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Caregivers of Intellectually Disabled Children: A Qualitative Study of Caregivers' Perceptions on Educational Services in Developing Areas of China

Xinqian (Nancy) Jiang

MSc Research Design and Methodology

Word Count: 16,980

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Abstract

This research was of concern to the fields of inclusive education and educational equity, specifically investigating caregivers' perceptions of educational services for their intellectually disabled children in China. The study adopted a constructivist perspective that emphasised the diversity of perceptions and self-constructed understanding of reality as an important information source to learn the social phenomenon. By employing Bourdieu's concepts of field, habitus and capital, an in-depth understanding of the educational inequality and segregation towards children with intellectual disabilities (ID) was acquired within developing areas of China. Through the use of semi-structured interviews, the study collected perceptions from a purposive sample group of 19 caregivers whose children receive different types of primary education in a prefecture of Henan province. The results showed that almost all the caregivers experienced a challenging process in seeking appropriate education for their children due to limited schooling opportunities, scarcity of educational support, and public stigmas towards disability. These results suggest that the children with ID were disadvantaged in accessing, and benefitting from, formal education, despite their caregivers having sacrificed excessive family capital to improve the situation. Thus, these children and their families require more social support and public awareness to participate in schools and even in society. Caregivers' perceptions should be taken into account as an indicator of the accessibility and quality of education for future service implementation and improvement.

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List of Abbreviations

ASD	Autism Spectrum Disorders
CDPF	China Disabled Persons Federation
GDP	Gross Domestic Products
ID	Intellectual disabilities
LRC	Learning in Regular Classrooms
SES	Socio-economic Status

Chapter 1: Introduction

Historically, children with disabilities, across cultures, have been deprived of the education right (Calderon-Almendros, 2018; Cui, 2016; Kluth et al., 2007; Singal, 2016). Despite the United Nation's call for equal access to quality education for all children by 2030, there is still a huge population of school-age children with disabilities who remain out of formal education, especially in developing countries (World Bank, 2017). The over-emphasis of academic success in institutionalised education has often overlooked the needs of disabled children (Reindal, 2021; Runswick-Cole, 2008). Pring (2012) forwarded criticism in this regard, stating that "target-setting culture" in schools meant that no educational opportunities were provided to children who are considered as "ineducable" to develop their capacities. He advocates that education should nurture the capacities of a fully human life and respect what it means to be and to grow as a person, especially in the field of special education (Pring, 2012). The ultimate goal of education should be enabling individuals to achieve a valued way of living (Hart, 2019). For children with ID, rehabilitation intervention is part of education, due to its effects on improving one's cognitive and learning abilities (Reindal, 2021). Meanwhile, the majority of existing research on special and inclusive education has been conducted in socio-cultural and political contexts other than China. The unique features embodied in Chinese culture related to disability, education, and parenting may cast new light on understanding special and inclusive education implemented around the world.

1.1 Chinese Context

Educating children with disabilities as a complicated initiative has achieved limited progress in China due to the fact that the country has the largest disabled population in the world (Jiang et al., 2013). According to the China Disabled Persons' Federation (CDPF) (2012), more than 85 million people were identified as disabled in China by 2010, which is more than the total population of the UK. Although the Chinese economy has roared in the past few decades and has overtaken Japan as the world's second-largest economy since 2010, its Gross Domestic Products

(GDP) per capita was only $10,276 in 2019, giving it a ranking of 65th in the world (World Bank, 2020). It was still below the world average GDP per capita ($11,460). Moreover, China is an economically unequal country: its Gini Coefficient was as high as 0.61 in 2010, which is much higher than the world average (0.44) (World Bank, 2020). Despite the economic prosperity in metropolitan cities and developed areas, many families in rural developing areas still live in poverty. However, the majority of disabled people (81.7%) live in these areas of the country (CDPF, 2012).

According to the national survey conducted in 2006, in that year there were over 7 million school-aged children (years 6 to14) registered as being disabled (Deng & Holdsworth, 2007). ID, as one of the three main types of disabilities, accounts for 70% of all disabilities among children in China (CDPF, 2012). ID is defined as "a group of conditions of arrested development of mind", such as Autism Spectrum Disorders (ASD), Down's syndrome, and cerebral palsy (CDPF, 2006). ID is characterised by subnormality of intelligence and impairments in social adaptive ability, although it is narrowly diagnosed by an IQ<70 (Wang, 2009, p.72). It is often referred to as "mental retardation" in China (Wu et al., 2010). Zhang and Ji (2005) reported that up to 84% of children with ID had never received services such as rehabilitation training or community-based care. There were many unattended needs in terms of educational services for these children and their families, especially in developing areas where the services are limited. Therefore, it is worthwhile investigating the accessibility of education services for children with ID in developing areas.

1.2 Special and Inclusive Education

Unlike western parents' legitimated right to make schooling decisions for their children, Chinese parents have not, thus far, had this luxury, since China prohibits parental selection of schools (Chen, 2016; Li, 2009). School placements are mandatorily assigned based on the Hukou system (enrolment at neighbourhood schools according to registered residence) (Holt, 2019). It was designed to minimise the school selection or exclusion of students based on their intelligence or social classes (Holt, 2019). Indeed, it is felt that school segregating based on intelligence undermines sense of dignity and

personal wellbeing (Pring, 2012). However, the current educational services for children with ID are still determined by the nature and severity of their disabilities. There are three schooling options which serve children with mild to severe levels of ID: the Learning in Regular Classroom (LRC) programme within mainstream schools; special schools; and remote learning at home (Huang, 2019). Research shows that children with disabilities have significantly higher rejection rates (Li et al., 2021), lower graduation rates (Dong et al., 2017) and fewer years of education (Cui, 2016) than typically-developing students, even at the primary school level.

1.2.1 The LRC Programme

The LRC programme is the Chinese practice of western inclusive education which has been modified to fit into Chinese society and is used to educate children with mild to moderate levels of disabilities in a mainstream classroom (Foster & Pearson, 2012). The LRC programme differs from western inclusive education in terms of its lack of tailored support in mainstream classrooms, because it was designed to compensate for the shortage of special schools and special education teachers in China (Deng & Holdsworth, 2007; Deng & Zhu, 2016). Physical integration of students with ID into mainstream classrooms does not guarantee true inclusion (Brown et al., 2011). Therefore, it has often been criticised as a pragmatic strategy for placing more children into education (Deng & Poon-McBrayer, 2012). Zhao et al. (2021) suggested, based on their findings, that Chinese parents of children with ID have the lowest satisfaction with the quality of the LRC programme compared to other types of disabilities, because their children's needs are often unattended. Although the Compulsory Education Act (1986) stated that every school-aged child has the right to receive free education for at least 9 years, previous studies suggested that there was a gap between policy documentation and real practice (Cui, 2016; Huang, 2019). Schools prefer students with the potential to achieve high academic attainment and who do not place a large demand on resources (Runswick-Cole, 2008). Indeed, disabled children require a significant amount of educational support and resources, meaning that they become unattractive candidates for school enrolment (Lunt et al., 1994). As a result, 28% of children with disabilities experienced school rejection in 2017 (Su et al., 2020). Only children who have proved that they are capable of sitting quietly and learning effectively can be enrolled

in the LRC programme (Dong et al., 2017).

1.2.2 Special Education

According to policy, children with moderate to severe disabilities should be allocated to a designated special school. However, not all disabled children enjoy equal access to special education. Receiving special education may be limited by where they live, the cost of getting to school, and school provisions. As of 2019, there are a total of 2,107 special schools serving all school-aged children with disabilities in China (National Bureau of Statistics, 2019). Despite the fact that the majority of disabled people live in rural developing areas, special schools are mainly located in urban developed areas. Therefore, special schools are not accessible for children in developing areas (Wang & Michaels, 2010). Moreover, the quality of special education is also of concern. Each special education class has over ten students, with a variety of diagnoses, supervised by only one teacher. The high student-teacher ratio has resulted from a lack of qualified teaching staff (Yu et al., 2011).

1.2.3 Home Education

This three-tier educational system is criticised for differentiating children's capacity to provide education (Lim, 2020). The real educational context for children with ID is possibly even worse than documented. Many children with ID in developing areas have access to neither a well-supported inclusive education nor a well-functioning special education in their local areas. They depend on their families to survive and develop (Yang et al., 2016). It was reported that approximately 36% of the school-aged children with disabilities did not receive any formal education in 2008 (National Bureau of Statistics of China, 2009). However, Su et al. (2021) suggested that this estimate of the excluded population of disabled children was larger than the official statistics reported.

To conclude, the current education system is not well established for children with ID in China, since there are no perfect schooling options available to them. They may encounter social stigmas or inappropriate treatments respectively, despite being sent to mainstream schools or special schools. Therefore, there is an urgent need to improve the current services based on the perceived difficulties in educational processes.

1.3 The Caregivers' Roles

Parents have an inborn aim to raise their child to be cognitively, emotionally, and socially competent (September et al., 2015). However, the role of parents is more vital and complex in facing difficulty when it comes to accessing quality education (Hu et al., 2019). Hence, understanding parents' perceptions and experiences in connection with accessing education services could be a key source of information for service improvement in China (Shang et al., 2011).

1.3.1 Gender Difference

Due to the patriarchal nature of the traditional Chinese culture, a female family member, usually the mother, tends to sacrifice her work, social activities and personal leisure to look after the disabled child (Chou et al., 2009; Gau et al., 2012; Yang et al., 2016). However, the child-caring task requires full-time devotion, including the schooling days, when the family member must serve as an aide to the child in the classroom (Wang, 2011; Alshatti et al., 2021). Therefore, many caregivers live under psychological stress, thus increasing their risk of poor mental health outcomes, including depression (Findler, 2014; Li et al., 2012; Wang et al., 2010). In contrast, fathers have traditionally occupied the roles of "family disciplinarians" and "financial providers", and thus they have been participating less in child-caring than the mothers (Ho et al., 2010). Wang et al. (2011) argued that Chinese mothers tend to perceive more child-related problems than fathers in families of children with disabilities. However, it is suggested that fathers and mothers may have different perceptions of child education due to their distinct roles in caregiving (Hu, 2020).

1.3.2 Grandparents' Commitment

Chinese society is an ethics-orientated society where people are bonded by different kinds of obligations and ethical relations (Liang, 2005). According to Confucian teaching, family members should take care of each other as a unit without expecting equal rewards (Zhang & Rosen, 2018). The extended families, especially grandparents, often share the responsibility of child-caring with parents (Wang, 2009; Wang & Michaels, 2010). Previous research found that grandparents often provide physical, financial and emotional support to the parents of children with disabilities (Huang et al., 2020; La Valle, 2013). Given the significant grandparents'

involvement in child-caring, this study invited parents and grandparents who identified themselves as the primary caregivers of their child with ID at home in order to trace a more comprehensive understanding of these children's educational process.

In conclusion, caregivers significantly contribute to, and participate in, their children's educational processes. They provide a unique perspective as they may view the challenges of education services through the lens of the direct impact on their child's development in daily life. Further, they may offer insights into the interactions between the perceived effectiveness of services and the capital which the family has invested for their child's education.

1.4 Theoretical Framework

Pierre Bourdieu's social and cultural reproduction theory is one of the most prominent attempts to facilitate a more finely-grained explanation of social inequality, and contains three main concepts, namely capital, habitus and field (Edgerton & Roberts, 2014). Limited studies have employed these concepts to explain the segregation and equity in special and inclusive education (Li, 2013; Zhao et al., 2021; Trainor, 2010). Therefore, this paper takes forward past debates by examining the intersection of educational opportunity and family capital in the primary-education-level segregations of children with ID within the Chinese context.

Capital. Economic, cultural and social capital can be exchanged for access to power and privileges within specific fields (Bourdieu, 1984). One's educational opportunities and experiences are shaped by his/her stock of capital (Molla & Pham, 2019). Children from more affluent and educated families are more likely to enrol in the "best" education institutes, regardless of their capability (Holt et al., 2019).

Habitus. Habitus is defined as "a set of dispositions" including a "tendency", "propensity" or "inclination" through which one perceives the social world (Edgerton et al., 2012, p.214). It is explained as subjectivity conditioned by structural circumstances (Sullivan, 2002). The mutual relationships between habitus and capital are that the habitus affects one's acquisition and use of capital; the availability of capital shapes the formation of one's habitus (Abel & Frohlich, 2012). In this case, the shared culture of reservation towards inclusion might influence the parents' perceptions about placement options and the quality of the educational

provision offered to their child (Correia et al., 2021; Ng & Kwan, 2020).

Field. The field refers to "the objective rules of the game", which are pre-existing (Li, 2013). It could pertain to political, social, or symbolic institutions where social rules and positions of agents are located such as the family, law, and education (DiGiorgio, 2009; Macaulay et al., 2016). For example, educational institutions select students based on their stock of capital, which prevents disadvantaged students from being able to access quality education (Molla & Pham, 2019).

1.5 Research Questions

Equal access to education is a universal child right which respects human diversity. Previous studies regarding the actualisation of this initiative mainly focused on economic-developed areas in China, since those areas have made obvious progression in recent decades. So far, little is known about the accessibility and quality of education services in developing areas, although it has been suggested that it is more challenging to access services in such areas. Therefore, it would be vital to examine the situation through caregivers' relevant perceptions and experiences, which might shed light on the circumstances in other developing areas. This research aims to better understand the difficulties that hinder children with ID and their families in receiving appropriate educational services. Therefore, two research questions inspired by Bourdieu's concepts of habitus and capital were addressed as follows:

RQ 1: How do caregivers perceive and react to challenges in effectively accessing educational services in developing areas of China?

RQ2: How does raising a child with ID affect one's family capital (e.g. social, economic and cultural capital) in China?

1.6 Dissertation Outline

Following this chapter, the remaining part of the present dissertation is divided as follows. Chapter 2 reviews the existing relevant literature on the research topic. Chapter 3 introduces the methodology adopted by this study, touching upon research design, research method, participants, ethical considerations, data collection, and analysis, as well as the

trustworthiness of this project. The research findings are presented as themes to answer the two research questions in Chapter 4, following which Chapter 5 discusses the findings of the study while referring to the results from previous work. Finally, Chapter 6 provides concluding remarks, limitations of the current study, and recommendations for further research.

Chapter 2: Literature Review

This chapter reviews the previous research relevant to the present study. It is organised into three main themes: the unfavourable socio-cultural context, the geographical disparity of education services, and the role of family capital in the educational process.

2.1 Unfavourable Socio-Cultural Context

The socio-cultural context is identified as one of the most critical factors determining the accessibility and quality of education for students with disabilities (Han et al., 2021). There has been a widely agreed principle that issues related to social services should be bonded with a context-specific interpretation (Diken, 2006). According to previous cross-cultural studies in this area, it is suspected that segregation and discrimination towards ID are more common in the Chinese context, because the country's traditional values have been heavily influenced by meritocracy and collectivism (Shulman, 2015; Werner et al., 2012). Thus, the attitudes and practices of key stakeholders are shaped by these cultural values and social norms in disabled children's educational processes (Diken, 2006).

2.1.1 Cultural Stigma towards Disability

Chinese families not only face financial and psychological burdens in child-caring, but also have to deal with stigma towards disability (Chiu et al., 2012). The Chinese culture heavily emphasises individuals' social identities and social conformity (Huang et al., 2020). Academic success is always seen as a child's obligations to the Chinese family (Chao, 2020). Children with ID often fail to fulfil the obligations of their social identity and violate social norms in many domains (Fung et al., 2007; Poon-McBrayer & McBrayer, 2014). Therefore, widespread discrimination against ID in China may initiate unfair restrictions on the social life of these disabled individuals and their families (Chiu et al., 2015). Traditionally, a child's failures are taken as family failures, as can be seen in the following Chinese saying: "if you see the son has no prospects [i.e. is good for nothing], then there is no need to respect the father" (Chao, 2020; Mak & Cheung, 2008). Having a child with ID may weaken the family's social network and affect their social status and relationships within the larger social circles (Chiu et al., 2012; McCabe, 2007). Therefore, Chinese families are often unwilling to disclose their child's ID

diagnosis to their communities or seek external support (Huang et al., 2011; Rohde-Brown & Frain, 2013; Wang, 2009). The diagnosis of ID may imply that the child's biological roots are contaminated and the family's genetic value is reduced (Chiu et al., 2012). Some people may even superstitiously view one's disability as a punishment for his/her ancestor's misbehaviour (Rhode-Brown & Frain, 2013; Wang et al., 2011).

These traditional cultural beliefs contribute to a great sense of shame, guilt and despair for the child's parents (Pan & Ye, 2015; Chiu et al., 2015). The internalisation of cultural stigmas may also influence parents' perceptions of schooling options (Mak & Kwok, 2010). In this case, special education often suffers more from negative labels and discrimination from the public, creating barriers for meaningful participation of the disabled and their families (Hess et al., 2006). To avoid the label of being "othered", some parents insist on sending their children to mainstream schools, since they feel that having children in special schools leads to the loss of a sense of being "normal", and they continually suffer from such loss (Runswick-Cole, 2008). Previous studies presented that some parents tended to emphasise their child's "normality" and highlight their child's progression or achievements (Dickinson, 2018; Su et al., 2017; Wong et al., 2015) They viewed inclusion as an opportunity for them to stretch their child's learning potential. Due to the culturally situated stigmas, the LRC programme in mainstream schools is still the dominant choice made by Chinese parents (Su et al., 2020).

2.1.2 Unsupportive Social Environment

Public attitudes towards inclusion affect the disabled children's development and serve as a moral compass of the society (Babik & Gardner, 2021). The unsupportive social environment towards disability in China hinders the implementation of inclusive and special education, especially stakeholders' attitudes and practice towards inclusion in and out of schools (Wang et al., 2015). In Hu and Roberts's (2011) study, the school administrators indicated that Chinese society does not support the inclusion in schools. Teachers' fundamental attitude towards inclusion, regarded as the most decisive factor for successful inclusive education, was lacking (Deng et al., 2017). They were sympathetic to children with ID but were reluctant to have them in their classrooms (Hu & Roberts, 2011; Deng & Holdsworth, 2007). A more recent survey of attitudes towards

inclusion also demonstrated that the classroom teachers held the least favourable attitudes among all key stakeholders, including educational psychologists, parents and administrators (Su et al., 2020). They often harboured significantly lower educational expectations for adolescents labelled with ID, which prevented these children from achieving a high academic level (Shifter, 2013; Wong et al., 2015). The above finding was confirmed by Yan et al.'s (2021) large-scale teacher survey regarding the progression of children with ID in inclusive schools, which showed that teachers only perceived the disabled students as gaining significantly in terms of social and life skills domains, but minimally improving in terms of their academic performance. Qu (2019) further investigated teachers' perception of inclusion through in-depth interviews and found that the LRC programme was all about enrolment and physical attendance in teachers' eyes, without any intentions to provide any additional support to meet disabled children's needs. This kind of mere physical integration was criticised as one of the most dishonest and insidious forms of exclusion (Qu, 2019). The unsupportive teachers' attitudes mean that many disabled children's needs are unattended in mainstream classrooms. Numerous caregivers stated that such inclusion was "a general disillusionment with integration" (Jenkinson, 1998, p.195).

Social conformity is a part of the collectivist norm which guides one's attitudes and interactions within the society. Chinese caregivers' perception of the social environment and key stakeholders' orientation towards inclusion affect their value judgements of schooling options (Lui et al., 2015). The unsupportive school climate explains Leyser and Kirk's (2004) finding that parents whose children studied in mainstream schools were less optimistic towards inclusion than their counterparts whose children studied in completely secluded settings. Furthermore, Deng and Holdsworth (2007) found that parents doubted the use of education for their child with ID, while they also had concerns of being bullied or discriminated against in schools. Wong et al. (2015) discovered that some parents also had a low academic expectation for their children and accepted their child's ID as a cap on their academic potential which departs from the conformity to "normalisation" due to the teachers' influences. As a result, the caregivers place emphasis on the child's physical wellbeing in schools, as they well acknowledge the benefits of exercise for

their child's development (Yang et al., 2020). They hold schools responsible for promoting physical wellbeing through safe and stimulating opportunities for children with disabilities (Stanton-Chapman & Schmidt, 2017). However, Chinese schools often restrict children with disabilities' opportunities and their broader participation in the everyday routines of school (Chen et al., 2006; Wong et al., 2013; Shields et al., 2011; Srinivasan et al., 2014; Steven & Wurf, 2020).

2.1.3 Research Gap

A closer look into the Chinese socio-cultural context towards disability and inclusion in the studies mentioned above reveals that researchers have often demonstrated the impacts of raising a child with disability in an unsupportive social climate, but have failed to thoroughly investigate how these impacts are embodied in individuals' daily schooling experiences. A deeper understanding of caregivers' perceptions and individual coping strategies when it comes to their encountered difficulties in accessing education is required for service improvement adequate to their needs.

So far, only a few studies have focused on these children's lived experiences, and were mainly conducted with participants from economically-developed areas, such as Beijing and Shanghai (Ellsworth & Zhang, 2007), Hong Kong and Guangzhou (Wang & Michaels, 2010), and Chengdu (Chen, 2016). However, limited research has focused on developing areas, where it is difficult to reach these children and their families, especially when they are unable to access external support in any form. As Wang and Michaels (2010) suggested, including caregivers from developing areas would provide a more comprehensive understanding of Chinese families' needs and difficulties in the process of educating their child with ID. By doing so, researchers would unmute the difficulties and needs of this underrepresented population and advocate for more public attention and action, which is one of the aims of this study.

2.2 Geographical Disparity of Education Services

Previous research suggested that the availability of resources and teachers' expertise in special education are key to the success of inclusion (Deng & Holdsworth, 2007). However, these domains are of concern in China, especially in developing areas (Fu et al., 2020; Wang &

Mu, 2014).

2.2.1 Access to Education

Much research has demonstrated that a geographical disparity of educational resources remains a prominent issue in China (Deng & Holdworth, 2008; Liu et al., 2020). The statistics also confirmed the geographical disparity, where the enrolment rate of children with disabilities in eastern provinces could be 27% higher than in western and central provinces (Li et al., 2021). Deng and Holdsworth (2007) investigated the educational services for children with disabilities within four poor counties in west China. There were neither special schools nor government-supported education/rehabilitation programmes available for children with disabilities in these areas. The educators did not recognise the necessity of educating such children, since compulsory education was not prevalent for every typically-developing child in the local area. Within a relatively more developed area, Correia et al. (2021) surveyed 115 parents in relation to their experience of finding a school placement for their child with a disability, and only 11 of them described the process as easy, whereas the majority of them said it was very difficult. Similarly, McCabe's (2007) parental interview study also suggested that Chinese parents of children with autism had difficulty in finding their child a school placement. Despite the scarcity of educational resources in rural areas, Deng (2008) produced contradictory results following a large-sample teacher survey, i.e. that teachers in rural areas were more positive towards inclusion than the urban ones. Deng (2008) explained that this notable difference is caused by low academic stress in rural schools. Based on said finding, children with ID in rural areas may encounter fewer challenges when it comes to accessing formal education. However, future studies are required in order to verify the assumption of accessibility in rural areas of China.

2.2.2 Inadequate Teaching Expertise

Lack of qualified special education teachers is a challenge threatening the quality of education (Han et al., 2021). The distribution of special education teachers has been found to be uneven among schools in urban and rural areas (Boe et al., 2013). The majority of qualified special education teachers plan to teach in high-achieving schools in developed cities because of the higher salary and adequacy of educational resources (Wang & Gao, 2013). In contrast, special education teachers in rural areas often face lower salaries, heavy workloads and vague

teaching commitment (Li et al., 2021). Due to the uneven distribution of expertise among teachers, caregivers' satisfaction with education services also varies according to their area of residence. Liu's (2016) parental survey revealed that parents of children with disabilities had high satisfaction with the education received in Shanghai, especially with the school facilities, the school climates, and teachers' proficiency. A lack of expertise in special education among teachers is often reported in rural developing areas of China (Han et al., 2021). In Yang et al.'s (2016) study, caregivers in Henan province complained of a lack of professional support available in their local community.

However, Deng et al. (2017) indicated that even urban schools do not provide all teachers with special education training. Their survey showed that over half of all surveyed mainstream teachers did not receive special education training in Beijing, which is considered to have the most qualified teaching forces in the country. Therefore, the ratio of special education training might be even lower in other areas. Many untrained teachers indicated that they often have difficulties in differentiating instruction and handling behavioural problems of children with disabilities (Deng et al., 2017; Deng & Poon-McBrayer, 2012; Feng, 2010). Parents perceived the lack of expertise in mainstream classrooms where their child's special needs were not well identified, evaluated, or accommodated (Dong et al., 2017). Loss of parental confidence in the LRC programme's expertise leads to reduced enrolment rate, early drop-out and high transferring rates. As the National Education Statistics established by the Ministry of Education (2020) show, the enrolment rate of the LRC programme decreased from 63.4% in 2004 to 49.15% in 2019.

Given the lack of quantity and expertise of special education teachers, parents are given the role of their child's central teacher figure in developing areas (Shen et al., 2008, Zhu, 2017). In Wang et al.'s (2015) large-scale teacher survey, the parental contribution was considered one of the primary support sources in educating children with disabilities. Zhu (2017) suggested, based on findings, that parents of children with disabilities more actively support teachers' work in school and recognise the importance of their involvement in their child's education. Children with emotional issues, problematic behaviours or low independence may require a parent or nanny to full-timely accompany them to school. Parental accompaniment has become a heated

social phenomenon that brings about controversy (Dong et al., 2017; Zhu, 2017). It has often been criticised as a source of distraction by other typically-developing children's parents in the classroom (Zhu, 2017).

2.2.3 Research Gap (2)

With regard to previous studies regarding the quality and accessibility of educational services, the most common approach was to only ask caregivers about their experiences and perceptions regarding the specific schooling option that their children were studying in, without asking about their overall experiences in seeking appropriate education and their perceptions of other schooling options. Therefore, the findings on the accessibility of educational services may be positively biased because of successful enrolment. In contrast, those who are rejected or expelled by inclusive or special schools may have different perceptions regarding the accessibility of the educational services. A more comprehensive understanding of the encountered difficulties in accessing education services is required, and this calls for the recruitment of participants from a variety of schooling options. So far, there appear to only be a few qualitative studies that include the school rejection experiences of children with ID studying in home education. Thus, the present study attempted to address this issue with a more comprehensive sample group from all types of education.

2.3 Family Capital in Accessing Education

Sacrifice is a way to show love in Chinese culture (McCabe, 2007). Parents often dedicate a significant amount of time, effort, and money to ameliorating their children's difficulties once their child is diagnosed as disabled (Lu et al., 2018; McCabe, 2007). Their possession of capital influences their child's access to education.

2.3.1 Social Capital

Despite the prohibition of parental selection of schools in China, social connections could give students an advantage when it comes to admission to key schools (Li, 2009; Gindi, 2020; Wu, 2012). McCabe (2003) reported that many children with disabilities attended mainstream education through personal connections. Otherwise, they would find it impossible to be enrolled. Social capital is not limited to obtaining school placements, but also the helpful information

gained through relationships. Cai (2016) found that Chinese parents collected school information through various means, 67.45% through social connections, 11.12% through the school website, and 9.65% through connections with other children's teachers. Moreover, Trainor (2010) also confirmed that relationships with professionals, educators and administrators help acquire child diagnosis and education information. On the other hand, some studies suggested a high prevalence of social isolation among caregivers, since they were stuck in the extensive caregiving responsibility and feared discrimination towards disability in public exposures (Shang et al., 2009; Yang et al., 2016). Thus, many caregivers might seek psychological comforting by building connections with members of parental support groups who are in similar disadvantaged positions. However, limited studies have investigated the relationship between social capital and educating a child with ID.

2.3.2 Economic Capital

Financial wellbeing is considered one of the most prominent factors affecting family quality of life across different socio-cultural contexts (Rillotta et al., 2012; Hu et al., 2012). Research has shown that financial hardships often haunt families of children with disabilities, especially those living in rural developing areas (Li, 2013). Following a comparison of survey results between two groups, Xiong et al. (2011) suggested that parents with disabled children have heavier economic burdens than typically-developing families. More specifically, parents of children with ID, especially ASD, spend significantly more on child rehabilitation and education than do parents of children with other types of disabilities. Children could receive better education and intervention if their parents are willing and able to pay high tuition fees (Lan, 2003). Those living in financial hardship are less likely to receive appropriate education. Gindi (2020) reviewed the student records of 210 Israeli students with disabilities and found that special schools had more students on low socio-economic status (SES) than did mainstream schools. The review suggested that families with sufficient economic capital are more likely to acquire the educational opportunity they prefer. Similarly, He et al. (2018) found a strong association between SES and the utilisation of rehabilitation. However, the strength of the association becomes weaker as the government increases its financial support to people with low SES in accessing rehabilitation services. As a result, the utilisation rate of rehabilitation

increased from 10.7% in 2007 to 33.7% in 2013 based on a nationwide survey in China.

2.3.3 Cultural Capital

As financial barriers of attending educational services have been gradually removed by the government, the importance of cultural resources has increased over time (Sullivan, 2002). Previous research confirmed that caregivers' understanding of their child's conditions affected their access to education services, involvement in schooling activities, and school support expectations (Wong et al., 2015; Jæger, 2009). Consequently, having limited parental knowledge often leads to delays in diagnosis (Alshatti et al., 2021), violent parenting (Shang et al., 2009), obedience of schools' decisions regarding their child's education, and no expectations of additional support (Wong et al., 2015). Correia et al.'s (2021) parental survey in Macau reported that parents were not receiving sufficient school information in decision-making for their children's schooling before the enrolment and did not receive assessment feedback from the teachers during their children's studies. Yan (2012) found inconsistent parental attitudes towards the LRC programme through surveys, thus reflecting that parents lack a clear perception towards different schooling options. They were not satisfied with the current services but did not know what to expect, since the LRC is the only alternative besides special education, the latter of which is considered stigmatised. Therefore, they have inconsistent and even contradictory attitudes towards the LRC programme. Conversely, caregivers with certain levels of knowledge are more determinate about their child's educational path and more confident in requiring school support (Wong et al., 2015). They may be more motivated to gain certain educational opportunities and strive to remove barriers for their child in schools. Consequently, their involvements are more meaningful for their child's development. However, contrary findings suggested that educational level is not a significant factor mediating parents' participation in schools, but the severity and nature of their child's disability predicted their behaviours (Wang & Zou, 2019).

2.3.4 Research Gap (3)

Although Bourdieu's concepts have often been used in studies addressing the segregation and equity in mainstream education for typically-developing students, limited studies have employed them in special education. Family's sacrifice of capital has become more important in

areas where the social services and support systems for disability are not well-established. Previous studies have separately mentioned the effects of different types of capital on caregivers' experiences, but rarely summarised the uses of all three kinds of capital with the same group of participants in their child's educational process.

Chapter 3: Methodology

This section explains the rationale for the overall design of the study. It includes (1) the philosophical assumptions of the study; (2) the selecting rationale of a qualitative design and semi-structured interviewing method; (3) the characteristics of samples and the research context; (4) the ethical considerations; (5) the procedures of data collection; (6) data analysis and (7) trustworthiness.

3.1 Philosophical Assumptions

The underlying philosophical assumption of the study was situated on the paradigm of social constructivism, which builds knowledge based on one's interaction with his/her world (Crotty, 1998). Every interpretation of participants' perceptions and behaviours should be made according to the situated context, since their experiences are "socially produced and reproduced rather than inhering within individuals" (Braun & Clarke, 2006, p.81). The ontological assumption of the study was in alignment with "idealism", which holds that reality is made up of subjective interpretation and socially produced representation (Guba & Lincoln, 1982). In this case, the reality of the educational services was perceived to lie in caregivers' expression of their own experiences and evaluation based on their values. Constructionism is not entirely subjective but attempts to theorise the surrounding contexts and structural conditions so that individual description can be provided. The present study attempted to examine caregivers' interaction with educational services and their meaning to their child's schooling.

3.2 Research Design

The research design connects the research question with the research data (Punch & Oancea, 2014). Because of the exploratory nature of the research questions, the present study used a qualitative research design comprised of the conducting of semi-structured interviews as the research method. As a "naturalistic inquiry", qualitative research has the advantages of gaining in-depth subjective description and understanding phenomena that

participants bring up in natural settings (Denzin & Lincoln, 2005; Lincoln & Guba, 1985). In addition, this design allowed for an in-depth exploration of caregivers' perceptions and coping behaviours of the challenges encountered in accessing educational services based on their previous experience.

Although the quantitative design has benefits of high generalisability due to large sample size, standardised measures and statistical analysis, it is limited in presenting caregivers' complex and even conflicted attitudes towards current educational services, as suggested by previous studies (Leyser & Kirk, 2004; Jenkinson, 1998). Furthermore, given that perceptions are dynamic and multi-faceted, research with a qualitative design enables participants with a voice to emerge and resonate their experiences, viewpoints, and feelings within their specific socio-cultural context (Hay, 2000). As such, it was decided to adopt the qualitative design, which would extend our understanding of this topic.

3.3 Research Method

The semi-structured interview approach was chosen because it has attractive features of being unrestricted and flexible in accessing the insights of caregivers' perceptions and lived experiences, while other designs may not be structured to do so (Pichard & Swezey, 2016). The in-built flexibility of the semi-structured interviewing method makes it possible to investigate further by adjusting interview questions in real-time (Silverman, 2021). It also enables researchers to learn about the authentic accounts of subjective experience, which allows for spontaneity to emerge during the interview (Silverman, 2021). It respects the uniqueness of each individual's context and his/her context-specific interpretation.

The individual interviews offer an inclusive environment in which it is possible for the participants to disclose more personal perceptions about sensitive topics, including experiences with discrimination, attitudes towards disability, and negative feelings of "being different" than participants in the focus groups (Kruger et al., 2019; Guest et al., 2017). As a result, individual interviews also have another benefit, i.e. reaching

theoretical saturation with fewer participants (Namey et al., 2016). At the same time, a focus group inhibits comments that may be perceived as violating the social norms.

3.4 Research Context

This study is set in Henan province, characterised as a developing area in previous studies (Huang & Zhang, 2019; Yang et al., 2016). Huang and Zhang (2019) assessed the quality of special education based on indicators such as proportion of pupils, the student-teacher ratio, the average area occupied per student, educational resources, and so on. They found that Henan was ranked 15th among all 31 provinces and municipalities in China. It was suggested that Henan is considered as relatively developing but not the most undeveloped area in terms of the development of special education.

Henan province is geographically located in central China between the eastern coast and western inland provinces. Henan's economy relies on agriculture and manufacturing, with a GDP per capita of approximately $6,000 below the national and the world average. As the birthplace of Chinese culture, Henan was heavily influenced by the values of traditional culture. According to the 7th national population census, there were 99.36 million permanent residents living there in 2020 (National Bureau of Statistics, 2021).

The city of Jiaozuo, as a prefecture in Henan province, had 3.54 million permanent residents in 2010, which is more than double the population of Birmingham (1.14 million in 2018) – the second most populous city in the UK (National Bureau of Statistics, 2012; Birmingham City Council, 2019). However, Jiaozuo is only considered a small, developing city considering the total Chinese population. There are only two government-funded special schools which provide 9-year compulsory education for children with disability. No official summary of mainstream schools operating the LRC programme has been established. Therefore, the enrolment conditions are individualised according to the child's condition and his/her family's capital.

3.5 Accessing and Sampling

3.5.1 Access

Firstly, the researcher initially contacted the administrator of a child rehabilitation centre through its official social media page and arranged a meeting to introduce this research project and the recruitment plan. Subsequently, the administrator agreed to provide necessary support with the participant recruitment and data collection phrases. Next, the study recruitment information was posted on the social media page of the child rehabilitation centre. Finally, if caregivers indicated that they were interested in participating in the study, the administrator contacted them with dates and made the arrangements for attendance. The interview schedule was settled in advance of the data collection.

3.5.2 Sampling Method

The purposive sampling method was used in recruiting participants for this study, so as to increase the scope of data, as this would uncover multiple realities. A maximum variation sampling approach was employed to maximise the diversity of reported experiences (Ryan & Quinlan, 2017). Therefore, the study invited caregivers of children attending a variety of educational settings, namely mainstream schools, special schools, and home schools. To reach “theoretical saturation” is a vague guideline of sample size (Guest et al., 2006). Previous research suggested that the sample size depends on its heterogeneity and the research objective (Kruger et al., 2019). Kuzel (1992) suggested 12 to 20 data sources when the study attempted to maximise participants' variation in a qualitative project. However, it is not a case of, the bigger the sample size the better, since there is a greater risk of being unable to justify the complexity and nuance contained within the data (Braun & Clarke, 2006). Therefore, the aim was to recruit a sample of 20.

3.5.3 Sampling Criteria

Criteria for selecting the participants were as follows: (1) identified him/herself as the primary caregiver of a child diagnosed as intellectually disabled at home; (2) the child must be of primary school age; (3) the child must attend government-funded educational

services or home education in the city of Jiaozuo. As a result, 20 caregivers (19 females and one male) were recruited in the first place. The first participant's interview was excluded from the study for the purpose of piloting.

3.5.4 Participants

In total, 19 participants (15 mothers, three grandmothers and one grandfather) made up the final sample group, and they all self-identified as the primary caregiver of the focused child at home. All participants spoke Mandarin as their first language and only had one child with an ID; seven of them had another typically-developing child. The 19 focused children in this study were diagnosed with ID in a wide range of conditions, including Down's Syndrome (n=2), Autism (n=6), Cerebral Palsy (n=1), Developmental Delay (n=2), Cognitive and Language Disorder (n=1) and unspecified mental retardation (n=7). Boys (n=13, 68.4%) were more represented than girls (n=6, 31.6%), and were aged between 6 and 15 years old. Despite the older age of some of the children, they were all in the primary level of education, since late enrolment is common among children with ID. There is no consistent standard to measure the severity of their disabilities. However, the government has acknowledged such children's intellectual impairments with the official entitlement of financial subsidy and special education, called the license of disability. According to their caregivers, these children were attending a variety of educational settings. Nine children (47.2%) were attending a special primary school, six children (31.8%) were attending a mainstream primary school (the LRC programme), and four children (21.0%) were attending home education. Other demographic information of participants (e.g. age, educational levels and SES) was not collected in this study, because it was considered irrelevant to the data analysis due to the qualitative descriptive design. Asking for personal information during the interviews may embarrass or even cause offence to the participants because most of them were in disadvantaged positions in these domains. Table 1 summarises the characteristics of the participants:

Table 1 Characteristics of Participants

Participants characteristic	Mainstream Education		Special Education		Home Education		Full sample	
	n	%	*n*	%	*n*	%	*n*	%
Gender								
Female	6	100	7	0	5	100	18	45.3
Male	0	0	1	60	0	0	1	54.7
Child's Gender								
Female	3	50	1	12.5	2	40	6	31.6
Male	3	50	7	87.5	3	60	13	68.4
Relationship								
Mother	5	83.3	6	75	4	80	15	78.9
Grandmother	1	16.7	1	12.5	1	20	3	15.8
Grandfather	0	0	1	12.5	0	0	1	5.3
Child's Diagnosis								
ASD	2	33.3	4	50	0	0	6	31.6
Down's Syndrome	0	0	1	12.5	1	20	2	10.5
Cerebral Palsy	0	0	0	0	1	20	1	5.3
Developmental Delay	0	0	2	25	0	0	2	10.5
Cognitive and Language Disorder	0	0	0	0	1	20	1	5.3
Unspecified Mental Retardation	4	66.6	1	12.5	2	40	7	36.8

Note. $N = 19$ ($n = 6$ for Mainstream Education; n = 8 for Special Education; n = 5 for Home Education).

3.6 Ethical Considerations

This study requires the participation of human subjects. To ensure that all processes and measures followed ethical guidelines, the researcher sought approval from the Central University Research Ethics Committee (CUREC) at the University of Oxford (see Appendix D) to lead the investigation as planned. The participants' identities were protected throughout the study. They were not required to produce identifiable information to participate in the project. The administrator of the child rehabilitation centre communicated with the researcher and the participants to protect the participants' contact information from any risk of privacy leak. All participants gave verbal consent on a voice recording before the interviews took place and were informed of their rights to skip any uncomfortable questions. They also retained the right to withdraw before the 1st of August, 2021 by contacting the administrator of the child rehabilitation centre. According to the order of interviews, participants were assigned a pseudonym (e.g. P1, P2…P19) to appear alongside any of their quotations.

3.7 Data Collection

Before the official start of the data collection for this study, one mother of a boy with ID in mainstream education was interviewed as a pilot. The purpose of this was to check for understanding of special terms, any use of offending terms, and wording and sequencing of questions. The selection of piloting was purely based on participants' availability. The first interview was used as a pilot study and excluded from the results. The following interviews benefitted from the changes in the structure and sequencing of the questions. Questions asked were related to the research topic but were not identical for each caregiver, since the researcher moderated according to contents they mentioned, and the interview flows.

Each interview lasted approximately 40 to 60 mins in a face-to-face format, and was conducted in one of the rehabilitation centre's meeting rooms by the researcher – a postgraduate student in Education with a native tongue of Mandarin. Each participant received a Mandarin-translated version of the 'Participant Information Sheet' (see

Appendix B) which introduced this research prior to the interview. If willing to take part, he/she was invited to sign a translated 'Participant Consent Form' (see Appendix C) at the beginning of the interview. The researcher employed the voice recorder on a password-protected iPhone and iPad to safely store the data. After starting with the basic demographic information of the caregiver's child, the researcher guided the interview with open-ended questions, including "what was your experience of enrolling your child to the primary school?", "What concerns or difficulties of schooling did you encounter in the process?", "what were additional supports provided to meet your child's need in schools?" and "in what ways does your family capital affect your child's access to education?" (see Appendix A for Interview Guide). At the end of each interview, participants were asked if they had any comments or questions for the researcher.

3.8 Data Analysis

Transcription. All audio recordings of the interviews were firstly transcribed through a transcription software programme named iDiyun Listen and Read. However, the local accent significantly reduced the accuracy of the transcribed result. Depending on the severity of the accent, the research either manually typed out the interview transcripts or corrected the software-generated transcripts. The thematic analysis identifies and analyses patterns within interviews' literal content, which does not require extensive details in the transcript as conversation or discourse analysis (Braun & Clarke, 2006). Therefore, the researcher eliminated the pauses, emotions, and other background noises in the recordings. The accuracy of the interview transcripts in Mandarin was checked by a native Chinese with the same accent.

Thematic Analysis. All interview transcripts were imported into NVivo for systematic coding in Chinese with the employment of Braun and Clarke (2006)'s thematic analysis. Thematic analysis has the advantages of being flexible and accessible when it comes to discovering descriptive meanings and interpretive meanings of the qualitative data collected in naturalistic settings (Braun & Clarke, 2006). This study used an inductive approach of thematic analysis whereby codes and themes are actively sought

out through reviewing the dataset rather than fit into a pre-existing coding frame (Srivastava & Hopwood, 2009; Xu & Zammit, 2020).

According to Elliot (2018), coding involves separating data to establish what it means before meaningfully grouping the data back together. Therefore, it is also called the conceptual abstraction of data (Elliot, 2018). A good thematic code captures the qualitative richness of the focused phenomenon (Xu & Zammit, 2020). The coding process employed in this study considered the density, frequency and size of the data pieces coded. The frequency of occurrence was not a sole indicator for significance, since it assumed that all codes should be given equal emphasis.

Codes related to similar contents were gathered and assigned labels to become themes. Data should connect together meaningfully within themes, but show clear distinctions between themes (Braun & Clarke, 2006). The researcher re-evaluated the independence of each code and attempted to combine or group codes based on the established connections between said codes (Braun & Clarke, 2006). A theme should represent certain levels of patterns within the dataset addressing the research question (Braun & Clarke, 2006). Unlike codes, themes did not emerge independently but were shaped by theoretical frameworks, ontological and epistemological positions, and the researchers' understandings of the field (Srivastava & Hopwood, 2009).

To answer the first research question, three main themes and eight sub-themes were formulated and developed, namely Values Affected by Social Norms and Discrimination, Difficulty in Accessing Formal Education, and Inadequate Schooling Quality. Another three main themes were named after three types of capital in answering the second research question, namely social, economic and cultural capital.

Selective Translation. After coding and data analysis, selective translation of important quotations from Mandarin to English was conducted by the researcher – a native Mandarin speaker with eight years of studying experience in English-speaking countries. Later, the researcher requested that another native Mandarin speaker studying at the University of Oxford proofread the translation. The researcher did not disclose the participants' personal information to the proof-reader. The translation was conducted

after the data analysis so as to maintain the data's originality within the situated culture and social context. Not all transcripts were translated in this study, and instead only selected passages were used or quoted in presenting the findings.

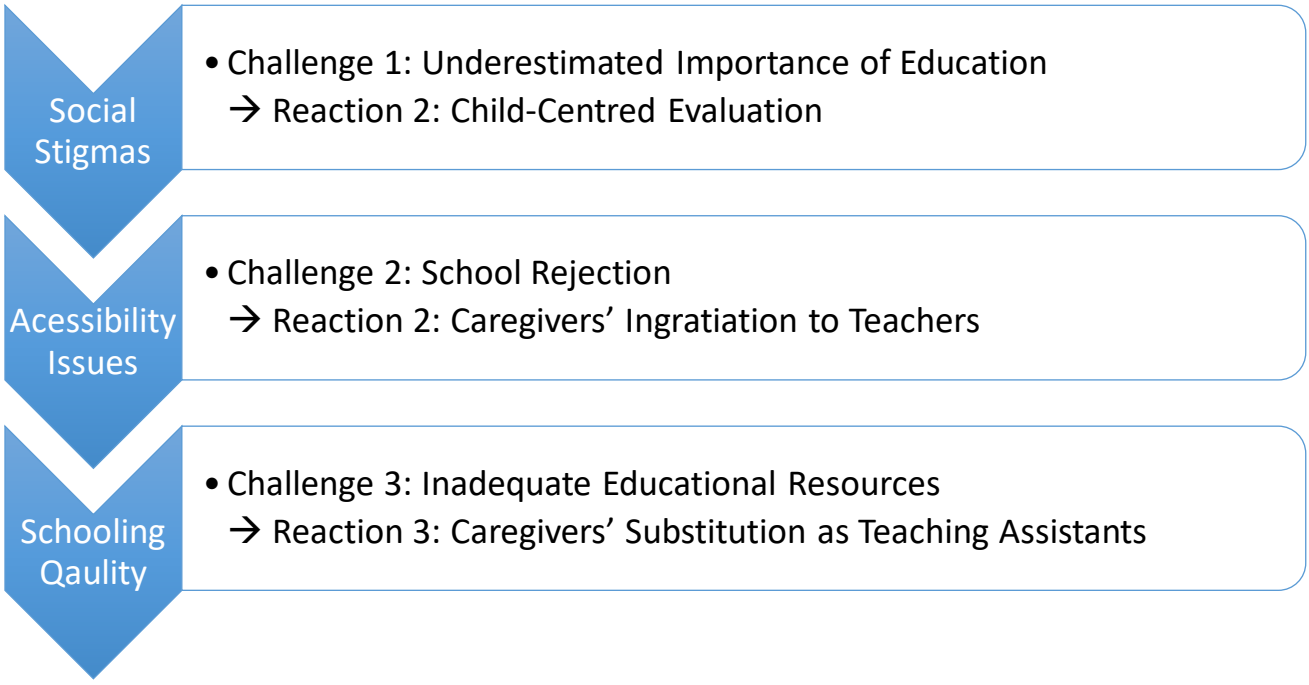
3.9 Trustworthiness

According to Guba's (1981) trustworthiness criteria for qualitative design, there are four factors which researchers need to consider, namely credibility, transferability, dependability and neutrality. The present study realised these aspects in the following ways. In each interview, the researcher confirmed the accuracy of her understanding with the participant if his/her expression was ambiguous. Another native Mandarin speaker proofread the interview transcripts and selection translation; this person had eight years of studying experience in English-speaking countries. According to the philosophical underpinnings of the study, this qualitative designed research did not attempt to seek generalisations, because "all social phenomena are context-bound" (Guba, 1981). Although the participants' individual experiences and perceptions may not be generalisable to the larger population, they may offer some ideas and foundations for further exploration on this topic. In addition, the detailed descriptive data might be transferable and could be used to shed light on a similar population in similar contexts. The interview approach acknowledges the importance of the subjective interpretation, but also values outright some notions of objectivity because of the insider knowledge of the participants (Baxter & Jack, 2008). With a qualitative design, the researchers themselves are the instruments which achieve greater flexibility, but this comes at the cost of a certain level of objectivity (Guba, 1981). At the beginning of each interview, the researcher explained her neutrality and encouraged an open conversation with the caregivers. The researcher did not know any of the caregivers before the interviews and maintained a reasonable distance from the participants throughout the study.

Chapter 4: Results

This chapter reports the main findings regarding caregivers' perceptions gained from semi-structured interviews. It is divided into two sections corresponding to two research questions. Sections 4.1-4.3 presented the difficulties caregivers perceived in accessing educational services (Figure 1) and section 4.4-4.6 demonstrates the relationship between family capital and educating a child with ID (Figure 2). Both sections respectively include three main themes and multiple sub-themes.

Figure 1 The Outline of Difficulties and Caregivers' Reactions in Educational Process



4.1 Values Affected by Social Norms and Discrimination

The socio-cultural context heavily influences caregivers' values and perceptions of educational services. The public stigmas towards disability and special education lead caregivers to underestimate the importance of their children's education. It also prevents caregivers to choose the appropriate education for their children's best interests rather

than fulfilling others' expectations and meeting social norms. To avoid the internal dilemma, some caregivers choose to solely focus on their child's wellbeing.

Challenge 1: Underestimated Importance of Education

The use of education caregivers perceived is underestimated due to the influences of public stigmas of disability in Chinese society. Many caregivers have received advice from key stakeholders in the educational process that their children cannot benefit from formal education (P14, P17, P18). Under these influences, some caregivers become pessimistic about the use of education. P17 stated: "school is just somewhere that keeps him busy, so the parents could have to work or take some time off for themselves." P3 also has seen schools as "somewhere good to place them". Some participants did not observe obvious progressions of their children's cognitive abilities from daily schooling (P2, P4, P6, P8). Thus, they were convinced by social stigmas that their children were "uneducable".

Because they did not recognize the use of education, some caregivers selected types of education based on their social conformity rather than the children's sake. They viewed education as a mandatory part of social norms, especially mainstream education. P3 illustrated: "if I keep my child at home without sending him to school, my whole family would be gossiped about not being responsible. Similarly, P2 also stated: "my neighbours already talk on our backs about my child's disability. If I do not send my child to school, they will assume that her abnormality is even worse." The social pressures contributed to negative feelings of participants whose children in home education. P3 expressed: "If my grandson stays at home, I feel he has been abandoned. I cannot gather my strength to keep fighting for stimulating his best potential."

The stigmas of special education contributed to caregivers' preference for mainstream education (P7, P9, P13). P19 explained her preference for mainstream education is for "protecting her self-esteem." P11 explained:

> "I have spent so many efforts in educating my child about social rules and how to fit into the society. I cannot accept if he ends up in a segregated school with other disabled peers who are in much worse conditions."

In this case, caregivers were motivated to live up to social norms and other's expectations since their children were already considered as being far from "normality".

Reaction 1: Solely Focusing on Child Wellbeing

To avoid the social pressures of fitting in with the norms, some caregivers placed their emphasis on their children's wellbeing in schools. Six caregivers indicated that they do not have any academic expectations for their children (P5, P7, P12, P13, P16, P17). Instead, they valued their child's physical and mental wellbeing over their academic attainment. For example, P7 always comforted her son not to be stressed out by academic performance as long as he tried his best. She explained: "we only hope he is happy and gets along with his peers in the mainstream class (P7)". P10, P12, P17, P19 also expressed that their children's happiness is the priority of schooling. Therefore, they emphasised the importance of school activities, such as sports competitions, school trips and daily playing (P3, P9, P13). For example, P3 stated: "we feel satisfied if our child could get along with typically-developing peers in school".

This internal coping mechanism was also used by caregivers in special schools. According to this child-centred approach, caregivers were satisfied with special education if their children could eat well and play well in establishments (P2). Caregivers perceived the benefits of special education for their children's mental wellbeing as it provides "a sense of belongingness to a community" (P6). Moreover, "there was no need to concern about that the children are bullied or discriminated in special schools since they are all disabled (P4)." However, some of them were more concerned about the lack of physical activities within special schools (P8, P9, P10, P17). Exercise is a significant part of education for children with ID since excessive energy causes many behavioural problems. However, P9, P10, and P17 complained that special schools intentionally reduced the proportion of physical education classes for safety considerations. P17 described the lack of physical exercise in special schools as "sitting in the jail for children" "Children barely move in special schools except going to the bathroom (P10)." P8 explained the consequences of reduced exercise:

> "my son is almost as tall as his teacher but only has a mind like a 5-year-old child. He becomes more and more insubordinate as he grows older. With excessive energy and growing strength, he is often too excited to sit in class for the whole day."

To solve the issue of excessive energy, P5 and P7 indicated that they would take their child to exercise in parks every day after school to keep them in good health and consume their excessive energy. The child-centred approach of evaluating and perceiving educational services relieved caregivers' stress of living up to social norms. They intentionally place emphasis on their children's needs instead of placing on others' judgements.

4.2 Difficulty in Accessing Formal Education

Some caregivers insisted on sending their children to mainstream education without a realistic understanding of their children's capability. Many of them experienced rejections and expulsion from mainstream schools. Limited school placements for children with ID also contributed to the difficulties of accessing formal education. Thus, caregivers ingratiated themselves with teachers and muted their ideas of their child's education to "earn" educational opportunities.

Challenge 2: School Rejections

Many caregivers' children have experienced rejections and expulsion at some points of their educational process. Twelve out of nineteen participants (except P3, P5, P6, P8, P10, P14, P19) reported that their children had been rejected or expelled by mainstream schools. These participants were either transferred to other mainstream schools (P7, P11, P16) or ended up in special education. It was not always a straightforward process in direct applying to special education.

Despite the schools claimed to be non-selective in enrolment, many caregivers reported that they faced entrance examinations when applying to mainstream and special schools. P5, P11, and P19 mentioned that their child had to pass entrance examinations including an interview and written quiz when they applied to the mainstream and the

special schools. “The entry requirement becomes higher and higher. Parents have to figure out other ways to educate children with severe disabilities if they are rejected by special schools (P11).” Children who failed in entrance examinations were even rejected by special schools (P3, P10, P14). They were ended up in home education which is called the “Delivery Education to Door” programme. P14 described her child’ rejection: “the teachers suggested my child choose home education because they thought her capability could not benefit from formal education”.

Reaction 2: Caregivers’ Ingratiation to Teachers

Caregivers have a variety of reactions in response to school rejections and expulsion. Some parents tried to trick the school admissions by covering their children’s conditions. For example, P15 was firstly rejected by a mainstream school and then applied to another one without disclosing her child’s diagnosis. She hoped that this strategy would allow her child to remain in the mainstream school. P15 explained: “It has been in the new school for one month and the teacher has not discovered yet. Our family has been worked very hard to cover my child’s disability by tutoring at home.” Some caregivers tried to ingratiate themselves with the teachers hoping to exchange their children’s educational opportunities. P16 had sacrificed a lot to “earn” this placement: “I cleaned the teachers’ office and children’s classrooms in exchanging the school placement for my child.” Similarly, P7 and P19 also described that they actively supported teachers in organising school activities and made them hand-painted cards every festival by which they hope the teachers could be more patient with their child in the classroom.

On the other hand, caregivers lower their expectations of school inclusion and have high magnanimity towards unfair treatments within schools. For example, P12 explained: “as long as any school willing to take my child in, I do not have other expectations about teacher’s attention or individualised supports.” P10 would not investigate whether her child has been discriminated against or bullied in schools because she perceived “discrimination towards disability is a natural thing in schools and is unable to be prevented”. Moreover, P7 attributed school bullying or discrimination to

herself for not accompanying her child in the classroom rather than blaming the school management and teachers. She explained:

> "being included is mainly parental responsibility, others do not have the obligation to do so…It is not reasonable to require teachers and peers to include my child regardless of his disability. The disabled people have to adapt the society."

Moreover, participants were concerned that their suggestions and complaints about their child's education would irritate teachers and lead to school expulsion. For example, P12 found her child not attending regular classes but unattended running around in the playground during class-time. However, she said: "I do not dare to complain about this unattended absence to his teachers because I fear they would expel my child if I have too many requirements." Many participants also indicated that they felt sorry for adding burdens to teacher's work because of their children's disabilities (P7, P10, P15). Therefore, they retained humble towards the teachers, even when they failed to support their child's needs.

4.3 Inadequate Schooling Quality

Despite the types of education, caregivers reported that the adequacy of school facilities, quality and quantity of teaching staff are of concern. Their children's needs were mostly unattended. Thus, the schools required more parental commitment to facilitate teachers in daily schooling.

Challenge 3: Insufficiency of Educational Supports

Participants indicated that there were only two special schools in Jiaozuo which were established in 2017. P2's child was unable to enrol in any formal education until these two establishments. It resulted in her daughter's late enrolment that she only studied in fourth grade by 13. So far, these two special schools cannot meet the increasing needs of disabled children in the local area because "more and more families sending their disabled children to formal education (P8)". The schools expand the class size in order to cope with increasing needs. P4 described that "there were seven students in my son's

class and three more were transferred this year." It exacerbates the insufficiency of school facilities and teaching staff. For example, P1 and P10 explained the inconvenience of not having a bathroom on each floor. "My child has limited motor ability, so it will be challenging for him to go all the way down to the bathroom on the ground floor (P1)." Besides bathrooms, participants also complained about the lack of dormitories and playgrounds (P2, P7, P10, P18).

The insufficiency of educational supports was often reported by participants whose children were in mainstream education. For example, P2 complained: "the [mainstream] school only cares about registration and physical attendance, but do not truly welcome our child to join by providing the necessary facilities and supports." However, some participants like P6 reacted differently to the situation in mainstream schools as they explained for mainstream schools: "each class has only one teacher to manage over fifty students. Therefore, the teacher cannot watch my child all the time." Some participants indicated that a lack of individual supports in mainstream classrooms was their main reason for not sending their child there. P5 explained:

> "I do not think my child can benefit from mainstream education without individual support. Unfortunately, however, the mainstream school does not provide any of them which left me no choice but special education."

The issue of insufficient educational supports was also complained about by parents in home education. P3 described: "I was not satisfied with home education due to the limited teaching and resources provided. These families do not have any other options of seeking professional supports". P8 also confirmed that "the local school board barely provides any educational resources or teaching but just check on these families for home education once in two weeks and sometimes bring some snakes or toys for the children".

Reaction 3: Caregivers' Substitution as Teaching Assistants

Participants indicated it is more important to have a good teacher than studying in certain types of education (P2, P7, P8). P2 explained:

> "the schooling quality depends on class teachers. The good teachers are professional and responsible in promoting children's development, whereas the bad ones only look after the children rather than teaching anything."

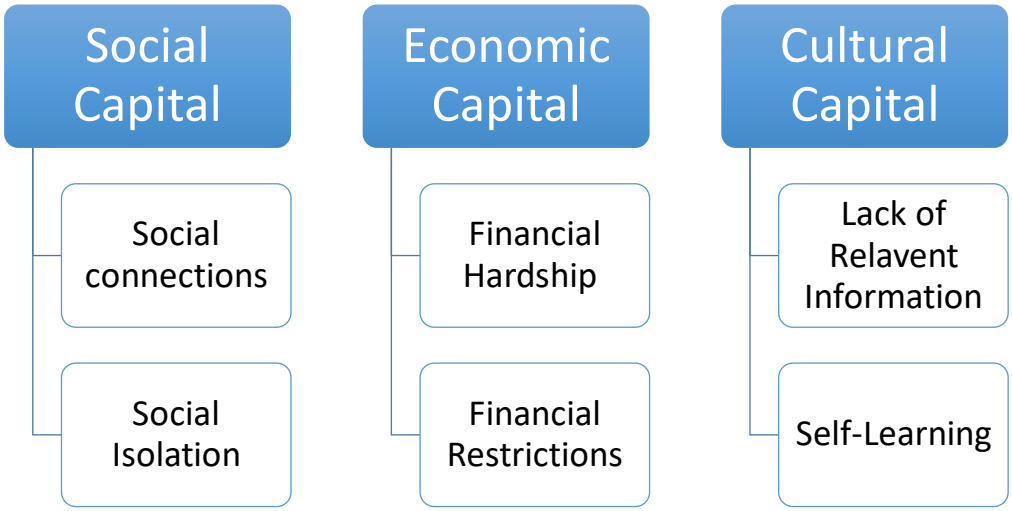
Full-time parental accompaniment for children with ID becomes a common phenomenon in schools due to the insufficiency of teaching staff and lack of expertise in special education. For example, P5 and P16 have been required to do so for their child as a prerequisite of enrolling on mainstream education. P5 rejected the condition and sent her son to special education because she has to take care of his younger sibling. Whereas, P16 was grateful for have the educational opportunity and explained: "not every parent of children with disabilities are allowed to stay in the classroom." P16 saw the school condition of parental accompaniment as an opportunity to stretch her child's capability.

Whereas, the special schools expect that caregivers provided individualised supports to their children in classrooms. P10 complained about the lack of qualified special education teachers in attending their children's needs:

> "These teachers were made up of retired mainstream teachers who did not have any training or experiences in special education. They teach disabled children like the typically developing ones. The teachers do not try to improve our children's capability but exclude them for a variety of reasons like excessive energy, emotional or hygiene issues. They expect parents to teach their child."

Some caregivers also offered facilitation to teachers in daily schooling. As the special school runs from 8:30 am. to 3:30 pm, they stay around schools and wait to be on call for helping out any incidents, especially during lunch and napping time (P2). In some classes, all parents were taking turns to be "volunteer parents" helping out the teacher inside the classroom(P8). P8 complained: "the schools failed to provide quality education for our children, so they squeeze out parents' energy and leave no time for parents to live nor work."

Figure 2 The Outline of Family Capital Invested in Child Education



4.4 Social Capital

Social connections help caregivers to obtain school placements, provide necessary supports and helpful information in the educational process, especially from professionals and grandparents. However, caring for a child with ID may weaken one's social network.

4.4.1 Social Connection

Some participants sought a school placement for their children through social connections. P15 explained that her granddaughter has enrolled at a mainstream school affiliated with the enterprise that all of her family members have been working for. She has known the headmaster personally for many years. "Sending our child to this school is part of the welfare for our employees (P15)." P12 also used her work relations managing to find her child placement in kindergarten. "I am a kindergarten teacher, so the kindergarten I am working in exceptionally enrolled my child (P12)." P7 and P17 used indirect social connections through the introduction of the third person. The rehabilitation therapist working with P17's child has known the headmaster of another mainstream school. With her introduction, P17's child successfully enrolled this year. Similarly, one

of P7's friends knows a headmaster of a village school. The village school enrolled her child and paid extra attention to help with her disability because of the social connections. On the other hand, some caregivers made new social connections with other caregivers through schools, rehabilitation centres and parental support groups (P2, P3, P11). These social connections bring all caregivers together like a "big family" which provide them with a sense of belongingness, emotional comforts and helpful parenting strategies (P3, P9, P11).

Grandparents heavily involve in child-caring tasks, especially when their grandchild is diagnosed as disabled. Eleven out of nineteen participants described the burden of raising and educating a child with ID was shared with the child's grandparents (except P1, P2, P5, P8, P10, P12, P14, P19). Three participants were grandparents who considered themselves as primary caregivers of the child with ID. In other cases, grandparents took care of the other siblings which saved parents time to only focus on the one with ID. Therefore, it was a great relief for parents of a child with ID to balance life and child-caring (P19). However, grandparents usually take physical work like cooking and housecleaning since they were considered incapable of tutoring a child's education (P13).

4.4.2 Social Isolation

Caregivers reported that the child-caring responsibility requires full-time devotion, which often drained their time and weakened their social networks. P11 described:

> "full-time caring for a child at home is a very stressful task but often not have adequate respect from other family members. we often quitted jobs and did not have personal time to hang out with friends."

The majority of people in society lack awareness and compassion towards disability. P1 explained: "people who did not interact with children with disabilities before are assumed our children were quite strange and unusual, so they discriminate us when we are in the public spaces or public transportation." Because of the social climate, P10 was depressed and felt inferior once her child was diagnosed with ASD: "I had self-enclosed myself for

a period of time. I did not want to talk with anybody since I felt my life was ruined." A feeling of "being abandoned" was also reported by caregivers (P3, P7).

4.5 Economic Capital

Almost all participants reported that the whole family was facing financial hardship for supporting their child's rehabilitation. The situation was worsened by the excessive child-caring commitment that occupied one adult full time. Some families thought of moving to larger cities for better rehabilitative and education services but failed due to their financial conditions.

4.5.1 Financial Hardship

Educating a child with ID often leads to financial hardship for the whole family because of the excessive spending on rehabilitation training and educational services (P1, P2, P3, P4, P11). Caregivers were required to pay extra tuition as conditions of enrolment for their child with ID, especially during the kindergarten stage since it was not included in the 9-year compulsory education. "The tuition of kindergarten was double for our child which worsened our financial burdens (P1)." Moreover, the cost of rehabilitation is a major expense for families of children with disabilities. P3 described:

> "each session (45 mins) costs 50 yuan, my grandson has been receiving two sessions every day for several years, each month costs about 3000 yuan. It is almost the average of one's monthly wage in the local area. All my pension and savings have been spent on his rehabilitation. We have even sold our house."

P4 was in debt because of the spending on her child's rehabilitation. P10 described the financial burden of raising a child with a disability as a "devastating disaster" for the whole family. Although there is a governmental subsidy for people with disabilities, it is minimal compared to the rehabilitation costs (P7).

The financial burden worsens due to a child with ID's high demanding caring responsibility (P3, P8, P10, P11). It often requires one of the family members' full devotion of time, so the caregiver has to quit the previous job. P1 quit her job after her child's diagnosis. "The financial burden is laid on the father's shoulder since he becomes

the sole source of family income (P1).” Unlike many participants willing to sacrifice all of their time and money on children’s rehabilitation and education, P7 continued to work after the diagnosis. She opposed this sacrificing and explained: “my child may not have any progression, even I give up my work and full-time support him at school. It will worsen the financial burden of the family and lead to no time for yourself.”

4.5.2 Financial Restriction of Accessing Better Education

Due to limited service available in the local area, many caregivers took their children to larger cities for better treatments, including Zhengzhou (P5, P10, P11), Beijing (P6), Shenzhen (P3), Qingdao (P10). For maximising their children’s best potential, they undertook additional costs in these developed areas, including the “rent of a residence and living costs for two family members accompanying the child, one for cooking and the other taking the child to rehabilitation (P8)”. The total cost for each month treating in Zhengzhou (the provincial capital) is about 10,000 yuan (P10). “The rehabilitation at Qingdao was even more expensive than Zhengzhou (P8)”. None of these participants stayed long-term in larger cities for rehabilitation due to financial consideration. P11 explained:

> “a short period of rehabilitation at larger cities was already the best we could offer to our child considering our family’s financial conditions. It is not realistic to continually receive it due to its expensive costs.”

However, some parents felt guilty about not providing the best treatment to their children. P10 expressed that: “I was regret about the decision of not continuing due to the financial consideration. Otherwise, our child will be much better now.”

4.6 Cultural Capital

Participants indicated that they had limited prior knowledge of developmental trajectories that caused delays in their child’s diagnosis. Moreover, many of them also have limited access to parenting and schooling information after diagnosis. Therefore, they attempted to learn relevant information from the internet and other caregivers.

4.6.1 Lack of Relevant Information

Many caregivers do not have any prior knowledge about developmental disorders. Despite many participants whose child was diagnosed around 2 to 3 years old, delay in diagnosis was also experienced in these participants (P1, P5, P8, P9, P10). For example, P8's child was not diagnosed until eight years old, when he could not enrol on mainstream schools. P5, P9, P13 suspected the abnormality of child development for three months. However, they did not go to the doctors until three years old. P5 explained: "the elders in the family convinced us that our child was typically developing when we doubted his development." P9 and P10 expressed their regret of missing the early treatment because of their lack of knowledge regarding developmental disorders.

> "I was truly regretting that I listened to other's advice and did not let my child get rehabilitation therapy earlier than he had. He must be in a much better position if I did so (P10)".

Some caregivers who had specific knowledge about developmental trajectory learnt from their previous child-rearing experience would notice the developmental difference between their children earlier than three months (P1, P4).

On the other hand, caregivers did not have access to information on special education and parenting strategies for children with ID even after the diagnosis. Nine out of nineteen participants received the child's diagnosis as "mental retardation" rather than specifying any disorders or causes. These participants did not have a comprehensive understanding of their child's conditions. Without a professional-given cause of the disability, mothers often blamed themselves for having done something wrong or missing any examinations during the pregnancy (P2, P15). Some caregivers did not have a realistic understanding of their child's capacity and progression but relied on their subjective perceptions to make schooling decisions. P10 suggested: "I could feel that child is progressing now. I am sure that he could make it to mainstream schools after a period of rehabilitation."

4.6.3 Acquired Information through Self-Learning

Caregivers often acquired information and knowledge regarding a child's diagnosis and parenting strategies after the diagnosis through self-learning on the

internet, seeking professional advice and other parents' successful cases (P8, P10, P11, P12, P19). Many of them benefited from other parents' advice and tips (P8, P13). P4 and P6 learned from professionals and conducted additional training at home. For example, P4 explained: "each rehabilitation sessions only take place 45 mins with high costs. So, I conducted the majority of the training done for my son at home." On the opposite, caregivers have gained a significant amount of parenting strategies and schooling information from other caregivers (P3, P4, P9, P11). For example, P11 found out mainstream education was not suitable for her child based on other children's schooling experiences.

Unlike the active learning of above-stated caregivers, some caregivers refused to correct their prejudice about special education by gaining more relevant knowledge: "I know nothing about special schools because I never think of this option. All my family members agree on sending him to the mainstream (P13)." P7 and P16 also blindly trusted mainstream education and believed that their children would be better surrounded by typically developing peers without further investigation. On the opposite, P8 was active in investigating schooling options but lacked access to school information:

> "I truly wanted to know more about different schools and education. However, I did not have any access to the school information except through other parents. The schools do not allow visits or providing information for us to make rational decisions."

Chapter 5: Discussion

There is a rising trend of research focusing on human diversity and educational inequality (Zhu et al., 2019). To fill the gap related to studying the education services in developing areas of China, this study explored the perceptions of caregivers with ID children regarding their difficulties in the educational process. The present chapter discusses the main findings of this study through the lens of the results derived from the previous literature. The consistent and contrary findings from relevant studies were analysed. This study constituted an extension of the literature on the educational process of ID in the unique socio-cultural context of China and revealed barriers which caregivers encounter in accessing services.

5.1 Hindered by Social Norms and Stigmas

The current study detected evidence that social stigmas towards disability and special education hinder caregivers as they attempt to make rational schooling decisions in order to maximise their child's potential. The influences of social norms were also noticed by previous studies that social conformity is served as a cover value of Chinese culture (Wong et al., 2015). Attending formal education, especially mainstream education, is perceived as a part of mandatory social norms (Lui et al., 2015; McCabe 2007; Yan, 2012; Wu, 2020). Chen (2016) also argued that parents perceive inclusive education as a neutral option itself but it is the most common way to cultivate one's development and prepare for meaningfully participating in society. Thus, it is preferred by majority of caregivers. The above study confirmed that parents' value judgement is shaped by their perceptions of social norms (Lui et al., 2015).

Whereas, children in special education or home education are discriminated for being "othered" from the normality (Runswick-Cole, 2008). Despite special schools providing better support and facilities to meet their children's needs, Yan (2012) contended that caregivers still prefer inclusive education since special education is stigmatised in Chinese society. Some participants in this study confirmed that mainstream schools will bring them a temporary relief of public discrimination and some hope that

their children could just be back to “normal” by integrating with typically-developing peers. The finding is consistent with previous research that parents tended to emphasise their child’s “normality” when discussing school options (Dickinson, 2018; Su et al., 2017; Wong et al., 2013). It suggested a sense of being “normal” is important for caregivers of children with ID. By sending their children to special schools, they continually suffer from the loss of a sense of being “normal” (Runswick-Cole, 2008). Similar to the result in this study, caregivers’ preference of mainstream education is for protecting their own self-esteem since they cannot accept the fact that their children would always be different and special from the majority of the society.

The participants in this study were consistently optimistic about mainstream education in preparing their children to meaningfully participate in society after graduation. Contrary to the findings in this study, Leyser and Kirk (2004) found that UK parents whose children studied in mainstream schools were less optimistic towards inclusion than their counterparts whose children studied in special schools. A plausible explanation of the cross-cultural difference may be that Chinese children in mainstream schools usually have less severe levels of disability compared to children studying in special schools in China due to the entry requirements. Therefore, Chinese caregivers whose children are in mainstream schools have more confidence in their children’s independence and progression.

The distinct caregivers’ perception was characterised by their emphasis on different aspects of education. The data suggested that some caregivers place more value on their child’s mental and physical wellbeing than their academic attainment. Some participants in this study only hope their children to have progression in their social skills by integrating with typically-developing peers. The practicality of their expectations was confirmed by the teachers’ report in Yan et al.'s (2012) study that children with ID have significantly improved their social and life skills but not their academic performance in mainstream schools. Having low academic expectation helps reduce tremendous parental stress experienced as a result of educating a child with a disability who cannot follow up the academic progression in the mainstream classroom, as suggested by Su et al.’s (2017)

study. However, Shifter (2013) criticised the low academic expectations from parents and teachers, stating that they significantly restrict children with ID from achieving a high level.

The results of this study demonstrated that participants whose children study in special schools were more prone in advocating physical and extra-curricular activity in schools. Consistent with the findings of previous studies, caregivers well acknowledged the benefits of exercise and physical fitness for their children's development and supported them in being physically active in different ways (Yang et al., 2020). For example, exercise reduces behavioural problems caused by excessive energy for children with ID (Shields et al., 2011). Despite their supports of exercises, children with disabilities often undertake levels of physical activity which are lower than those of their typically-developing peers (Shields et al., 2011). Wang et al.'s (2018) cross-sectional study with 524 Chinese children with ID found that 31.3% were overweight or obese, which was higher than their typical counterparts. The concern of disabled children's fitness was universal across countries (Chen et al., 2006; Wong et al., 2013; Shields et al., 2011; Srinivasan et al., 2014). The results extend the applicability of these findings regarding the concerns of physical activities to special schools within developing areas of China where the importance of physical education has been clearly underestimated.

5.2 Difficulty in Accessing Formal Education

The present study showed that almost all the participants had experienced difficulties in seeking an educational placement for their child. This finding was directly in line with previous studies on the accessibility of educational services in China, which revealed the issues of insufficiency of school placements and unwelcoming school climate hindered children with ID as they attempt to access to education (Cui, 2016; McCabe, 2007; Zhao et al., 2021). According to Correia et al.'s (2021) large-scale parental survey, many respondents reported similar perceptions that the process of accessing educational services is challenging for their children with ID. Besides the complicated educational options, a significant school rejection rate among children with

ID was found in China (La Valle, 2013). Although it was suggested that the services are less accessible in developing areas (Han et al., 2021), the result of this study indicated better quality of education only in larger cities, but was unable to demonstrate this comparison of accessibility between developing and developed areas. On the contrary, one caregiver in the study even indicated that the village school was more inclusive and welcoming to her child because of the smaller class size and less academic pressure on rural teachers. It partially confirmed the validity of the finding suggested by Deng (2008) that teachers in rural areas were more favourable towards inclusion than their counterparts in urban areas.

Previous studies discovered that parents of children with ID were more disadvantaged on the hierarchy of power between parents and schools in China (Chen, 2016; Su et al., 2018). Parents' rights were not equal to their obligations due to the lack of policy protecting their voices and authority in their child's education (Zhang et al., 2017). Some parents were even concerned that their behaviours of visiting schools, questioning progression, and reporting any issues would indicate of distrust and disrespect for the teachers (Chen, 2016). Therefore, they were afraid to reveal their thoughts to the school for fear of causing any offence to the teachers. Similarly, a finding of this study suggested that caregivers had high endurance of teachers' neglects and discriminations within schools for fear of offending to teachers and their child possibly being expelled. They were hesitant to ask for more support or report complaints about school mismanagement. Poon-McBrayer and McBrayer (2014) explained that caregivers do not know that their child's access to education is their inherited right, and instead contributed to teachers' sympathy. Therefore, they assumed that "irritating" teachers with more requirements would lose their current placements. Zhou et al. (2019) suggested that the relationship between teachers and parents should build on the equal status of the power hierarchy and mutual respect.

5.3 Inadequate Schooling Quality

The results indicated that the current LRC programme merely integrates children with ID into mainstream classrooms but does not provide any additional supports. The present study confirmed La Valle's (2013) finding that mainstream teachers pay even less attention to disabled children than do their typically-developing peers. The validity of such insufficiency perceived by parents is confirmed by the findings of Qu's (2019) teachers' interviews. Qu (2019) found that the LRC programme is all about school registration and physical attendance in teachers' eyes without any intentions in providing any additional supports. McCabe (2007) explained that individual support was unrealistic within the Chinese educational context. Usually, between 40 and 70 students per elementary classroom are taught by one teacher without teaching assistants (Ellsworth & Zhang, 2007; McCabe, 2007). Thus, teachers are unable to distribute additional attentions to students with disabilities since their energy and time are already drained by the heavy workload in such large class. The scarcity of educational support to meet their children's needs was also reported by the UK parents which was one of the main motives for parents choosing home education (Kendall & Taylor, 2016). Unlike the UK parents, none of the caregivers in this study voluntarily chose home education despite their complaints about the lack of support in mainstream and special schools. Whereas, they did help attend to the child's daily needs (such as bathroom trips, behavioural issues, emotional support) and facilitate teachers in maintaining classroom order. This research produced results that corroborate the social phenomenon of a parent or guardian accompanying a child in school activities (Wu, 2020).

In line with the previous findings, it can be concluded that both the quantity and the quality of special education are of concern in China (Fu et al., 2020; Wang & Mu, 2014). The high student-teacher ratio in special schools reported by participants in this study is consistent with Yu et al.'s (2011) findings. As a result of the shortage of teaching staff in developing areas, they were often overloaded with extensive tasks and long working hours, but with a low paying (Yan et al., 2014). As a result, approximately 40% of special educators reported leaving intention which is relatively higher than mainstream education teachers (Boe et al., 2008).

The study suggested that the schooling quality in current educational services was also impacted by the lack of expertise among teaching staff. Johnson (2008) indicated that fewer than 100 special education teachers graduate from Chinese educational programmes annually, which confirms the finding of inadequate expertise among teaching staff. Over half of the special education teachers had not completed their undergraduate studies (Ministry of Education, 2011). Among those who had completed undergraduate studies, only 21.8% of special education teachers completed their undergraduate studies in a related field (Wang, 2012). Elisworth and Zhang's (2007) study suggested that special schools were well structured and professionally managed in metropolitan cities such as Beijing and Shanghai. These qualified and well-trained teachers are more likely to teach in developed larger cities, entailing the geographical disparity of educational quality.

5.3 Social Capitals

This study found that caregivers garnered school placements through social connections. Trainor (2010) elaborated on the social phenomenon whereby parents manipulate their connections with teachers, professionals and administrators to gain information and educational opportunities for their child with ID. In this case, social capital was seen as a currency used to purchase educational opportunities or outcomes (Bourdieu, 1974; Chiu et al., 2012). The findings of this research are consistent with those of Wang et al. (2004) and McCabe (2002), who suggested that social networks helped the children with ID access specific educational opportunities. As new social contacts built up through parental support groups, child rehabilitation centres and schools, many participants indicated that they truly benefitted from such social connections for a sense of belongingness and valuable coping strategies shared by others. In line with previous research findings, the social network is considered the most effective way to acquire this capital (Trainor, 2010).

Another critical finding was the feeling of social isolation caused by the caregivers' full-time devotion to child-rearing and the internalisation of stigma towards

disability. This supported Chiu et al.'s (2012) argument that having a child with ID may weaken or even sever key connections in social networks, which may reduce the family's resources and opportunities. Within the collective society, stigma towards disability not only restricts the social participation of individuals with ID, but also that of their families (Mak & Kwok, 2010). As a result, having a child with disability may be viewed as an inauspicious or contaminated sign based on traditional beliefs (Rhode-Brown & Frain, 2013; Wang et al., 2011). Despite other social connections falling, grandparents and extended families often share parents' burdens in caring for and educating children with disabilities (Huang et al., 2020). They can share the child-caring responsibility, and provide the family with practical help as well as emotional and financial support in the child's rehabilitation and education (La Valle, 2013).

5.4 Economic Capital

In terms of economic capital, this study found that families raising a child with ID often experience financial hardship, consistent with Zheng et al.'s (2011) results, which suggested that children with low SES are overrepresented among those with ID. However, their explanation of this social phenomenon was that families with higher incomes are more likely to access prenatal examinations, genetic counselling and early interventions. This study has not demonstrated that the financial hardship may serve as a prerequisite to their child's disability. Another finding showed that child-caring responsibility leads to economic loss because it requires a family member's full-time devotion. Full-time parental accompaniment in schools further intensifies a caregiver's employment difficulty and economic loss (Wu, 2020). These results are evidence that a family's economic capital shrinks because of caring for and educating a child with ID.

Another finding to emerge from the analysis is that a child's access to education and services is often restricted by the family's economic capital. The costly nature of rehabilitation services is difficult to cover for the national health insurance (McCabe, 2007). Therefore, the expense of services means that caregivers are relied upon. This explains the findings of previous research which discovered that the utilisation rate of

rehabilitation and the enrolment rate of inclusive education are significantly associated with the children's SES (He et al., 2018; Gindi, 2020). Building on the results, financial hardship provides obstacles for parents and their children when it comes to accessing the necessary support and services.

5.5 Cultural Capital

This research produced results that corroborate the findings of previous studies which found that almost all caregivers lacked information relevant to the diagnosis, parenting strategies and social support when they first discovered their child's disability (Alshatti et al., 2021; Correia et al., 2021; Shang et al., 2009; Wong et al., 2015). Previous research also demonstrated that parents would blame themselves for failing to recognise symptoms and then missing the early intervention (Chen, 2014; Chiu et al., 2015). Chien and Lee (2013) discovered that the specific diagnosis permitted parents to access external support to attend to their children's needs, which involved manoeuvring the educational processes. Moreover, parenting a child with ID requires specialised caring skills and knowledge, since many caregivers experience difficulties in managing their child's temper tantrums and behavioural issues (Wong et al., 2004). This adds credence to the suggestion that parents should be educated with relevant information before the pregnancy.

Although cultural capital is most often obtained and manipulated in undeliberate ways (Trainer, 2010), a contrary finding suggested in this study indicates that caregivers intentionally acquire relevant information and knowledge through self-learning on the internet or connections with members of a parental support group. This has provided evidence in support of suggestions by previous researchers, such as Huang et al. (2011), who argued that it is beneficial for mothers to acquire relevant knowledge and perform rehabilitation therapy for their child at home. Parents reported similar learning intentions in Wong et al. (2004)'s study. These studies suggested that it was essential for the caregivers to acquire relevant knowledge of their child's needs and support so as to become meaningfully involved in home–school interactions. However, this depends on

the caregivers' educational levels, as they may have different levels of adaptation to new knowledge and conduction of rehabilitation training at home. For example, Leyser and Kirk's (2004) study found that younger, more educated and wealthy caregivers would have more positive attitudes towards the child's disability.

Chapter 6: Implications, Limitations and Conclusion

6.1 Implications and Suggestions

This research study explored caregivers' perceptions of the challenges in effectively accessing educational services for their child with ID in developing areas of China. In doing so, the study revealed insights into educational inequality and segregation for children with ID and their families in this specific context. The greatest potential yielded by this study is the expression that caregivers desire to access appropriate education and improve quality of education, but are significantly hampered by a shortage of capital in various ways. This research may lead to social betterment by creating a foundation for disabled children to meaningfully participate in formal education and even in society. The present research study has use in advocacy of equal education, improvement of school facilities and teachers' expertise, and raising public awareness of disability.

6.1.1 Theoretical Implications

This study deployed Bourdieu's theory to enhance the reliability and generalisability of the findings in the present work and to deepen our understanding of the segregation within special and inclusive education. With the facilitation of the theoretical framework, the study demonstrated caregivers' sacrifice of family capital to maximise their child's potential, while it also revealed a great need in social, economic and cultural domains. Future research could further investigate how caregivers' value (habitus) affects their capital investment in their children's education.

6.1.2 Contextual Implications

Although the majority of studies in this field have been conducted in metropolitan cities and economically-developed areas, this study specifically illustrated the challenges of the educational process within a developing area in Henan province. Henan does not have the lowest investment in special education among all 31 provinces in the country (Huang & Zhang, 2019). Based on the current findings, it is assumed that provinces with lower investment of special education like Qinghai, Xizang, Gansu may have even more

difficulties in accessing educational services for children with ID. Further studies need to take into account the variation of educational context in different areas within a country. The suggestion is to examine the geographical disparity of educational services for children with ID between developing and developed areas through direct comparisons of stakeholders' perceptions.

6.1.3 Methodological Implications

This study provided details on, and insights into, caregivers' lived experiences and perceptions of education through semi-structured interviews. To provide a more comprehensive understanding of educational services, this study recruited caregivers whose intellectually disabled child was studying in mainstream education, special education and home education, rather than having a unified sampling group. Future studies could learn the strengths of the method used in this study and duplicate the study design in other developing areas in China to investigate any differences and similarities.

6.2 Limitations

The first notable limitation is the sampling bias in this study. The study was limited to 19 caregivers' perceptions of educational services for their child with ID in the one developing area of Henan province. It is reasonable to assume that the participants in this study have better access to child diagnosis and education than the rest of the population in the focused area, since their children attend rehabilitation therapies regularly. In a culture emphasising that family scandals should not be disclosed, caregivers who volunteer to be interviewed may have extreme attitudes and a strong inclination of expression regarding the topic. Consequently, findings cannot be generalised to other regions or populations. However, the purpose of this study was to gain insight into the unique perceptions of caregivers, and so a qualitative design was used to create detailed descriptions and allow participants to have an active voice in the study.

Additionally, another limitation is related to the gender of the recruited participants. In this study, participants were made up of 18 female caregivers and one

male caregiver. The unbalanced gender ratio reflects the traditional gender role in Chinese culture, whereby female family members often take the primary child-caring responsibility, while male family members are providers of the financial income. In addition, different genders of caregivers may have distinct perceptions of educational services, which were overlooked in this study. Future studies could investigate the relationship between gender roles and parental perception of child education.

Finally, this study did not gather participants' demographic information, such as educational attainment, SES, or age. The study aimed to present distinct experiences rather than establishing any relationship between them. Future research could explore whether these factors have any influence on the parents' perceptions of educational services.

6.3 Conclusion

This study aimed to understand Chinese caregivers' perceptions and experiences of educational services in developing areas. The qualitative research revealed findings that are critical to understanding these children's disadvantaged status in access to, and quality of, education. The results demonstrated that caregivers in developing areas are constantly concerned about the public stigmas towards disability, limited educational opportunities and poor quality of education. They actively react and overcome these difficulties by providing adequate support and investing family capital in their child's education. Undoubtedly, raising and educating a child with ID also requires excessive devotion of family capital and caregiver's commitment, especially in developing areas where services and support are inadequate. The investment of family capital determines the access and quality of services for the child. This study adds a new dimension, highlighting the importance of hearing from diverse caregivers to improve the educational services for children with ID in developing areas. It is hoped that this information will assist the field in understanding appropriate services and the rationale for those services.

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Appendix A Interview Guide

Demographic Questions

1. What is your child's diagnosis?
2. What is the diagnosed severity of his/her needs?
3. Which types of schooling did you choose for your child?
4. How many years has she/he been studying there?
5. What is your family structure (e.g. how many children do you have?; Do grandparents live with your core family?)
6. Which socioeconomic status do you identify your family?
7. What are your and your partner's educational levels?
8. How did you realize your child may have special educational needs?

Optional Questions

subjective perceptions of schooling options

- In your knowledge, what are the types of schooling available for your child?
- What is your opinion/ perception on Special/ Inclusive/ Home schooling?
- What differences do you suppose lie among these types of schooling?

factors affecting their thinking process

- Why did you choose the one your child is studying in?
- Who did you consult/ ask for suggestions before you made the schooling decision?
- What are factors affecting your decisions for placing their children in inclusive/special/ home-based educational settings?

personal experience of enrolling and studying in the chosen schools

- What was your experience in choosing / applying to the current school?
- What was your experience being denied enrolment in terms of your child's schooling?
- What is your most or least favourite memory about your child's schooling?

- What is your experience of being discriminated as a parent of child with ID?
- How does the school support your child's needs?

satisfaction of their choices

- What is your academic expectation for your child?
- How does this type of schooling facilitate your child's academic goal?
- How satisfied/ unsatisfied are you in term of your child's schooling experience?
- Why do you want to transfer your child to another type of schooling?

suggested improvements for current educational services

- What advice for schooling do you give for parents of child with ID like you?
- What would you hope to know before making the schooling decision?
- What would you like to change about the current schooling options?

Appendix B Participant Information Sheet

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Director Professor Jo-Anne Baird



Caregivers of Intellectually Disabled Children: A Qualitative Study of Caregivers' Perceptions on Educational Services in Developing Areas of China

Participant Information Sheet
CUREC Approval Reference: **[**ED-CIA-21-111**]**

1. ***Why is this research being conducted?***

In response to UN's calling for equal education for all, inclusive education (IE) as a humanistic approach for children with intellectual disabilities rapidly gains popularity throughout the world. Although developing countries like China made a substantial progress in establishing relevant educational policy, practical issues existed in special and inclusive educational systems require effective parent-teacher partnerships to improve the schooling quality for children with ID.

As the decision on types of schooling purely relied on parental judgement, it is important to explore parents' experience and perspective on the decision-making process. The current research proposal will investigate the multifaceted natures of decision-making process in schooling for children with ID in China from parents' experience and perspectives. It aims to enhance the understanding of parental engaging experiences, explain relevant decisions in schooling, and promote rational decisions of schooling for the best interests of the child in developing countries.

2. ***Why have I been invited to take part?***

Participation in this study will add to our understanding of parents' decision-making process. You have been invited because you are meeting all of inclusion criteria 1)

having a primary-school aged child 2) is diagnosed with ID by educational psychologists or professionals and 3) is studying in one of three schooling types, namely special education, inclusive education or home education

3. ***Do I have to take part?***

No. You can ask questions about the research before deciding whether or not to take part. If you do agree to take part, you may withdraw yourself from the study, without giving a reason by advising me of this decision. The deadline by which you can withdraw any information you have contributed to the research is August 1st 2021. Once you indicate your willingness to withdraw, all your data will be deleted completely.

4. ***What will happen to me if I take part in the research?***

If you are still happy to take part, I will ask you to sign a consent form. You will be invited to have a one-to-one interview with me in your native language, mandarin, at your preferred location. The interview should take approximately 1 hour. You can also ask to pause or stop the interview at any time. With your consent, I would like to audio record our interview, so I can have accurate record of your thoughts.

5. ***Are there any potential risks in taking part?***

The risks of this study are quite low. With regards to questions about parents' decision-making, we are only interested in the personal experience, shaping factors and perceived social norms. Participants may find some of the questions regarding their child' conditions a sensitive matter in which case they are free to omit the questions or withdraw from the study at any point with no explanation required. Their data can also be removed from the study at their request.

Also, participants will be provided with psychological support contacts if they request it at the end of the interview. Details of local psychological services as well as the contact details of parental support groups will be included.

The risk on breach of confidentiality is low since the data will be stored in a password-protected computer and then encrypted and stored using the University's secure storage system, OneDrive. Parent participants will be given pseudonyms, by which their responses will be identified throughout the research.

6. ***Are there any benefits in taking part?***

There will be no direct or personal benefit to you from taking part in this research.

7. ***What happens to the data provided?***

The information you provide during the study is the research data. No personal data other than audio recording will be collected which participant can be identified with. Sensitive data about their child's condition and severity will be collected. Personal and sensitive data will be stored in password-protected computer and then encrypted and stored using the University's secure storage system, OneDrive, for the duration of analysis.

Other research data (including consent forms) will be stored for at least 3 years after publication or public release of the work of the research.

The researcher and supervisor will have access to the research data. Responsible members of the University of Oxford may be given access to data for monitoring and/or audit of the research.

We would like your permission to use direct quotes against a pseudonym in any research outputs.

8. Will the research be published?

On successful submission of the thesis, it may be deposited both in print and online in the University archives to facilitate its use in future research. If so, the thesis will be openly accessible.

9. Who has reviewed this study?

This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee (Reference number: ED-CIA-21-111).

10. Who do I contact if I have a concern about the study or I wish to complain?

If you have a concern about any aspect of this study, please contact [redacted] or [redacted] and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:

11. Data Protection

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study.

The University will process your personal data for the purpose of the research outlined above. Research is a task that is performed in the public interest.
Further information about your rights with respect to your personal data is available from http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/.

12. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Appendix C Participant Consent Form

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Director Professor Jo-Anne Baird

Participant Consent Form

Central University Research Ethics Committee (CUREC) Approval Reference: ED-CIA-21-111

Caregivers of Intellectually Disabled Children: A Qualitative Study of Caregivers' Perceptions on Educational Services in Developing Areas of China

Purpose of Study: This research proposal aims to enhance the understanding of parental engaging experiences, explain relevant decisions in schooling, and promote rational decisions of schooling for the best interests of the child in developing countries.

		Please initial each box
1	I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any adverse consequences or penalty.	☐
3	I understand that research data collected during the study may be looked at by authorised people outside the research team. I give permission for these individuals to access my data.	☐
4	I understand that this project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee.	☐
5	I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.	☐

6	I understand how this research will be written up and published.	☐
7	I understand how to raise a concern or make a complaint.	☐
8	I consent to being audio recorded	☐
9	I understand how audio recordings will be used in research outputs	☐
10a	I agree to the use of pseudonymised quotes in research outputs	☐
10 b	I agree to take part in the study[1]	☐
10 c	I agree for research data collected in this study to be given to researchers, including those working outside of the UK and the EU, to be used in other research studies. I understand that any data that leave the research group will be anonymised so that I cannot be identified.	☐

Appendix D CUREC Approval

Dear Xinqian,

Title: “Parental Judgement and Decision-Making on Types of Schooling for Children with SEN in China”

The above application (reference number ED-CIA-21-111) has been considered on behalf of the Departmental Research Ethics Committee (DREC) in accordance with the procedures laid down by the University for ethical approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to DREC, the proposed research has been judged as meeting appropriate ethical standards, and accordingly, approval has been granted.

If your research involves participants whose ability to give free and informed consent is in question (this includes those under 18 and vulnerable adults), then it is advisable to read the following NSPCC professional reporting requirements for cases of suspected abuse
http://www.nspcc.org.uk/Inform/research/questions/reporting_child_abuse_wda74908.html

Should there be any subsequent changes to the project which raise ethical issues not covered in the original application you should submit details to research.office@education.ox.ac.uk for consideration.

Good luck with your research study.

Yours sincerely,
Joshua McGrane
Member of DREC