulgations, they naturally treat the students with disabilities with “exclusion through segregation,” with a clear-cut intent of separating these students from the majority and having their educational needs taken care of by other institutions such as special education schools.

Even if students are taken in and granted a status of the LRC (i.e. enrolled as students who are “Learning in Regular Classrooms”), “internal segregation” may very likely happen to them, as a result of the teacher no longer giving them necessary attention, since they are not held accountable for the grades of these students. Therefore, at the beginning, most parents would choose to let them “pass” as students without any special needs. However, this might incur another form of exclusion, when schools and teachers expose students to exactly the same tests and teaching methods and content that they apply to typical students. Translated into Ravaud and Stiker’s (2001) terms, it

becomes “exclusion through marginalization” that is “moving to the side as a consequence of refusal to accept or of an impossibility of accepting currently recognized rules of operation.” Under this exclusive practice, the students are perceived as the ones not playing the game of the norms. As a major norm of educational outcomes in Chinese public elementary schools is students who are able to continually build on their “high quality” by elevating their own test scores (Kuan, 2015), students with disabilities can easily fall into the group of students who receive teachers’ constant punitive “correction,” generally utilized to help the average students learn. Students with developmental disabilities would only be further dismayed and deprived of the drive to learn with teachers’ directive manner in instructional activities (Mahoney & Wheeden, 1999). As a result, after struggling long enough in this mechanism, these students will be marginalized as students with “low quality,” a terminology in Chinese educational system denoting personal failures of the student.

***Exclusion by discrimination and abandonment.*** In the lives of the children and their families, exclusion is not confined to education settings. Added to all the above mentioned exclusions, there is the overt “exclusion through discrimination” from the people around the students, who can be the children’s teachers, typical children, adults who are acquaintances or strangers. In addition, Chinese doctors’ suggestions to parents to give up their children due to their impairments are suggestions of “exclusion through abandonment.” Many parents embraced the sense of duty to stand by their family members in their continual care of their children, but the awareness that others in society did not see their children as worthy human beings instilled in them great sadness and distress.

Beyond the infrequent mentions of acts of kindness and acceptance, parents were overwhelmed by the intense rejection and alienation both within and outside of schools. What is especially notable is the systematic exclusive practices by schools that has been found throughout this study. This verifies the proposition made by Wilde (2001), in his UNESCO China-commissioned comparative study on disability laws of the United States and China, of the necessity to set up due procedures to protect parental rights when parents are dissatisfied with the educational placement and quality for their children with special needs. It is subject to doubt whether this will happen in the very near future, since it is a wide consensus that, in China, laws are subordinate to social custom (Potts, 1999), and in this country there have already been such a pervasive assumption of the inferiority of children with disabilities by both educational institutions and ordinary individuals.

**Expectation-based central preference for LRC placement.** Among all the parents interviewed, few seemed to heed the commonly agreed dilemma that disability researchers thought to be embedded in inclusive education. Although parents were well aware of the negative outcomes from both settings, they cast their vote for a placement in the mainstream school instead of the other.

Therefore, before the well-known dilemma, which is generally related to stigma and prejudice against the individuals with different levels of abilities, parents in China took a stance of determination endowed with high level of preparedness. Unlike findings in the Netherlands, another two-track country, where teachers and administrators affiliated with general institutions were not mindful enough of methods that could be utilized to resolve the dilemma, parents in China of either school-aged or preschool-aged children with disabilities, although less involved in the school teaching than the staff, actively thought

about the ways to diminish the impact of the dilemma. Clearly, they sought to address their children's future living needs by sticking to the idea of the LRC, as well as by actively define their children's characteristics as suitable for it, which may, in practice, shield them from being harmed by the stigma inherent in this setting.

At the same time, parents were not at all unaware of all the predicaments that were present around their children during their time in the mainstream classrooms. They mentioned a number of the predicaments during the interview, from the schools' constant rejection of their children, to the teasing perpetrated by typical peers and rude treatment from general education teachers. However, they displayed their enthusiasm for mainstreaming, which is attached to their primary life goal for their children—to become self-reliant (“stand alone” or *zi li*), to live independently, and to communicate independently. In fact, besides their emphasis on this expectation among all their stated expectations, for each of the other expectations, parents made further connections to self-reliance, whether it be having a job, being able to complete daily self-care, learning to communicate effectively, or engaging in appropriate behaviors.

In particular, all of them who had the seemingly unrealistic dream for their children's academic progress remarked that they had this ambition because they foresaw some practical link to some future guarantee of their children's self-reliance; sometimes this was expressed with self-consciousness, that they may be perceived as too eager for things that could not be achieved. For example, they talked about a wish for their children with autism to nourish friendships by studying together with typical children and then gradually developing life-long relationships. For these parents, this type of relationship is a signal of a high quality adult life for their children in which their children could still

have companionship and supervision after the parents pass away.

The Chinese parents' fervent hope for an improved quality of life for their children in the future may be the strongest reason for them to view the so-called dilemma lightly, although this dilemma is assumed to be inherent in the double jeopardy that a child with disability could encounter whether in mainstream or segregated settings in any geographical areas. Unlike what has been expounded as a conundrum where advantages and disadvantages are hard to be compared, it occurred to the parents that there were more benefits from being placed in the LRC than in a segregated setting. In effect, parents regarded all the positive impact that would be brought about by mainstreaming as not being able to be produced by the other setting, mainly because in the special schools there was a missing modeling effect from typical peers and a scarcity of opportunities to incorporate the children with disabilities into a setting that resembles a common school.

In other words, according to the parents, they did not believe that the latter type of schooling could foster social ability in the children to a sufficient level to enable them to communicate naturally with ordinary people around or familiarize the children with the "normal world" that they would finally (and hopefully) live in by themselves. These weaknesses undermine the most important premise that the parents have been holding for an ideal education for their children. In this way, special education is substantially devalued in their appraisal. In segregated special education, being free from bullying was the only advantage that was alluded to by the parents. However, when all the benefits from mainstreaming were considered, the bullying issue becomes a non-influential factor on the value of the LRC.

The parents certainly thought hard on ways to help their children best avoid



humiliation or embarrassment in their mainstream study. Mentally, they bestowed their children an identity that was supposedly less prone to eliciting negative opinions from others, namely, parents tended to assume that their children were not “so different” from the other children, at least not “different enough” to provoke worrisome stigmatizing actions. One thread of the related observations was that their children were motivated to live and learn with typical peers, and were more or less ready for it. The degree and level of either the motivation or the school readiness might be in question, but the parents claimed that they existed in their children, like in any of their typical peers. Another thought relating to the parents’ relief was the assumed congruence in their coveted schooling goals to the ones designated to the typical students. To the parents, what their children were proposed to learn were exactly subsets of the general curriculum. Although there might be barriers for them to overcome in order to achieve these goals, their children’s learning targets were regarded as being tightly related to those of the other children in the same classroom.

In addition, there was mentioning of welcoming personalities by parents of some children in support of their preference to have the children mainstreamed, together with gestures of acceptance that they observed in others around them. These traces of friendliness detected in the mainstream environment gives parents hope that their children might not be disparately treated as inferior individuals, thus further adding to their confidence in the feasibility of including their children in the general setting.

Even in direct face of discrimination and prejudice, parents did not view their children’s encounter with unfair treatment as an absolute downside of being placed in the mainstream. While some of them described this circumstance as a chance for their

children to build their character as “anyone else could experience,” a few others also assessed their children as naturally insensitive to any hostility from others. Their perception of the otherwise adverse experience to a certain degree redefined the occasions of being bullied in a positive light, as a constructive learning opportunity, or at least, as harmless occurrences instead of an unfavorable outcome.

Besides, parents also tended to largely attribute teachers’ inability to address their children’s learning needs, harsh attitudes, and the irritability in their teaching and disciplining manners to the test-driven, elitist criteria in student evaluation and to the over-populated, under-staffed classrooms. Even peer exclusion was sometimes believed to derive from impersonal and external reasons such as the excessive time that had to be spent on subject studying. With this mindset, in the eyes of the parents, most of the neglect, reprimands, and threats from others around the children with disabilities appeared to be an organic effect of a disoriented, inefficient and stressful national educational system, instead of something targeting the disability specifically.

Given their children’s typical peers at mainstream schools and their parents’ near universal disagreement with the curriculum and criteria governed by Chinese educational authorities, parents recast their children with disabilities as belonging to a larger, “more normal” group that deviated from the elitist “norm” and were discriminated against (Feng, 2007; Yang, 2003), rather than belonging to a smaller group of children with physical and cognitive deficits and were derogated simply due to those limitations. In this way, the children of these parents, instead of bearing a label of “disabled,” were cognitively integrated into “the discriminated majority” of Chinese students in general. After all, the parents belonged to a group that did not quite buy into the popular standards

for schooling success in current China. Under this mindset, and based on many of their own observations of and personal experience with the so-called “education as a failure” in China, they have come to believe that except for a small number of the highest performing students, most of Chinese students, including children with disabilities who are enrolled in the LRC, together with their families, have been tasting the bitterness of poor treatment.

Besides, to further guarantee their children’s eligibility for the LRC placement (“Learning in regular classrooms”), the parents opted for taking certain measures toward keeping their children in the LRC and to optimize the learning benefits that their children could reap from the LRC. These strategies are actively planned and put into practice by the parents, such as looking for more tolerant LRC schools, being flexible about the school-entry ages of their children, finding ways to communicate effectively with educational authorities, getting ready to make sacrifices in their own personal lives, and being flexible with their children’s placement.

As described in the previous chapters, many scholars view the “educational dilemma” as a problematic situation in which people with disabilities encounter unfavorable results both when they are in an inclusive setting or in a segregated setting (Minow, 1998; Norwich, 2008). In this conundrum, it is suggested that only resolution could be found, not solutions. However, what remain unclear are the thoughts and considerations that enable a particular stakeholder of special education in a specific country to form a certain resolution. The present research finding highlights the answer—parents in China resolve this conundrum by coming to terms with the adverse overall schooling environment, realizing their own ultimate expectations for their children and

act accordingly, with a determination to fulfill these expectations. With these expectations, it is not so much comparing the “bad” amongst the two options as it is picking the option that can most likely fulfill expected educational purposes and then using all their means and resources to tackle the negative consequences.

Therefore, these findings are consistent with the theories of major educational choices, especially about the roles of expectations and values and the subjective evaluation of the possibility of fulfilling the expectations embedded in the choice (Eccles & Wigfield, 2002; McClelland, 1987). Particularly, it can be seen that in the Chinese context of disability, parents’ expectations, especially expectations tied to the long term life outcomes of their children, are so high that they transform some of the parents’ understanding of their children’s current difficulties in the exclusive culture across general schools in China, and also provoke an assortment of parental action plans. To add to it, the findings also suggested that besides the parents’ realistic expectations and their subjective judgment of their children’s ability to meet them, other elements also come into play in choice-making, such as the ideological element (the belief of the value for each life) and other novel beliefs (beliefs that their children could excel as they had done in their own childhood).

Furthermore, the finding supports the call from researchers who proposed to include vital individual goals in the concept of disability instead of basing the conception only on general norms about disability (Nordenfelt, 2003; Reindal, 2008, 2009). In the case of this study, if parents’ expectation of their children to learn social knowledge and skills and obtain experience in a normalized social environment (such as a general classroom) cannot be met, few will regard their own and their children’s lives to be

meaningful and full of hope. In other words, it is hard to say that they are leading content lives that are free from negative labeling and tribulations raised by the disability, at present or in the foreseeable future, regardless of the standard measurements of the degrees of their children's losses of mental and physical functioning.

***Alternative interpretation for the overriding preference for LRC.*** In addition to the aforementioned reasons for parents' unanimous preference for the LRC, one other factor could also contribute to their stated choice—the scarcity of disability-related services in China that could, for example, brief the parents about all potential educational opportunities available to their children. The parents in China may not be very well informed about the role of the teachers and the curriculum especially in the special schools, due to the severe lack of information and resource outreach to people with disabilities and their families in China (Kohrman, 2003; McCabe, 2007). This might also contribute to parents' uniform disfavor of special education schools.

***Charting their children on the map of human differences. Beyond normal and abnormal.*** Therefore, parent participants in this study has drawn a new “map” to position their children relative to the others in society. It looks different from the much mentioned position of children with disabilities in literature that only captures parents' obsession with their children's “defects,” literature that had defined parents as mere followers of professionals or even persecutors of children with disabilities due to their own identity as typical individuals (Reeve, 2004).

Instead, as been revealed by the Chinese parent interviewees about their placement choice, not only did the parents refuse to convey their children as belonging to an inferior group of people with little worth, but many of them transformed the images of their

children from a smaller mass of students with disabilities into a much bigger, more widely recognized and sympathetic body of students in China (ranging from pre-school to college students), those who are not able to make their way into the small, selective club of elite students. In addition, all of the parents' children were regarded as belonging to the group of ordinary Chinese children who deserve a respectful and happy life. Besides, these parents portray their children as possessing all necessary qualities equal to or above the minimal level required to generate meaningful learning results in the mainstream education environment.

Along this path of thinking, Chinese parents manage to navigate their children's profile on the map of human differences as belonging to at least some place within the "discriminated majority" among hundreds of millions of Chinese students, and sometimes even the whole aggregation of children in China, each of whom having his or her own "problems," big or small. This coordinate system maps the children beyond a categorization of just "normal" or "abnormal," a categorization generated purely by gauging functional or social restrictions.

Thus, Chinese parents' view of the children confirms the many observations in the field of disability study that the boundary between normal and abnormal is blurry (Williams, 2001), that the categorization related to people with disabilities is arbitrary instead of predetermined (Bérubé, 1998; Smith, 1999), and that the lives of people with disabilities are one in betwixt and between (Titchkosky, 2003), mainly from the perspectives of disability scholars in the Western countries. This agreement between scholars and Chinese parents further implies that despite the strong medical model views of society, educational authorities, and medical and therapeutic service agents in China,

parents tended to not to see their children as qualitatively different from others. In fact, parents unanimously regarded the humiliation of their children overtly based on their disabilities as intolerable, and many even thought about transferring them to special schools from the LRC if it happened. The legends that they used to mark their children's position in the map largely overlap with that of typical children—all diverse but none to be stigmatized.

However, there is no guarantee that this map will still stay as it appears from the mindset of parents that are working on the schooling of their children at a young age. Very likely, the map will change when their children grow older, with evidence from parents defining the future independence of their children as being characterized by “proudly not resorting to any of the ‘others.’” Moreover, some parents who are up-to-date on Western thoughts on disability rights tended to view their children as conceptually belonging to an independent category of people and called the other children “NT”s (“neurologically typical”). In China, a country where English is rarely used in daily communication, using the name “NT” to refer to typical children implies an unusually detached position held by these parents. It might be the result of a popular observation that the imagined future for children with developmental disabilities could be more restrained and their choice limited (Grinker, 2007), or additionally, from an awareness of the “disability culture.” Therefore, parents’ views of their children should be studied in conjunction with their age.

***Parents’ efforts—a precondition to maintain the position of their children on the map.*** Driven by the most treasured life goals that Chinese parents hold for their children, these children tend to be positioned as close to the typical children as possible. As shown

by the current study, the legends of these children with disabilities on their parents' mental map of difference can be compared with those on a real map made up of hidden image stereograms. Just as the viewer of the stereograms must figure out the major images embedded in them by laboring their optical muscles in the correct fashion, to make the outlined image of the children stand out among many distractions, Chinese parents make unceasing efforts to provide all kinds of support to them to secure them a spot in the mainstream. This has been explicitly shown during the interviews, when most of them largely tended to follow up the description of their preference of mainstreaming immediately with what they planned to do in order to safeguard this placement.

In Kuan's (2012) remarks on the general attitudes and actions that Chinese parents took on behalf of their children's education, she highlighted the Chinese parents' unselfishness in striving to set up all the necessary conditions for their kids (she borrows a Mandarin word, "creating *tiaojian*"). Consistent with her finding, parents of children with disabilities exhibited similar enthusiasm in creating conditions for their children to be accepted in general education schools. Obviously, they consider their efforts to be indispensable for the fulfillment of their expectations.

***The power of stigma: mobilizing the parents' drawing hands.*** What emerge as the core factor underlying parents' mainstreaming-related drive and actions are the stigma and the consequent labeling and social abandonment.

To make sure that their children could fare well in the non-overtly discriminatory LRC ("Learning in Regular Classrooms") environment, parents diligently and proactively fight the stigma of being "disabled" or "underperforming" within general schools in order to protect their children from the harm of stigma and exclusion, from both their short-



term and long-term effects. It comes in line with a large volume of literature expounding on the detrimental effects of derogatory labeling in the welfare of people with disabilities (e.g., Barnes, 1992; Corker, 1998; Foreman, 1996; Gove, 1980; Persaud, 2000; Perusin, 1994).

The current finding stresses parents' negotiation for an identity of a "stigmatized majority" for their children in the general schooling environment in replacement of the labels as disabled. To do so, they noted similarities of their children to the other students in the same classroom. It likely reinforces the assurance that children with disabilities are merely part of all the children at general schools. For them, this new identity, or "labeling" that they create for their children may ameliorate the acute negativity that usually comes with the blatant humiliation and stigmatization imposed upon people with disabilities in China.

The observation of the parents, aligned with many studies done on disability in China, confirms that the social and governmental attitudes to people with disabilities are strictly medical (Stein, 2010; Kohrman, 2003; Meyer, 2010; McLaughlin et al., 2005; Wilde, 2001). This is a common perspective that regards the weak elements in a person as inherent and fixed and can only be rectified by interventions. It implies that instead of being a qualified member of the mainstream groups, this broken, "atomized" (Kohrman, 2003) person who is suffering from a mechanical failure within himself or herself, should undergo some sort of particular "repairing" before obtaining complete membership and "reentering" into the dominant group in which he or she "should have" belonged.

A daunting situation that this may create for the parents of children with disabilities in China is the excessive stigma that "being disabled" brings to these children, especially

in a collectivist Chinese society, where social structure is believed to be more segregated due to its pursuit for homogeneity and the resulting susceptibility to cliquish exclusion of individuals with difference (Meyer, 2010). Something adding to the pro-segregation atmosphere is the over-emphasis on competitions. It has been found that school areas that uses tests as the major criteria to gauge educational achievement possess a greater tendency to welcome segregated pedagogical arrangements (Timmons, 2007). Also, as Crowson and Brandes (2014) pointed out, the understanding of society as a competitive jungle as in Darwinism, exactly what the Chinese society is currently like, brews prejudice on certain groups. There is also suggestion that it might be even more the case in terms of schooling, as the institutional pressure is usually hard to battle against, further reinforced by the traditional reverence that Chinese people hold towards educational authorities.

However, under this circumstance, instead of agreeing to send their children to the government-run and high-profile public special education schools, Chinese parents persistently prefer enrollment in the mainstream elementary schools. Apparently, the above-mentioned general public's attitude does not affect nor completely alter the parents' belief of who their children can be, unlike what has been pointed out by some researchers (Reeve, 2004), but just as what Ferguson (2001) found. Parents' firm preference for learning in a typical environment clearly presents a mindset that contradicts the most steeped exclusionary opinion that Chinese society and the schools have been holding with regards to children with disabilities. Instead of conforming to the publicly prescribed fate for their children to "get well" outside the general schools before reintroduction into the majority's world, they seek immediately a group identity as

“ordinary students.” What stands out is a desire to see their children belong to a body of students who are neither to be avoided for their scary labels as “broken people in disease” (the literal Mandarin translation of the term “people with disabilities,” *can ji ren*) nor victims of prejudicial assumptions as people who live life through charity and make no contribution to society, qualities often criticized by social elites of China (Xun, 2010).

The currently available literature includes criticisms of parents as holding a medical perspective on their children, a perspective that results in adverse developmental and educational outcomes. These claims should be dismissed as meaningless. First of all, Chinese parents’ attitudes towards the placement, as being described in the preceding section, diverge from the popularly held medical perspective on disability that the Chinese government and society generally have. Secondly, even if in some of the parents, or somewhere tucked inside the mind of each parent, there is a belief that their children are “weaker” or less “normal” than others, this perception does not automatically lead to the jeopardy of the children’s equal educational rights and optimal educational outcomes, as parents are actively making attempts to assist their children achieve an independent and honorable life through mainstream schooling. What really matters seems to be the volition of the parents to fulfill their practical goals, not a narrow perspective of human or social properties of disabilities that their children possess.

### **Implications for Future Research**

The current study seeks to discover the thoughts and conceptualizations about inclusive education and mainstreaming by a group of parents of children with developmental disabilities under the specific socio-cultural context in China. The findings from it point to a few areas which are worth inspecting by future studies on

inclusion-related issues.

**A need for more contextualized investigations on the implications of inclusive education.** Higgins et al. (2002) delineated a process that individuals with learning disabilities underwent to accept their own disability over the course of 20 years, in that they made attempts to choose “the least stigmatizing label” for themselves, for example, between “mentally retarded,” “severely emotionally disturbed,” “learning disabled,” “hyperactive,” etc. In Goddard, Lehr, and Lapadad’s (2000) interview studies, they suggested the positive framing of children’s differences as a way to deal with the negative effects from the difference. However, under the research context of Chinese society, parents’ remarks on the aspect of avoidance of social discrimination in the current study further specifies other “strategies” that include taking refuge from acute humiliation in a bigger stigmatized group than in the population of students with disabilities, rather than merely weigh which label carries more stigma.

A doubtless nature of the dilemmatic choices is that they are persistently troubled by stigma that is entangled with certain differences from normality. In the case of Chinese parents, apart from a possibility that they might have been making ill-informed choices (about educational routines and practices in special education schools) during the interview, a clear outline of their thoughts emerges in the decision-making process by weighing the stigma attached to both settings. For them, the years that the children would spend in a special education school would solidify the children’s identity as people with disabilities, not to mention the lack of good behavioral modeling in this setting. Thus, the children would eventually become labeled as “abnormal” with the conspicuousness of their disability and the lack of living and communication skills commensurate with

societal expectations, which will greatly challenge their “ultimate task value” (Eccles & Wigfield, 2002) of “living independently with pride”.

This “double deviation,” from an identity featuring normal persons and from the expected life outcomes, as well as the inexorably profound stigma placed on their children in special schools and in their future lives, was perceived by the parents to put their independent adult lives in great jeopardy. In contrast, studying in general education schools were perceived to have the capacity to fulfill both goals. Therefore, the parents unanimously decided to drop the option of special education schools and go for mainstream education. Their choice, simply put, is highly related to their negative perceptions of current special education schools in China and subject to their perceived intensive degree of stigmatization, mentally, verbally, behaviorally, physically, and materially on people with disabilities, children and adults alike, particular in Chinese society.

Norwich has proposed that inclusion is made up of threads of concept and values so that continuing work needs to be done to identify what inclusion means for each particular group of people under a particular educational system (Norwich, 2008). Through this study, it can be seen that the interviewed parents from China hold their children’s assimilation into mainstream society in the future as their prioritized aim, which in turn leads to their enthusiasm in mainstream education and animosity toward segregated schooling. Obviously, for them, the former educational format means that their children could be offered more chances to observe, interact with and learn from typical children in a “typical world,” which may better prepare these children for their future life. Secondly, inclusive education is also a fulfillment of the requests from

many of them that children with “differences” should be treated the same as any other children.

Also, built on past attitudinal studies about the conception of inclusive education from its major beneficiaries and other participants, on-going contextualized understanding of it should be done. In the case of China, on the parents’ placement preference, future studies can investigate how the improvement in disability services such as effective dissemination of school information and construction of life-caring facilities for adults with disabilities may have influences on parents’ schooling objectives for their children with disabilities in China.

**The importance to detect new norms involved in inclusive education.** The “dilemma of difference,” which was regarded by Norwich (2005) as the basic dilemma underlying the dilemma of inclusive education, alludes to “a struggle to deal with children who were seen as “different” without stigmatizing them or denying them relevant opportunities” (p. 8) that is deeply embedded in special-needs education. The founder of this term, legal researcher Minow (1996), put forward certain principles that she thought would transcend the dilemma and introduce new opportunities for real inclusive education to be carried out. She especially hoped that institutions and agencies could adopt these principles and reexamine some firmly held assumptions underlying differences. Essentially, she proposed that to resolve the inclusion-related dilemmas, some taken-for-granted norms should be re-specified, and there needs to be a realization that judgments of difference should be considered based on the interests of the person who judged, and the social contexts. In line with her suggestion, parents in China, as revealed in this study, clearly presented their “resolutions” by forming their own “norms”

rather than the ones chronically held by Chinese society, namely, the norm of learning goals for students with disabilities under general educational settings, the norm of encountering unfriendliness at school, the norm of the life of an adult with disability in Chinese society, and the norm of the duties of a responsible parent in assisting the mainstreaming of their children.

Based on the findings of this study, the Chinese parent-created norms do not belong to the widely accepted norm of adequately achieving, well behaving students in contemporary Chinese general education schools, as can be seen in any crowded, sparsely staffed, poorly supported classrooms (Bennet & Gallagher, 2013; Timmons, 2007). Instead, the norms that the parents propose represent a predominant population of students, including those with and without disabilities, whose individual strengths need to be seen, whose unique interest needs to be counted on in order to build up a self-initiating learning trajectory, who constantly need to receive more positive treatment by teachers, and who need an education that can prepare for them a colorful and respectable adult life.

Consistent with this finding, in Norwich's (2005) study of the perception of school teachers and administrators across three Western countries, across the board, participants suggested one of the resolutions for the inclusive dilemma to be constructing an education service system which recognized differences among children as common rather than odd. On the opposite side of the globe, parents in China, by presuming a set of new norms of student life in for mainstream education, seem to be in congruence with teaching professionals in the studied Western countries. In Anita Ho's (2004) term, a truly inclusive educational practice should be the one that "refrain from pathologizing" children's difficult experiences in their learning environment. Along this direction, new

norms that reform the customary, disability-bound ones should be collected from not only parents, but also other people in the Chinese society. Collectively, these studies will contribute to cast light onto the “new opportunities” in inclusive education that Minow has mentioned.

**A need to study the attitudes of other stakeholders in China.** Despite many educational researchers’ findings and proposals that inclusive education may not serve children the best merely by putting them under one roof (Walnork, 2010), parents of children with disabilities in China deem this setting as the best option, aside from all its inadequacies in meeting the individualized educational needs of those children. As Zimbabwean educational scholar Chimedza (2007) pointed out, in developing countries, before waiting for enough resources to come into support for the inclusive education, it may be logical to first pull children into regular classrooms to jump start inclusion regardless of the quality of services. Chinese parents’ insistence on placing their children in the poor-performing LRC (“Learning in Regular Classrooms”) strengthened this point to a certain degree. With this momentum from parents of children with special needs, it is worthwhile to look into the opinions and attitudes of others besides students with disabilities and their families.

For example, opinions from parents of typical students should be learned, especially when, as discovered in the current study, the interviewed parents stressed the importance that their children are accepted by typical students and their families. Moreover, it is meaningful to study the opinions from the school administrators, educational policy makers, and the educators both in the field of general education classrooms and those working at special education schools in China. This research will



greatly contribute to the real operation of inclusive education by revealing varied perspectives for building a unified rationale to implement this educational format with more meaning for all the stakeholders.

### **Implications for Policy and Practice**

**The imperative need of providing sufficient legal safeguard for parents of students with disabilities in China.** The situation outlined by current findings forms a somewhat different picture from what was revealed in the first 10 to 20 years after students with disabilities were encouraged to attend regular schools in the United States, with research showing that parents were feeling divided in choosing between integrated settings with insufficient support and separated settings with better support to the children (Parrino et al., 1989). It seems that in China, parents' favor fall predominantly on the mainstreaming type of schooling.

The finding from this study testifies to the existence of the suggested dilemma of difference that educational policy researchers have delineated (Minow, 1985; Norwich, 2008), and goes on revealing the one “resolution” reached or planned by the parents in China for this dilemma. No presupposition of much struggle in the “dilemma” was found in the parents before they are trying to arrive at a conclusion on their more preferable format of education—mainstreaming.

Therefore, the almost unanimously shared ambition of enrolling their children into mainstream schools highlighted the urgent need of laws and policies that could effectively facilitate school entry of children with disabilities rather than hampering it, policies that are different from the current legal works which leaves too much leeway for general schools to reject them. It is especially urgent, when the findings bring into

attention a form of exclusion where both the general education school and the teachers frequently admit much inadequacy in themselves and express a well-meaning expectation that the child can be better “rehabilitated” in the other schools. As Ravaud and Stiker (2001) saw it, this form of “exclusion,” paradoxically named “differential inclusion,” sounds benevolent and is hard to combat without proper restriction by the law.

**Worthiness of building parent-professional partnership in China.** In the implementation of special-needs education, the Chinese parents possess flexible mindsets about their children’s encounter with potential academic difficulties. It was also shown that parents tend to take it upon themselves to obtain more tangible results in their children’s education. Further, in this study quite a few parents cited the inclusive practices happening in other areas of the world such as Taiwan, Canada, and Germany as a support to their confidence in China. Whether or not this was just a product of best wishes for a new, apparently more beneficial format of education for their children, this optimism and the accompanying zeal and initiative from Chinese parents of children with autism and intellectual Down’s syndrome in inclusive education is wholesome for an undertaking that is gaining more and more educational and governmental attention than ever.

Thus, the above mentioned characteristics of the parents serve as advantageous forces to relieve the inexperienced general schools and teachers of the stress of not being able to help the children make substantial progress under the current competition-dominated Chinese education. Therefore, schools and teachers should spare no effort to brew constructive partnership with the parents, in order to bring the best schooling outcomes to their children with disabilities and even their typical classmates.

Also, as partners, parents should be given detailed and systematic reports about the outcomes of the LRC. As shown in the findings, many parents, especially those with sufficient awareness of their children's rights of equitable learning outcomes, do not value the abstract term of inclusive education that simply designates the outward form of the education in terms of type of classrooms and settings, and a general atmosphere of embracing and support. Instead, for these parents, mainstream education is an educational undertaking where the "nature, implications and consequences" of the participation by all relevant entities should be carefully and constantly checked (Lipsky & Gartner, 2005).

**Importance to construct high-quality supplemental services.** In the meantime, specialized services, including special schools and adult supports for individuals with disabilities, if are designated to be important supplements to the LRC, should be provided with amply high quality. Vitaly important, valued learning and life goals set by each parents should be an important part of the working philosophy of these agents, instead of rigidly basing their services on the types of disabilities and ability levels of the individuals.

### **Limitations**

There are several restrictions in the generalizability of the findings that are hard to be overcome in this study. First of all, the study has not thoroughly investigated the entire subpopulation of Chinese parents whose children have disabilities. In China, there is stunning divergence between cities and rural areas, and in teaching standards and staffing and material resources (Lytle, Johnson, & Yang, 2013). In fact, the present study only focuses on urban settings.

Also, participants in this study are all parents whose children are relatively young

(at the age of attending daycare and elementary school). However, academic findings suggest that parents' values change over the course of their children's life (Landsman, 2003; Scorgie & Sobsey, 2002). Under this context of dynamic parental values, trends of expectancy uncovered in this study may only apply to those whose children are at their very early lives.

Another reason for the limited generalizability of the findings comes from my realization that the data were gathered from parents who are willing to admit that their children have disabilities, as having been mentioned in detail in the section of "learning from preliminary studies" in Chapter 3. Therefore, the targeted population of the research only includes those parents who believe the labeling of their children as being disabled.

Thirdly, people suggested both in the empirical literature (McCabe, 2007) and in person to me that many Chinese parents are not willing to send their children to general education schools for the fear of losing "face." At the same time, at least one information source of me, for example, a principal of a special education school in Beijing, commented that there were many cases in his school where parents simply left their children at the school for good, and paid almost no visit to them for months or years. There is also an astonishing record by a researcher that over 90% of a large number of abandoned children in China have disabilities (Shang et al., 2009). With all these empirical evidence of a much darker side of parenting in China, the findings that Chinese parents selflessly act as their children's guardian angels should not be automatically applied to every Chinese parent. As is the case for all research, independent variables need to be continuously added and samples diversified.

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## Appendix 1 Themes and Subthemes

Table 1. *Themes and Subthemes of Parents' Perspectives on Inclusive Education*

Theme 1. Parents' knowledge about real inclusive education	
Subthemes	Quotes
1. Warm acceptance	"Overall, in terms of the overall atmosphere, it is a very good one."
2. Rich activities	"...this is a large, comprehensive school, behind it there's powerful resource system. For example, in TH School, it has Special Olympics, it has many other activities for the students, like all kinds of clubs. They just sent some students to Athens. Only this type of school can have so many opportunities..."
3. Specialized curriculum	"in this education special education is integrated with typical education."
4. Teachers have special expertise	"The teachers have already had some special-ed experiences...this experience stuff really matters...without it...he's definitely not able to teach. I believe he'll just go astray."
5. Teachers are fair and loving	"Instead of looking down on the students...(they) look up to the kids...The precondition of 'inclusion' is that teachers know the needs of every kid, they learn their needs by heart."
6. Teachers assist the kids to assimilate	"I thought there must be some teachers in there (inclusive classrooms) to, among special and typical kids, help the kids be included with some tactics."
7. Teachers consistently and timely prompt the kids' progresses	"Under their close watch, what's missed was immediately made up for."
8. Peers accept the special-needs children in daily activities	"Seeing your own child discriminated or excluded when playing with other kids is saddening...if...they can play together, it's so relieving to the parents."
9. Peers try to fit to the special-needs students	"Inclusion can be understood as...putting children of different characteristics together, and ask the typical ones to adapt to those with differences. I agree with this perspective."

10. Peers are helpful	“Then the teacher will instruct the typical kids how to help the special-needs students.”
11. Typical parents welcome inclusion.	“Inclusion is ...parents including parents.”
<b>Theme 2. What Chinese education system falls short to meet and the needs of both disabled and typical children</b>	
Subthemes	Quotes
1. No real inclusion but <i>sui ban jiu du</i> (LRC) for children with disabilities	“The T school is the only one in Chengdu, just this one... We all...parents (whose children have disabilities) all want to get in, like trying to squeeze themselves in even with their heads pressed flat.”
2. Not much choices for children with disabilities	<p>“If he doesn’t go to school during such nine years, doesn’t he have to stay at home? At this young age, it’s too early for her to be trained with professional skills...but at this age, no agency will take him, or very few ... Generally they don’t admit children as old as this.”</p> <p>“We can let him go to regular middle school, but the goal of regular middle school education was to help children get into college—the college in which he can’t survive using his peculiar way of learning. On the contrary, special education schools only set such low standards in study. Those are the only two options that you have to choose from.”</p>
3. Limited accommodations available for all students	<p>“One class session lasts forty minutes. After one session follows another. (Sitting in these classes) he knows nothing, understand nothing.”</p> <p>“...What I’ve just laid out to you was only an ideal state. In reality, as a private institution has to survive in the larger environment of the society, it must buy in some popular rules of it. For example, my opinion is that children with disabilities should enjoy a lot of their time doing outdoor activities, but in my center we are lack of these activities...for example...game time in the open space...but we were simply not allowed.”</p>

4. China's education is a failure	<p>"China's education now is a huge failure, a tremendous failure."</p> <p>"Disorienting... In this education they push contents way beyond the average age level".</p> <p>"It (Chinese education) puts heavy pressure on the children... not only children with autism... Now education in China, its nature has (changed). It's not to educate for the sake of educate, but to test for the sake of test."</p>
<b>Theme 3. Dire performances of the disabled children in mainstreaming schools</b>	
Subthemes	Quotes
1. Never catching up with peers	"Among many things, one thing that I see is that he surely cannot catch up."
	"The older he is, the further his scores drags behind."
2. Needing special teaching	"The other kids just need to be taught once. Ours need five, six, eight, ten times."
	"You only want him to get what's easy for him to get, with a simple tipping toes... not those absolutely beyond him."
3. Lack of motivation to learn	"In academics, she doesn't have that motivation... those are really straightforward knowledge... but she just won't listen"
4. Not following the class routines	"In a place like a school, his impairments makes him appear kind of lazy... procrastinating on many things."
5. Difficulty to build relationship with ones they like	"Deeply in his heart he has such a craving (for friends), but he is inadequate in his ability."
6. Carrying out improper social interaction	"He loves finding others to play with... obsessing them enough when playing with him. He's done! This never works. They are tired of him."
7. Not attended to by peers	"Beyond Grade 3, things taught in the class become very hard, then they don't have things in common to work on... at that time, the hope of them sitting together to learn is dim."
<b>Theme 4. Current exclusion of children with disabilities by schools</b>	
Subthemes	Quotes

1. Rejecting entry upon learning the children's disability o  
"They just tell you briefly: "Our resources are limited. Openings at our schools are full.""
2. Requiring entry interviews which only screening for typical kids  
"After he graduated from preschool, we went to many interview tests, he did bad jobs and many schools didn't want him...like crying, sitting on the floor...the teacher asked him to stand still, but he chose not to; they asked him to crouch down, he refused."
3. Unreasonably expelling students with disabilities  
"The first semester, we brought him to special education schools for the Special Olympics training every Monday and Wednesday, so had to ask for leaves, couldn't go to classes at his elementary school. Then the second one, after Christmas, I had to bring him to hospital for his eye treatment. We did it everyday, so he went to classes only half day. Then his teacher started saying: "Probably he fits the special education school more. It might work better for him.""
4. Prioritizing in-take on the parents with personal connections  
"Now I hope his dad can find an acquaintance that can recommend us to some principal of a general elementary school."  
"Now I have to achieve the goal (of finding proper general daycare for my daughter) by using some unconventional means."
5. Inflexible school rules  
"The teacher must not start the class before each one of them got to the classroom. Sometimes the whole class wait for him to begin...(which) will affect the normal operation of the school day."
6. Discouraging parents to accompany their children in classroom  
"Anyway, we tried but still cannot come to the classroom. The school doesn't accept it...it said: "Parents are forbidden to come in." The teacher also told me: "Once you came, all the children saw you, and came up greeting you. This will influence them, even at their nap time."

#### Theme 5. Current exclusion of children with disabilities by teachers

Subthemes	Quotes
1. Inability to help kids improve	<p>"...however, it is impossible for him to succeed in academics."</p> <p>"(We) hired someone to observe the class...when the teacher's ways of teaching failed to make her understand properly, we teacher her in other ways."</p>

2. Teaching not centered on individual goals
 

“About that (inclusive) daycare, I feel like they didn’t meet the goals of really helping him included... When the time came for inclusive classes, one teacher just came over (to its collaborative training center for children with autism located next to it)” and took the kid to classes, and sent him back after it... but basically this was it. It was just hollow and disconnecting.”
3. Put unmodified criteria in disciplining students with disabilities
 

“The teacher led a bunch of kids out to the yard and was modeling them do some physical exercises. Then among them, there was a kid...having autism... When teachers called out: “Stand in lines!” everyone knew to immediately stand in two or three lines except for that one. He looked this way, and looked that way, just couldn’t concentrate. Then the teacher said to him: “Hey you, if you run away not lining up, don’t come back then!” ...there is a disciplining that’s somewhat military going on in this daycare.”

“You (the teacher) always asks him to speed up working. Why don’t you try to think how much difficulty he has in coordination of his muscles in his hands?”

“Many teachers are still holding those traditional concept of good students--“listening and obeying”
4. Harsh treatment of students
 

“He clang to the everyday-life teacher (another teacher who happened to be by him), dug his head into her and refused to raise it. Another teacher in the classroom was bellowing towards some other kids in the classroom.”

“From he was very young, from grade one to grade four, in every math class, the teacher... punished him by asking him to stand up. He just let him stand through the class and study, because he couldn’t sit as still as the others.”

“For example, when he feels bored at watching a video, he’ll just lie his upper body on the desk and fidget away. Then there’ll be someone (teacher or aide) yelled at him to sit straight, but he still feels bored. Because I (he) can’t understand that video. But he doesn’t know how to express it in a normal way. However, if at that moment, a special education teacher or any others who knows this type of children comes into the classroom and instruct him (to say it) the problem can be solved,
5. Not knowing the disabled students’ characteristics well

- and no behavioral disturbances would follow up.”
6. Uninterested in teaching the kids
 

“...if their test scores are not accounted for like in *sui ban jiu du* (LRC), the teachers can just make them sit in the classroom when others are learning...in such a big class, regarding the limited energy of the teachers, we’re concerned whether the true inclusive education can be done.”

“as if you are not existent, as if you are air.”
  7. Not providing the parents constructive information
 

“At the very beginnings, during parent conference, he told us “he is doing OK, volunteered to answer questions”, “he can do as what the whole class is doing.” But now, he told us “he can’t follow”.”
  8. Patriarchal stance in teacher-parent communication
 

“(My best hope is) that the teachers do not call me to their offices every two or three days.”

“(We) must communicate with the teachers...like printing out some paragraphs about autism for them to read...but at the same time you can’t, you can’t talk too much with the teacher, because he will talk back with one sentence: “I have thirty or forty kids in the class, you can’t let me just take care of your kid.” What else can you say?”

#### Theme 6. Exclusion from others around the children with disabilities

Subthemes	Quotes
1. Peer alienation	“Generally his classmates don’t enjoy hanging out with him, thinking he’s too ignorant and naive.”
2. Peer bullying	<p>“I asked many normal kids this question. I asked my nephew. He’s older. He’s at an elementary school. I said: “do you usually bully them?” “Yes, all (of the typical pupils) do.” “Then I went on: “Do you?” “I don’t!” ...but I knew he must have. He probably didn’t mean to be evil, it was just something fun, but hurt has been brought to that child’s heart.”</p> <p>“You heard of the news about the parents’ joint petition for an autistic child to leave the class in Shen Zhen? It happens everywhere.”</p>
3. Attempt to have the disabled student kicked out of the school by parents of typical kids	



4. Life-ending recommendations of the pediatricians of disabled children
- “When is was decided (that her son had Down’s syndrome), the pediatrician’s attitude was that he should just be given up... “This type of kids, you don’t need to care much about...”
- “The kid gets sick...The pediatrician usually says: “you just take him/her back home and feed him normally. Important, when he gets sick again, don’t treat him.” This is like “just let him die and The End!”, like he really cares about you, like what he says is to the parents’ interests...but in your heart...I heard sometimes parents quarreled with the pediatrician for this.”
5. From random persons in the daily life
- “When he was very young, he got training at S street, so we took the bus everyday. Many people showed their surprise, “hey, isn’t this kid that type of patient?” They talked among themselves, kept talking, beside you .on purpose. There have been many of them.”

#### Theme 7. Parents’ firm preference for LRC at general education schools

Subthemes	Quotes
1. Central importance of mainstreaming	“Of course normal schools will do better (for him). After all we all want them to approach normality.”
2. Wide disregard for special education schools	<p>“No, I’ve never thought of sending him to special education schools...there the only result will be he gets worse.”</p> <p>“If (the worst thing happens) that his mom cannot or not allowed to sit in his classroom (to keep him from acting out), probably we still have to transfer him to specials schools, for some more training. But I’m at least confident that he can sit through classes in elementary schools...I really think that the worst thing is having to send him to the special education schools.”</p> <p>“I don’t think what they teach in special education schools fit the needs of children with autism...Why, because they are different, they have to be locked up at home? They have to be secluded in special institutions? They deserve the same colorful lives. ”</p>

#### Theme 8. Perceived advantages of studying in general schools

Subthemes	Quotes
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1. Adding a major normal experience to the disabled students' lives  
world  
"What am I thinking about? I want my kid to get into contact with a normal world. Normal school, learning normal stuff, being with normal kids. I want him learn normally. "
2. Inculcating about a normal world  
"He doesn't necessarily directly participate, but he should see them through his eyes. Even some normal kids are reticent, but he knows this world through seeing and understanding that's happening around him...He cannot just know by imagining... Like when he's at the door of a supermarket, he knows it's a market where you need to get what you want by paying for them, based on his past experience with other supermarket..."
3. Making the disabled students well aware of and used to a state of being with others  
"Human beings are gregarious creatures. If he cannot get any motivation to communicate and get along with typical kids, it will surely pose great difficulty for his future life when he has to live by himself...if he does not have an experience of remaining within a group (of typical kids), he will never get a real sense of what "group" means...that is, "others and I are actually together..."
4. Blessing the disabled students with delightful feeling of company  
"(Friendly contact) is, for example, holding hands. Just holding hands...Although he might just take his hand away from the other's, in his heart he knows: ...there is someone being with me...He looks at others. Although he does not have language, but he listens when others speak without a problem."
5. Typical peers can model to the disabled students on normal daily routines  
"Going to the general school make them see a normal regularity in life—when their classmates go to school, they go; when their classmates go back home, they do too."
6. Typical peers can help the disabled students practice communication skills  
"Normal kids can motivate our kids to learn to communicate."

7. Typical peers can help the disabled students learn more effectively  
 “I’m pretty sure that they learn faster following the typical students.”
8. Bringing long-lasting friendship between disabled and typical children  
 “... When he gets enrolled in elementary schools later, he will develop some degree of friendship with his desk-mate. Then the desk-mate will definitely give him much help... Friendship is the most important in my eyes... it is able to last for a long time... what his family members are not able to offer him, friendship can sometimes come to the rescue. There are things that I don’t want to tell mom, but I can tell friends... I think if one starts to work on friendship from a young age, there should not be a big problem (having it when grown up).”

**Theme 9. Hopes seen by the parents in LRC**

Subthemes	Quotes
1. Children gradually get adapted to the mainstreaming classroom	“This is what I least expected, so if he all of a sudden get everything, I’ll definitely get a blast of happiness. Because he can move upward is what I wish most.”
2. Teachers educate typical peers on acceptance	He demanded that “no one in the class teased the “little friend” (referring to “peer” in mandarin) with disabilities.” She told the class “this baby has some illness, so each one of our group ( <i>da jia</i> ) should give him more care, more protection, and play more with him.”
3. Teachers make some adaptations for the disabled students	“When doing “popcorn” in Chinese text reading, he (the teacher) always called on him to read a paragraph that he had always read”
4. Teachers grow with the disabled students	“At the very beginning the teachers required him to perform like the normal kids, such as do the same homework... they wanted to lift his scores to the same as the others... after having failed in a lot efforts, (they asked us to move him to special education school)... but he cried and cried in special education school, so I had to call the head teacher although it was so embarrassing. But after that call, attitudes of all of them toward my son started to change.”

5. Peers are friendly                    “I often paid attention to how his classmates got along with him... Always, when he got to the school gate, once kids of his class saw him, they came up to him, gave greetings, walked with him, literally arm in arm, into the school.”
6. Peers are helpful and            “(They) teach him! Like they came and told me it if, for example, longlong violated school rules instructive                    such as climbing over railings of the staircases. Whenever they did things like this... I told them: “if you saw him do that again, stop him.” They did!”
7. Peers’ attitudes improved        “An afternoon last week we were playing in the sandbox. There were also a couple kids from as being with the kids        classrooms upstairs of his, from those genearl education classes. They watched him and a girl in his special education class playing. Then one of them said: “I like his coat!””They referred to my son’s coat. They said they like it...I asked then: “Do you feel weird seeing them playing with the sand here?””They said: “No we don’t.””They said that “we could have picked on him before like he looks so strange, but now we just won’t.””
8. Typical parents are                “Her mom...had also seen this type of children. She then told us she met some of these kids when informative                    she went to pick up her daughter. She said she felt it was a nice school, and went on recommending the special olympics training, especially its reputation on roller-skating to me.”
9. Typical parents mobilize to        “At the moment I sensed there was a turning in the teacher’s attitude, but I didn’t know why... teachers to accept the kids        Later, teachers from the special school—they were also all wondering about it, told me it could be better                    the pressure from (other) parents on the teacher. Why? Because in the parent conference, so many of them asked: “when will L be back?” “Is he back to us at all?”... You know, the teacher has to consider the feelings of the parents, since he wants to lead a liberal atmosphere in the class... he doesn’t want other parents to view him as intolerant.”
10. Parents of other disabled        “Sharing with other parents (of children with disabilities) is so helpful. It’s real help, and it’s children being informative        meaningful...like someone opens a window (in your hopeless life) for you. The world that you are not familiar with, they tell you about. That is, you end up knowing all kinds information.”
11. Parents of other disabled        “Zhen Yuelai (a well-known advocate for autism, living in the same city as the interviewee), Her

- children set up examples to follow
- daughter had a typical version of autism. She said: "If I wanted to be free of stress, I could have just sent her to the special education schools, because she didn't have to learn hard and pass such strict tests as in general schools. But then I would have had stress later on (after she graduated). (So she chose to send her daughter to regular schools.) Her intelligence was OK, so she ended up graduating from high school...but they offered her "night school" through all these years, that is, tuition fees were paid to the general education school for no gains (because she couldn't catch up by being taught in the classroom only), while the parents taught her by themselves at home after school. This went on for around 10 years, and the whole process was, surely, torturing. But now the girl managed to get a job by herself...in a Seven-Eleven store.""
11. Parents of other disabled children bring benefits as allies
- "If you don't go together, then there're things that you just feel awkward to request (from the government), as if under some pressure."
- "The first time I heard inclusion was when I took him to rehabilitate at a center...basically I got it from chatting with other parents."
12. Family members pursue the common goal of providing the child most advantageous results
- "If nothing works out, then someone will need to sit with him at the classroom, that equals we parents play the role of special education teachers' (as in a "real" inclusive classroom) ... his mom will go, she can just quit her job then, and concentrate on working with him. This is actually part of nursing a child, so by design parents may guarantee a better outcome."
13. Inclusive education is just on its "initial stage" and starting to receive more attention from the government
- "Regarding how to include children with special needs, the government is fumbling around and slowly moving forward."
- "Chinese society is one against heterogeneity...but now it's being better."
- "This was when once in the Federation of People with Disabilities of Chengdu, the Association for People with Autism invited principals from all schools (for children with special needs) to come and brief the parents, including principal of W Special Education School, and the one of the

**Theme 10. Perceived suitability of their children for the mainstreaming schooling**

Subthemes	Quotes
1. Having higher ability levels than those fitting for the special schools	The student affairs director said: "Why are you so against special education schools? I said: "His abilities were not low to the degree to put him in special education schools. If he is, I'll just send him there."
2. Being motivated to learn	"I'm pretty optimistic (about mainstreaming), because he is willing to learn" "A successful inclusive education including the efforts made by the child... he likes to learn."
3. Equipped to learn in general classrooms	"There (special education schools...the children's symptoms are severe. Some of them even can't say a sentence after being trained there for one or two years. Ours, at least he speaks. He answers you. He might answer wrong but he answers. Those kids, they hardly speak in good half a day.)" I believe(d) that his IQ won't be bad. Even not talking in terms of IQ, I still think that he should be a very smart person. The look from his eyes and some of his manners...I often feel that there is sharpness in his eyes..."
4. Having the willingness to socialize	"I feel that slowly, he is willing to interact, although I cannot say for sure because interaction is not a simple stuff."
5. Being able to interact with typical peers	Mingle with normal students, he will definitely have breakthroughs in language. Why? Because he has language! ...If he is willing to communicate when he plays with others...then when there is a typical peer guiding him into the right direction, then <i>Bang!</i> He's gonna talk more and also more fluently."
6. Possessing pleasant personality	"Whatever you want him to do, he's super cooperative, at home and in his daycare. Once the teacher's face turns stern, he immediately complies to her. So I'm not worried that he desperately disrupts the classroom." "I've never thought of putting her into special education schools. Because I feel that...her personality is the one that makes others accept her easily."

7. Being possible late- bloomers “(In elementary schools) I won’t force (the homework) on him. I didn’t do my homework from very young (laughing)...No use in it! Is there any use the homework can bring to an elementary school student?... Only when you move on further upward in your study (e.g. get into college), you know what you want to know, identify your direction, and then make efforts to pursue your goals.”
8. They should live meaningful lives “Although many materials say that because of their bodily difference, they appear differently from the ordinary persons, I think he comes to this world to live a life with meaning. That is to say, we don’t let them doodle away each day, right? At least he should live a life of value. What he can learn, we should let him learn. We created conditions for him to learn.”
9. They should live lives with pride “We don’t want him, in the end, to struggle for a peaceful life by having to cover himself up and escape from those discriminating looks. Also we hope that he walked the path of his life holding his head high, like I don’t lay my happiness on your pity. Right?”
10. They are equal to other kids “I wanna say, children are children. These children are equal to those children. Actually my understanding of children with autism, is, they are just like the blind, they are the same, but having obstacles on cognition, which in his case is social cognition. This is just one type of obstacles. ”
11. They have the right to be present in other people’s lives “I think no matter what kinds of kids they are, like those with cerebral palsy or others, they should live with the others in the mainstream, they are part of them.”

Theme 11. Perceived disadvantages of going to special education schools	
Subthemes	Quotes
1. They are dumping grounds instead of schools	“That one (the special school)...how can anybody call that one a school?” “We want him to approaching the normal, it means they gets included into the society. But through special education schools he cannot have that inclusion. It equals you give him up.”
2. Depriving the disabled kids of the chance of transiting to the normal world	“I don’t agree to enroll him into that place (special education schools). Because, I am still hoping that he can slowly become not so special from where he is right now. Then if you send him there (special educations schools), he’ll forever be special. In that setting, what natural assimilation can he enjoy? I don’t see it can come easily.”

3. Disabled peers can not act as good role models and learning partners  
“(Those kids) don’t have such a rich expression of language (for him to imitate).”  
“Because children of special educational needs are all those surrounding him...On behaviors and habits...personally I don’t think there are many good ones for him to follow. Those are schools exclusively of special kids...It equals to rubbing shoulders with them for eight long hours per day ... so the kind of mutual influences between them can be very bad.”
4. Disabled children live a boring life without enough interaction with peers  
“Because if sending her to Peizhi School (“official special education schools in China), (we’ll find) the whole class of students with autism. They won’t approach each other to communicate, and their interaction will be purely directed to the teacher only. She won’t have activities of interaction with peers of the same age. We feel like, if it were us and if someone only make you stay with (adults like) the teachers, then you are surely not having as much fun as with your little buddies.”

#### Theme 12. Parents coming to terms with the drawbacks of LRC

Subthemes	Quotes
1. Thinking education in China is widely agreed to be in need of reform	<p>“China’s education now is a huge failure, a tremendous failure.”</p> <p>“Disorienting...In this education they push contents way beyond the average age level”.</p> <p>“It (Chinese education) puts heavy pressure on the children...not only children with autism...Now education in China, its nature has (changed). It’s not to educate for the sake of educate, but to test for the sake of test.”</p>
2. Holding a different view of their children from the popular singularized view of human characteristics	<p>“There’s a denial of multiple value of life now in the society. It only leads to a singularized standard that they see persons.”</p> <p>“In the Western society, in Christianity, these children with speciality, are thought as a gift from God. So this discrimination is a social problem.”</p>
3. Feeling at ease with the disabled children’s academic failure	<p>“I am not concerned about his grades. I always say: “This child of mine is just the last one in the whole class, by all means... Yesterday they taught year, months and dates in maths. The teacher must had emphasized to him that February has 28 days. This is the only thing he remembered. He</p>



might not have understood the other points...In Chinese class, he can hardly do the paragraph comprehension...Although now he can get a "pass" (which is regarded as an extremely low grade in Chinese elementary educational system), he definitely doesn't pass in maths though...there is no way that he can understand and solve those applied problems...(for the English course, the year before last I hired an English tutor for him. No use! He couldn't understand and recite even just one short text after more than ten, twenty sessions...Sometimes when he does not understand the homework questions, I just hand him the answers...)

"I am thinking that (in the future) I won't put too many requirements on his study, such as what goals to make in any area. I am not putting requirements."

4. Thinking that the current public education lack of meaningful goals      "(The useless subjects are ) just like math, physics and chemistry that I have learned when I was young. I learned so much about them, including history and geography that I memorized a lot. But my feeling now toward them is that all the learning was useless. It ended up just a drilling of rote memorization."  
 "The current public education... is disorienting...deviating from the most important role of education."
5. Dismantling the typical learning goals for their children      "We have shifted our emphasis away from her grades... It isn't a lowering of target. I would rather say that we dismantled it."  
 "I have never dream big for a college diploma. (I simply (hope) that he can go on into middle school, and read characters."
6. Patiently recognizing that learning is slow but on-going for their children      "Now at least he was made able to read a couple characters..."  
 "So I find that his moving forward in one aspect will actually trigger many things. For example, after he starts having language, we find out that he can recite what some content taught on the last day, like an ancient poem or a piece of Chinese text. You can also review with him something that we've done together yesterday."

7. Taking time to allow their children's interest to emerge  
"When you find that you have interest in something, the possibility will even be you learn it better than the others."
8. Thinking negatively about the stress-filled education in China  
"No just children with autism, but even among normal kids, there have been many cases of depression, many, many. We often hear suicides by college students. Under the context of China, education has essentially changed to not serve educational purposes, but serve those exams... you must take exams, and to get high scores you must rote memorize the contents you are taught, which are those decreed by the Educational Committee. So now even at an early stage as daycare, many elements of the elementary curricula are taught, and many of the daycares claim they teach in both Mandarin and English, only making the kids all stressed out of shape..."  
"Those parents blindly followed the teachers' direction and went astray again and again... "You must command math skills!" They forced these contents on their children, only to find that they completely grew sick of these stuff. Most likely they had been able to get them, but now they simply gave them up."
9. Refraining from following the teachers to put pressure on their children  
"In his classroom teachers all teach fast, because it's key to care for the needs of the normal kids. To receive such fast message, he can't, so he goes absent-minded in seconds... so with such a low ability what can be done is only through one-on-one teaching at home, starting from his level, the simplest ones."
10. "Running night schools"—providing more catered instruction on their own  
"Those kids all have to go to "night school!" You teach them yourselves at home!"  
"(About) those (academic contents), occasionally I try to teach him, but simply give up if he can't get it. I just leave it behind my mind. But life skills, and knowledge of self-protection, anything that can enable him to do things outside home, we are trying our best to make him learn. By whatever means, however long it may take, we are hammering them in him."  
"Now I'm cautious of putting too much requirements on him. There are some homework questions that he can't do, I just tell him the answers. You are not made for academics so I don't want to push

- you in that direction.”
11. Feeling bullying generally acceptable  
 “Small pushing or shoving, small frictions (are OK), except for really out-of-bound ones...I feel like no child go not bullied at school.”  
 “I thought as that bully got the message that he did wrong it’s fine. He was just a very young child, bare above ten years old.”  
 “Every child got bullied. You are not Obama.”
12. Thinking being mistreated as character training for their children  
 ““Dissatisfaction will always happen. Even you are a normal child, when entering the society... for sure you won’t just get what you want... Small trials and tribulations are good exercises for him, to show him what the society looks like... This is society, with bad and good, kind persons and unkind. Now you have both in your class, right? You’ll have them at where you will work, and in other part of your life. You’ll definitely go through the same thing in the society. ””
13. Being only alert to some certain types of bullying or mistreatment  
 “I don’t really fear him being bullied. I think this’s simply unavoidable. He’s definitely gonna be bullied. But the impact of the bullying—for example, he was bullied too much that he doesn’t wanna leave home. This is what I fear.  
 “What do I fear? I’m not so concerned about bullying from peer students... I fear most is he gives himself up in studying...”I can’t understand what the teacher teach, but he scolds me so hard, he even calls me idiot. Then why do I sit here studying?” ... This way, he extinguishes all his hope to move upward. Now it’s the real end of the story.”  
 “A girl likes treading on her bag on the floor on purpose. (In the beginning we cared), but later I found, she doesn’t mind those language or behaviors, like the one I described. As long as there ‘s no direct bodily aggression, she’s OK.”  
 “About (personal proudness) he doesn’t seem to care, nor does he understand. I really think he both doesn’t care and doesn’t understand.  
 “I don’t think he has self-esteem.”
14. Redefining their children’s self-esteem

15. Communicating with schools and teachers based on understanding  

“They were definitely unwilling to take him in, thinking this was a kid with problems...I said, please let him in just to test it. If you turn out feeling he’s OK, he’ll remain. If not, we’ll just leave. The director said “Alright! Alright!”

“(We) must communicate with the teachers...like printing out some paragraphs about autism for them to read...but at the same time you can’t, you can’t talk too much with the teacher, because he will talk back with one sentence: “I have thirty or forty kids in the class, you can’t let me just take care of your kid.” What else can you say?”

“The current teaching environment (is): a big class with many students, typically forty to fifty kids, that made me doubt whether the teacher will have sufficient energy and other resources to really embrace (our child).

“Let me tell you, during his elementary school years I presented gifts to the teachers every year. I hoped you don’t always scold him, don’t always put pressure on him about completing his homework, don’t always pick on him, don’t always nag around him.”

“That (general) daycare, I had her there for about half a year. From the very start the strategy that I took was that, you know because my child is a little bit weak in her ability, I need to let the teacher know she needs more care. So sometimes, including some festivals and holidays, I gave the teacher some presents... I just wanted her to give her some sort of training on whatever problems she spotted in her. But the teacher ended up misunderstood my message! She held her in her arms all day! She didn’t go to activities with others... Once she was unwilling to go, the teacher held her alone from them.”
16. Communicating with the teachers respectfully  

“To a real, well-planned out inclusive school, yes. *Sui ban Jiu du* (LRC), no.”

“What we’re thinking bringing him in are not those public schools at all, or not traditional ones. The one we are checking right now...is a church-run school.”

“We thought that was such a good school (for my son). Although it’s a school for the kids of vagrant
17. Trying to find some “nontraditional”, more accommodating schools to do the LRC

rural workers...a little boy helped him (a child with autism that they saw during their school visit), his hand was on him but he did not resist at all... such a little boy, he told him: "Hey, c'mon! Toss the ball over here!" At that time, at that very time, I was moved."

"The schools we just talked about (schools in Beijing) are all just common schools, not inclusive at all in the real sense....so this is why I'm thinking of immigrating to the United States (with my son)."

"You must choose among all the elementary schools... (if the schools are a prominent one that focuses on study, why I go there? I would rather let him study in a mediocre one... Now many of those well-off parents (with children with autism) are willing to send them to international schools.

"K has very restricted interest, but once we see him like anything, we go ahead do it together with him, period! Like in the future, if he cannot catch up with the general school and he doesn't want to go to the special schools, at least he's still interested in eating. He loves eating and likes watching me cook meals in the kitchen, so can't I try to make him team up with me in the cooking? Later, I, I could just go with him, to some restaurant to be a cook, right? I can accompany him anywhere to serve in the restaurants, I can work with him till the day I leave him, right?" (The speaker is a mom who is currently an economist working for a company.)

"Right now our state of mind is different (from before). We more tend to let ourselves less obsessed with empty imagination of what he will become of in the future, but concentrate on what we should do today, tomorrow, and the day after tomorrow."

"I'm just tackling what's there right now...I'm different than the past me, like before I was used to considering things ions away from the present. Now, after the first several years, I don't do it. Like I don't even think of what might happen half a year later from now. Why? Because kids grow so fast."

18. Ready to explore in any means other opportunities for the children's life development at their final failure in LRC

19. Recognizing life's unpredictability and deciding to face the music

20. Keeping some “red lines”	Withdrawing kids if they are reluctant to stay	“Now he is kind of resistant to come to classes...if he feels pain sitting there, we might have to transfer him to special schools.”
	Withdrawing kids if they encounter humiliation for their disabilities	“OK, so he’s just an idiot....Not a single piece of attention spared for him in <i>sui ban jiu du</i> (LRC), like his is just invisible air...that’s why I’m thinking of immigrating to the United States.” “If the larger atmosphere is not optimistic, I’ll try my best to find somewhere else for him, even try home-schooling...like being made fun of and jeered like a monkey in a circus...”

### Theme 13. Expectations for their children

Subthemes	Quotes
1. Exhibiting and developing their unique strengths and build on them	“(We) do not demand what type of person he must become. Let him slowly grow, until the time he shows real interest and liking in certain things, and we’ll then try our best to help him fulfill his interest. If he is not able to, we’ll just let it be, and let him just happily enjoy the rest of his life.”
2. Able to leave the parents clues about what to plan for their further improvement	“when he improved in his communication. (By it I) was able to know “oh! he already took this and that into his mind”. Then I can set about providing more teaching and information to him based on that point, so that he can be interested and follow and build up his knowledge from there.”
3. Mastering rudimentary interactive skills	“He must know that he shouldn’t get angry so easily”

4. Learning more complicated behaviors drawing recognition from others
 

“Then you appeared queerly so even others want to help you, they don’t know what to do... Really, they can’t understand you... I think his behaviors appear gross to those who don’t know him... You are already disabled, so at least you don’t appear loathsome.”

“(He should learn) if that person is hard to get along, I don’t get messed up with him. If that one is easy-going, I can have more exchanges of words with him... In this way he can be less stressed in the society.”

“Living in this society, you must consider other people’s feelings... being quite when eating out, lining up when shopping in supermarkets, these rules, if he understands and respects, then I dare to bring him anywhere, and he can then live a colorful life.”
5. Developing the initiative to communicate
 

“He spoke with kids of the neighbors for just a while, and then would just play by himself by their side... not matter how small he must make some progresses on this.”

“What we want her to improve most is being able to pay attention to people around and willing to communicate with them”. This is our priority among priorities.
6. Ability to complete basic interactions
 

“It’s not so simple for even an ordinary person to build up friendship. So if only he can deal with some simple relationships, just get the most basic ones, the ones that assist with his life, I feel it’s enough... just passively... like when others ask for something from you, you can make some response and give it to them... at least, you don’t just ignore others... probably in this way you get closer to others. I don’t know.”

“Living in this world, you have to respect what others around you feel, right?... For example, going to toilet at the right places, not make loud and annoying noises in any way, not throwing tantrums at random.”
7. Behaving properly in public
 

“As a human being you must grasp the basics to normally get along with people around, or your behaviors will look weird.”

so relieved. if this doesn't happen, no matter how much money and other stuff you have prepared for him (before you die), you feel very hollow."

9. Being embraced by the society

"The final goal is for the others to learn to somewhat accept him, and respectfully allow him to enjoy his own life, within the same society, under one sky...if they realize this, then no matter where he goes, there's inclusive education...like the X Center for Children with Autism, it's in an urban village, so the farmers in that village never make a fuss about those kids, they are used to them. They won't stare at one of them if he makes some strange noise and then come to ask you why. This way you feel light-hearted because you don't need to always explain. They all think: "This is normal! Autistic children do this. "You feel relieved. This is what I hope our surroundings can be—people know children having autism is like children having a cold, they are just sick. In them there isn't some serious problem, so no one will stare at them. That's all. ...but talking about whether he may or may not have friends, may or may not, like us, establish normal relationship with others as social companions to each other—I do not expect. Because this is exactly what their autism means, autism is a lack of this ability from birth."

10. Allowing their parents to have an easier life

"If he made big improvements in communication, I feel relieved... there won't be a string that's frequently pulled in my heart any more...If he won't always approach others by grabbing their arms and then scaring them, I don't have to explain anytime it happens, right?... Then I can just, although still watching you (her son), only stand by with a light heart, and maybe also chat with others... whenever I want."

11. Ability to address basic daily living needs

"I wish he could communicate with more and clearer language and not speak that fast... And you must know how to buy food and stuff that you need, you must stay well fed, stay warm. That's it."

12. Being able to financially support themselves

"I wish he can be independent....like, I go to work...I can be a janitor... then he can earn some bread for himself...we do not mean that he must work by sitting in offices. There's no such a need.'""



13. Obtaining a feeling of belonging  
 “To have or not have a job won’t matter much to his material life...with the financial efforts made by we as parents...But what does a job mean? It means you are being integrated into the society, that is, you are needed by others, and you need them too, in reciprocity.”
14. Minimal improvement in academics  
 “As long as he is moving upward to approach the level of his classmates...”  
 “I don’t have much high requirements on what he should learn. As long as he progresses as his classmates in the junior class in his daycare. Improving slowly seems enough for me.”
15. Equal or close-to-equal achievement compared with typical peers  
 “I hope that she ends up achieving at a level that’s only a little bit lower than the normal standards, only a little bit.”  
 “(Although he may lag behind a little), but don’t do too much, don’t score much lower than peer students. At least he should get into the upper middle group... You shouldn’t score too low...”
16. Enjoying friendship  
 “It would be the best if he can make good relationship with others around him, get quite close to them, and have fun together.”  
 “I only hope that he can get into an inclusive classroom, sharing with others the joyful atmosphere in their school...to feel the happiness and joy of the other kids. Just to feel what they feel is enough.”  
 “I just wish he had a deeply embedded memory in his experiences of hanging out and doing stuff together with typical kids.”
17. Enjoying some hobbies when alone  
 “Now he can recognize a lot of characters. He is able to read by himself at home. This is an example of his leisure activities. I’m saying, when you grow up, you have to do stuff. While you stay at home, you cannot just idling around without doing anything, right? Then I can simply pick up a book to read. I can read about those I’m interested in if I know the words.”

18. Being happy      “If he spends one or two years in the mainstream elementary school but still find staying there unbearable, I’ll send him there (to a special education school). It works simply if he enjoys learning there instead.”
19. Biggest expectations      “At the time when he was born...I and his mom said to each other: “it’s good enough if only he can live his life happy, joyful and healthy.”  
    “Living a happy, joyful and healthy life”  
    “to communicate with others”  
    “to rub shoulders with typical people around”  
    Being able to stay in mainstream schools  
    “complete his nine-year compulsory education (in general education schools).”
20. Most comforting of the accomplishments of the children      Being accepted--“the whole society approaches these children and take them as a part of it”  
    Being independent--“All meanings in my life will be found if he can stand alone in this world, alive, without relying on others.”  
    Earning honors--“Actually what I’ve just talked about are all just some ordinary hopes for his development. But the pride that I actually long for is he wins the Special Olympics prize... We want him to be a champion. The goal I set for him is at least the champion. That’s to say, he must excel among disabled children... When he learns in general schools, no matter how he tries, he cannot beat the normal children, reach their standards. But he can win in Special Olympics. Understand?”
21. No arbitrary requirements      Sharing feelings with parents--“As parents, every bit of progress makes us happy. But we most want him to understand, for example, love for him from the family. Sometimes when you have spent so much time on him and he can’t share your feelings, I feel upset. Sometimes I foresee in distress, when I grow old, he still ignores me. This feeling is so bitter.”  
    Learn well--“This is what I least expected, so if he all of a sudden get everything, I’ll definitely get a blast of happiness. Because he can move upward is what I wish most.”  
    “(We) have never been insisting that (he) should by all means be able to do something.”

their children

“(If he ends up not talking properly) Doesn’t matter...I think it’s sufficient if he expresses his needs in super simple ways.”

## Appendix 2 Concept Map

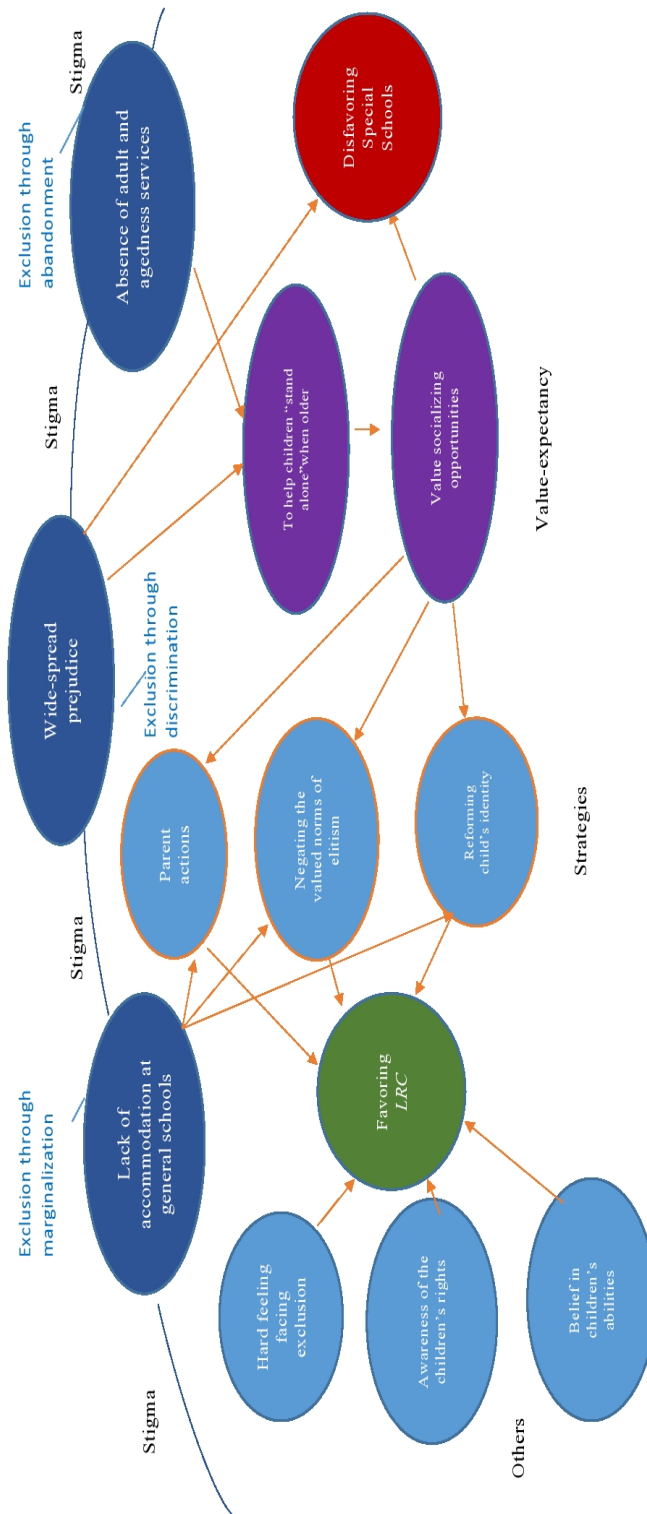


Figure 1 Ecology of parents' preference-forming on Learning in Regular Classrooms (I RC)

### Appendix 3 Interview Protocol

#### [English]

#### **Rapport Building Questions**

1. How old is he/she right now?
2. Could you give me a description of he/she as a child in your eyes?
3. Could you tell me a little bit about how you and your family found out about his/her difficulties at the very beginning?
4. What was the doctor's diagnosing process like?
5. What changes do you think that the diagnosis of his/her problems had brought to your personal life?
6. Could you describe the reactions that the other members of your family gave after knowing his/her diagnosis?
7. How have you and your family discussed his/her future education after his diagnosis?
8. How did you decide to send him/her into this school?
9. Could you describe to me how a typical school day of your child looks like?
10. What are about the current schooling of your children that you feel satisfied with?
11. What are that you do not feel satisfied with?

#### **Grandtour Questions**

12. Have you ever heard of "learning in the regular classrooms" (*suiban jiudu*)? How much do you know about it?
13. How do you know about "learning in the regular classrooms" (*suiban jiudu*)?
14. "Learning in the regular classrooms" (*suiban jiudu*) means that children with disabilities taking classes with their non-disabled peers. They are required to learn the same thing as everyone else, but can probably get some help from special education teachers or other assisting staffs. What is your opinion of this type of education?
15. What are the reasons that make you think this way?
16. The United States makes it illegal for the public schools to reject the students with disabilities. Suppose this law starts to be practiced in China, and the schools in your school are open to take children with disabilities. What choice are you going to make regarding your own children's education?
17. What are the reasons that will make you choose *suiban jiudu*/separated learning for your child?

#### **Minitour Questions**

- 17.1 Let's talk about this reason first (e.g. against inclusion because he does not want his child to be bullied by typically developing peers). What are the unpleasant results that you think might be caused by being bullied (for him as well as the child)?
- 17.2 What behaviors do you count as the bullying of your child?
- 17.3 Can you think of any such experiences related to the bullying of him?
- 17.4 Let us now segway to this other one that you have mentioned as one of the reasons (e.g. for inclusion because he thinks it can benefit the social development of the child). It sounds obviously that you stress social development of him a lot. What are the reasons that make you do it?
- 17.5 What do you think are examples that indicate social development?

17.6 Do you mind also talk about some experiences that you think might related to your thoughts about your child's social development?

17.7 (continue with the same set of questions about the other reasons that parents have mentioned before)

17.8 Just now I heard you talked about several educational outcomes that you are hoping that your child can achieve in an inclusive/a special education setting. Let me put them down one by one on these cards. Among them, what are those that you expect that he is able to achieve more than the others?

17.9 What are the reasons that made you think this way?

17.10 What are those that you think more valuable for his career and his life in the future?

17.11 What are the reasons?

17.12 What are those whose enhancement will make you feel much better than the others?

17.13 Do you mind describing some personal reasons for feeling like this?

17.14 Let's check them again one by one. If your child will be able to achieve every one of them, what do you think might cause the success?

17.15 Just now you also briefly mentioned that there are some educational outcomes that you do not expect your child to achieve. What are the reasons that made you think so for each of them?

18. Let me put all the reasons for the school choice we talked about earlier down on these cards. Now could you please sort them out according to their importance?

19. There could be a broad range of reasons that you wanted to sort them out in this way that we now see. What are the things that are about, e.g. your child, you, your family members, the society, that made you think that they are important, and some of them are important than the others?

20. Now let us talk about one issue that is related to the advantages and disadvantages that you might have thought about when you are making your choices just now.

a. Early on in the interview, I heard you talked about your opinions in your child's current education at separated special education schools. They are what I am now writing down on these cards, if I remember correctly. (If the parent prefers inclusion) Some of them show that there are certain things about the special education school that you actually like. So what have been going on in your mind that still made you think that inclusive education might suit your child more?

Or (if the parents prefers special education schools)

b. Early on in our interview, I heard you mentioned that once you thought about sending your child to regular schools. It looks to me that there are some things about inclusion (*suiban jiudu*) that you liked or even still like. However, you have made it clear that you still hope that he can continue studying in the special education schools. What are the reasons that make you still prefer special education school more than an inclusive one?

21. (If there are some concerns that the parent has not mentioned) (hand him the list of the six major ones) Here is a summary that I made regarding various concerns that parents might show when they are deciding on their placement. Could you please take a look at a couple of these that you did not talk about just now? I totally understand that

they probably do not mean much to you, but just checking whether you have given it a thought for a brief moment early on but forgot to mention them later. I would love to hear your opinions about them, too.

### **[Mandarin]**

#### **(背景问题)**

1. 您的小孩今年多大了？
2. 作为自己的孩子，他/她在您眼里是怎样的一个人？
3. 能告诉我您或者您的家人是怎么发现孩子不对劲的吗？
4. 送到医院确诊的整个过程能大概描述一下吗？
5. 孩子最后的这个诊断，对您个人生活来讲意味着一些什么改变？
6. 能说说知道孩子病情后您还有家里人都有些什么反应吗？
7. 确诊病情之后，在孩子以后的教育上全家人是怎么商量的？
8. 最后是怎样把小朋友送进这所学校的呢？
9. 能描述一下他/她全天的学校生活是什么样的吗？
10. 孩子目前的上学情况您觉得有哪些比较满意的地方？
11. 那些地方比较不满意？

#### **(主要问题)**

12. 你听说过“随班就读”这个说法吗？能大概谈一下您对它的理解吗？
13. 你是怎么知道“随班就读”的？
14. “随班就读”简要的讲就是有残障的小孩子跟其他正常同学在一起上课。学习内容差不多，不过如果条件允许的话，这些小孩子说不定可以有些个别指导或者辅助。你对这种教育模式的看法如何？
15. 美国的教育法有规定，不允许普通学校拒收有残疾的学生。假设这种规定在我们国家也开始实施，你孩子所在的学区里面的学校都严格遵守这个规定，您愿意让自己的孩子随班就读吗？
17. 能谈谈您的这一选择背后都有些什么样的原因呢？

#### **(分问题)**

- 17.1 我们先来谈谈您刚才讲的这个（原因，如：不想随班就读，因为不愿意被普校的同学欺负）。你觉得若是自己的孩子被同学欺负的话，会造成哪些不愉快或者说后果？（分：对他，对您）
- 17.2 在您开来，都有什么样的事情算是被同学欺负呢？
- 17.3 关于被其他小孩欺负的事情，您和您的孩子曾经有过这样的切身经历吗？
- 17.4 咱们再来看看您刚才讲的这个（原因，如：想随班就读，因为对培养孩子的社会性来讲可能比较好）。看得出您比较强调孩子社会性的养成这个方面。有哪些原因让您比较看重这一点呢？
- 17.5 请您再具体的举例说说您提到的这个社会性的养成都包括些什么内容。
- 17.6 在这一方面您都有哪些亲身体会？

17.7... (家长提到的其他原因)

17.8 刚才您讲到您对孩子的自身发展的有几个方面寄予希望。我来把它们都写在这几张卡片上。您觉得他在哪些方面进步的希望比较大？

17.9 您是因为什么这样认为的呢？

17.10 你觉得你的孩子在哪些方面的进步对他今后的发展和生活来讲意义比较大？

17.11 这样想的原因是什么呢？

17.12 您觉得您的孩子在哪些方面的进步能最让你感到欣慰？

17.13 这里面有些什么个人原因吗？

17.14 对于这几个方面，如果孩子能达成您的期望的话，您觉得主要应该归功于哪些因素？

17.15 还有刚才偶然听您提起这几个您不太抱希望的方面，您觉得主要是因为什么让您这样想？

18. 我现在把您刚才所谈到的，选择/不选择随班就读的原因都写在这几张卡片上。现在麻烦你按照它们在您心中的重要性排一下序。

19. 您既然把这几张卡片都依序排好了，我猜肯定有各种各样的原因促使您作出这样的排列。简单假设一下，可能跟您孩子的自身情况、您和您家里人的想法、或者整个社会的看法和趋势都有关系。能告诉我您刚才是怎么想的吗？

20. 现在让我们来谈一谈在选择学校这个问题上的利与弊的衡量问题。

a. 我们在采访刚开始的时候，聊过您孩子目前在特殊教育学校里面的一些情况，您也谈了您的一些感受，主要有这些（也在卡片上写下来）。这个表明您对于特教学校里目前开展的某些做法其实是挺有好感的。是什么原因让您仍然愿意把自己的孩子送到普通学校里去随班就读的呢？

或者（根据家长的最终选择）：

b. 刚才您也提到了您当初想过把孩子送进普通学校的，这说明普通学校对您来讲应该还是有一定的吸引力。但是您目前仍然考虑的是让他继续留在特殊学校就读。能告诉这是出于怎么样的一些考虑呢？

22. (如果在那六个关注点里面，家长有些没有提到的) (递给家长一张单子，上面是那六个关注点) 这个是对目前家长关切的各种问题的一个简单总结。请您看一看这几个刚才您没有谈的，不知道您有没有想过它们？虽然它们可能在您刚才提到的各种考虑中不占什么比重，但我还是很想听听您的想法。



#### Appendix 4 Demographic Information

Table 2. *Demographic Information of the Participants' Children*

		Beijing (person s)	Chengdu (persons)
		8	8
General elementary schools		3	3
(in LRC)		(0)	(3)
General daycares		3	4
Rehabilitation agencies		2	1
Disabilities	Autism	8	5
	Intellectual Disability	0	3