



A Qualitative Study on Parental Experience of Involvement in the Transition from Kindergarten to Primary School for Chinese Children with Intellectual and Developmental Disabilities

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Abstract

Parental involvement plays a vital role in the transition from kindergarten to primary school among children with intellectual and developmental disabilities (IDDs); this study aims to explore Chinese parents' experiences of parental involvement during this period. Informed by interpretive phenomenological analysis, semi-structured, one-on-one interviews were held with 10 parents. Three major themes were identified: (1) “aggressive” involvement; (2) factors in transforming parental involvement; and (3) “rational” involvement. Participants reported their perceptions, attitudes, and parenting behaviors in different phases of involvement in the transition to primary school. These findings highlight the need to support parents of children with IDDs during this time of change.

Keywords Parental involvement · Chinese parents · Transition · Intellectual and developmental disabilities

Introduction

The transition from kindergarten to primary school is a crucial period for children as they embark on their journey of formal education (Hong et al., 2022). For children with intellectual and developmental disabilities (IDDs), the changes in their life schedules, teaching and learning styles, and classroom routines during this transition pose a great challenge, which affects their adaptation to the new school environment and subsequent academic achievement and social development (Quintero & McIntyre, 2011; Nuske et al., 2019; Marsh et al., 2017). According to social support theory (Cohen & Wills, 1985), parental involvement is an essential social resource to help children cope with different challenges in their learning and development. Particularly for children with IDDs, parental involvement during

the transition to primary school not only strengthens their cognitive development and academic achievement, but also effectively alleviates their emotional and behavioral problems (Dockett, 2007; Pears et al., 2015). Recognizing the importance of parental involvement, in 2021, the Chinese government issued *The Guidelines on Vigorously Promoting the Scientific Transition from Kindergarten to Primary School*, which regards parental involvement as one of the best educational practices targeting children (Ministry of Education of China, 2021).

Owing to disorders in cognitive and language development, children with IDDs need parental involvement to improve their school readiness to address the challenges they face during transitions (Wang & Zhang, 2020). However, although there have been increasing studies on parental involvement in the transition from kindergarten to primary school in China (Lau, 2014; Xia et al., 2020; Hong et al., 2022), studies on children with IDDs are scarce. Further, most existing studies use quantitative methods to examine the predictive factors of parental involvement in the transition to primary school and the influence of parental involvement on children's school readiness (Lau et al., 2011; Slicker et al., 2021); however, we know little about the experiences and process of parental involvement in the transitional stage, including how it occurs, how it evolves, and

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what kinds of psychological experiences parents encounter in a natural and dynamic context. Hence, the current study aims to trace the trajectories of parental involvement to understand parents' experiences in the transition from kindergarten to primary school among children with IDD in the Chinese context.

The transition from kindergarten to primary school in China

In China, kindergartens provide early educational services for children aged 3 to 6. Generally, children are assigned to classes by age (in years) in kindergarten, including the bottom class (3–4), the middle class (4–5), and the top class (5–6). When children graduate from the top class in kindergarten, they enter primary school to receive compulsory education by the local education department. Due to greater demands for academic abilities (e.g., reading, writing, counting), social skills, and higher expectations of independence when children start primary school, Chinese parents help their children develop their school readiness as early as possible, even when children are just entering kindergarten (Gan et al., 2016). School readiness includes not only cognitive skills, but also all developmental domains, including learning methods and physical, social-emotional, language, and cognitive development (Xia et al., 2020). Poor school readiness during the transitional period may lead to children having academic difficulties and maladaptive behavior, increasing their likelihood of dropping out (Davies et al., 2016).

For children with IDDs, school readiness during the transitional period not only influences their future academic achievement and social development, but also determines, to a great extent, the educational placement of children with IDDs at the primary school level. In China, when children with IDDs graduate from the top class in kindergarten, local education departments bring in professionals (e.g., special education teachers, psychologists, clinicians) to assess their school readiness, thereby deciding whether children with IDDs will receive primary education in regular schools or special schools (Guo & Deng, 2021). Legally, only those who have the ability to receive general education (e.g., taking care of themselves, controlling their emotions and behaviors, and following instructions) can enter regular schools (Regulations of Education of People with Disabilities, 2017). Therefore, Chinese parents of children with IDDs are actively involved in their children's transition to improve their school readiness and strive for a more inclusive educational placement.

Parental involvement in the transition to primary school

Parental involvement refers to a broad range of parenting practices to promote children's learning and development at home and at school, including their educational beliefs, academic expectations, and various parenting behaviors (Seginer, 2006). Parents can be involved in their children's education in many ways, including providing parenting support at home (e.g., assisting with homework, monitoring the completion of an assignment, managing children's time) (Lee & Bowen, 2006; Clifford & Humphries, 2018) and participating in school activities (e.g., attending school events, volunteering, chaperoning, parent-teacher conferencing) (Barbarin et al., 2008; Hill & Tyson, 2009). An increasing number of studies have demonstrated that children with IDDs benefit from parental involvement in various developmental areas, including improved academic performance and social competence, reduced challenging behaviors, and enhanced maintenance and generalization of social skills (Brajša-Žganec et al., 2019; Otani, 2020; Yan & Hou, 2022).

In the transition from kindergarten to primary school, parental involvement (i.e., engaging parents in their children's education and learning) is positively associated with the skills necessary for school readiness and school adaptation, which are the pivotal parts of transitioning (Ahtola et al., 2011; Lau & Power, 2018). Positive parenting behaviors in parental involvement, such as parent-child interactions and parents' empathy and support for their children's negative emotions, can improve children's emotional adjustment and school readiness skills (Fenning et al., 2011; Demby et al., 2017). For example, Lau & Power (2018) found that mothers' involvement in language and cognitive activities during the transitional period predicted better school adjustment in primary school. Xia et al. (2020) reported that parents' home-based, school-based, and home-school conferencing engagement positively related to children's school readiness. In addition, when parents and teachers collaborate to support children, children with IDDs are more likely to experience a successful school transition and show enhanced school adjustment and engagement (Almalki et al., 2021). Given the strong and positive associations between parental involvement and children's transition to primary school (Hill & Tyson, 2009), a comprehensive understanding of parents' experiences to promote their children's school readiness during the transitional period is needed.

Parents' experiences of involvement in the transition to primary school

There are different perspectives in comparative quantitative studies on parental perceptions and experiences of

involvement among children with IDD during the transitional period. Some research suggests that parents of children with IDD are less involved in transitional activities for several reasons, such as a lack of time to participate in transitional planning, insufficient knowledge related to the transition, and low expectations for their children's development (Fontil et al., 2020; Almalki et al., 2021). Even if some parents of children with IDD have limited involvement in the transition to primary school, they always experience greater levels of parenting stress and depressed mood (Barker et al., 2014). In extreme cases, due to the fear of stigma, Chinese parents may choose to keep a child with a disability a family secret and are reluctant to send their children to primary school (Acar et al., 2021). Other studies, however, suggest conflicting results indicating that mothers of children with IDD perceive less stress and more control over their children and thus adopt more coping strategies (e.g., positive reappraisal, a way of rethinking the child's disability positively when families perceive it as a challenge and not as an immutable complication) to be involved in their children's education compared to mothers of children without IDD (Villavicencio & López-Larrosa, 2020).

The inconsistencies described above may reflect differences in parents' experiences at different stages of child development during the transitional period. In the early development of children with IDD, parents generally suffer from anxiety, stress, frustration, and hopelessness during their involvement in their children's education and interventions (Hsu et al., 2017). With the provision of social support and the improvement of parental psychology, parents gradually adjust their parenting behavior and actively participate in their children's education (Wang & Zhang, 2020; Chao et al., 2017). In fact, the view of parental involvement as a dynamic (rather than static) variable represents a major conceptual shift in the literature that acknowledges parents' accommodation of changes in their children's development and age-graded expectations (Hill & Taylor, 2004). Some studies show that the experiences of parents of children with attention-deficit/hyperactivity disorder (ADHD) are influenced by several factors such as guilt, hope, blame, stigmatization, exhaustion, reconciliation, and professional collaboration, which encourage parents to seek to overcome challenges and adapt to their new situation over time (Laugesen & Groenkjaer, 2015). Given the dynamic process of parenting, Chua (2015) proposed a "Triple-E framework" of parental involvement among children with autism spectrum disorder (ASD) comprising three phases: (1) parent enablement, in which parents need to be equipped with relevant information and resources on autism when their child has recently been diagnosed with autism; (2) parent engagement, in which, with support and resources, parents and school staff form a collaborative partnership to support

and improve children's learning, development, and health in the early stages of education; and (3) parent empowerment, in which parents experience personal and social changes, allowing them to take action to influence school organizations and institutions after establishing a cooperative relationship. Moreover, parental involvement varies across developmental age groups, as indicated by a qualitative investigation of experiences of parental involvement (Lisinskiene & Lochbaum, 2019). Further research is needed to examine whether parents of children with IDD have different experiences of involvement at different stages of the transition to primary school.

The present study

Increasing evidence suggests that culture shapes parental involvement in children with developmental disabilities, especially in non-Western cultures (Mitter et al., 2019). In most research, parental involvement tends to emphasize traditional forms of engagement practiced by the dominant White middle-class culture (i.e., school-based over home-based involvement) (Hill & Torres, 2010). Culturally responsive research conducted to understand parenting features in different cultures is essential for successfully enhancing transitional opportunities for children with IDD. Currently, relatively less is known about parental involvement in non-Western cultures. In particular, Chinese parents are more likely to participate in home-based educational activities rather than school activities due to the refusal of both principals and teachers to let parents take part in school management (Lau et al., 2011). Given their distinctive parenting behaviors, it would be interesting to examine experiences of parental involvement in Chinese culture.

Compared to parents of typically developing children, parents raising children with IDD face unique problems in the transitional stage. Influenced by the elite education of an exam-oriented system that emphasizes students' test scores, Chinese parents of children with IDD pay great attention to skills training and academic achievement and ignore children's social competence during the transitional stage (Yang, 2013). Some parents even implement advanced training to require their children to study the first-grade textbook in kindergarten (Yang & Wu, 2007). Limited research has been carried out on experiences of parental involvement among parents of children with IDD; further, some parents have expressed concerns about lacking skills and confidence to improve their children's school readiness (Wu & Sun, 2014). For example, Chen (2006) found that parents of children with visual impairments have weak enablement and empowerment in decision-making about transitioning to the placement that is best for their children. Other studies suggest that, due to lack of support, many parents want to

send their children with IDD to primary schools but fear rejection from teachers and schools (Guo & Li, 2019; Wang & Zhang, 2020).

This study seeks to build a detailed, contextualized understanding of the experiences and process of parental involvement in the transitional stage for children with IDDs. The findings are essential for putting forward more targeted strategies to improve the quality of parental involvement and to meet the needs of families of children with IDDs. Hence, the purpose of this study is twofold: (1) to explore the changing experiences of parental involvement during the transition from kindergarten to primary school among Chinese parents of children with IDDs; and (2) to describe what enablers and barriers lead to the changes.

Methods

Methodological approach

Due to this study's exploratory nature regarding the dynamic process of parental involvement, a qualitative research design was utilized. This study used interpretive phenomenological analysis (IPA), a qualitative research method with a small sample size and a focus on process change (Murray & Holmes, 2014). IPA is an inductive ("bottom up") technique to understand the subjective processes and meaning-making of individual experiences through analysis and interpretation (Smith et al., 2009). It focuses on individual experiences and reflections such as the cognitive, emotional, and behavioral changes that occur during important life events. IPA allows participants to voice their views by telling their stories in great depth, thus building up a detailed picture of complex issues that are under-explored (Goddard & Cook, 2021). In this study, the phenomenon of interest was the experiences of educational involvement among parents who have children with IDDs in the transitional stage from kindergarten to primary school.

Participants

Parents of children with IDDs were recruited using purposive sampling by collaborating with local resource centers of special education, which provide services and support to schools and parents of children with disabilities. They were asked to forward an ad including information about the study and the criteria for participation. Parents who met the following inclusion criteria were selected: (1) their children had been formally diagnosed with one or more developmental disorders (e.g., ASD, developmental delay, ADHD) by qualified medical institutions or health professionals; (2) their children were in the stage of transition from kindergarten to primary school (we decided that children with IDDs

who were preparing for or had just entered primary school and their parents would be eligible to participate); and (3) the parents had good verbal skills to smoothly communicate with the interviewers. The parents who volunteered to participate were asked to contact the first author through the e-mail address or phone number mentioned in the ad. They were contacted in response to validate the inclusion criteria, to provide them with further information about the study, and to schedule an interview. Additionally, snowball sampling was utilized to find participants willing to be interviewed by familiar parents and educators (e.g., teachers and principals).

An adequate sample size was established according to the researcher's evaluation that data saturation had been reached at this point, meaning that no new information or themes on core domains of parental involvement experiences emerged despite interviewing additional participants (Sparkes & Smith, 2014). Finally, 10 parents (8 mothers and 2 fathers) of children with IDDs were invited to participate voluntarily. All participants were biological parents of children with IDDs living in the provinces of Beijing, Henan, and Hebei. Parents were on average 37.50 years of age ($SD=4.17$). The children (six boys and four girls) ranged in age from 6 to 8 years ($M=6.70$, $SD=0.82$). All participants signed informed consent forms before participation. Additionally, they were told that participation was completely voluntary and that they were free to withdraw at any time. Pseudonyms were used to protect their identities. Table 1 shows the demographic traits of the participants and their children.

Data collection

According to the study's design, a semi-structured qualitative interview protocol was used as a data collection tool. As a first step, our interdisciplinary research team defined the broad topic areas related to the research question. The topic areas were: (1) the involvement process of promoting their children's transition from kindergarten to primary school; (2) factors influencing parental involvement; and (3) parents' feelings and perceptions about involvement in the transition to primary school. Subsequently, based on prior qualitative empirical studies on parental involvement (Lau, 2014), Chinese families, and the guiding theoretical framework, a stakeholder panel was convened to brainstorm questions related to each topic area. The panel comprised professionals from the disciplines of family education, psychology, special education, and the parent of a child with autism. After the brainstorming session, the first author, who has expertise in qualitative methods, crafted the interview guide. The final questions are presented in Table 2.

Table 1 The demographics of the participants

Participant	Age	Gender	Education level	Child's gender	Child's age	Diagnosis	School
Gong	32	Female	Junior high school	Female	6	ASD	Regular school
Jiao	39	Female	College	Male	6	ASD + ADHD	Regular school
Pei	42	Male	Bachelor's	Male	6	ADHD	Regular school
Liu	36	Female	High school	Female	7	ASD	Special school
Yang	42	Male	Master's	Male	6	Intellectual disability	Regular school
Zhou	35	Female	Bachelor's	Female	7	ASD	Special school
An	41	Female	College	Male	8	Angelman syndrome	Special school
Zhang	38	Female	Master's	Male	6	ADHD + Intellectual disability	Regular school
Yan	40	Female	Bachelor's	Male	8	ASD	Special school
Jia	30	Female	High school	Female	7	Intellectual disability	Special school

Note. ASD = autism spectrum disorder, ADHD = attention-deficit/hyperactivity disorder

Table 2 Semi-structured interview questions

Questions about parents' perceptions of parental involvement

1. How do you understand parental involvement?
2. What role do you think parental involvement plays in children's transition from kindergarten to primary school?
3. How do you think involvement in the transitional stage is different from other phases?
4. How do you feel about your involvement in the transition?
5. What areas of your children's development do you focus on in the transition to primary school?
6. How do you feel about your child's school readiness?
7. How do you feel about your parenting behaviors in your involvement in the transition?

Questions about the involvement process of promoting their children's transition from kindergarten to primary school

1. When did you begin to prepare your children for the transition?
2. What have you done to promote your children's academic development during the transition?
3. What have you done to promote your children's social competence during the transition?
4. Can you talk about your experiences of involvement in the transition?
6. How did you change your perception, feelings, and experiences during the transition?
5. What difficulties/challenges have you encountered in the transition? How were they solved?
6. As far as you know, what work did the parents of other children with IDD do in the transitional stage?
7. How did you communicate with teachers and school leaders during the transition?
8. How is your child adjusting so far? What problems have you encountered? How were they solved?
9. How did your parenting behavior change during the transition?
10. What adjustments have you made to your parenting behavior during the transition?
11. Please tell us about the events that left an impression on you at that time.

Questions about the factors influencing parental involvement

1. What are the factors that influence your involvement in the transition?
2. What kinds of support did you have during the transition?
3. What strategies have you used to improve your involvement in the transition?

All interviews were held between September and November 2020. COVID-19 has made face-to-face interviews difficult, so individual interviews were conducted over the phone. The collected data were analyzed and compared continuously to form a preliminary theoretical understanding, which then guided in the next direction of data collection until saturation was reached (Guest et al., 2017). Several parents were interviewed more than once to obtain more detailed information about their experiences. Overall, 22 formal interviews were held with 10 participants; Each interview lasted 30–90 min. Two researchers completed all the interviews in Chinese. The first author asked the main questions, and the corresponding author asked several supplementary questions as required. Each interview was audio-recorded with the participants' consent. Notes were taken during the interviews, and reflective diary entries were made afterward.

Data handling and analysis

The recordings were transcribed verbatim by professional transcribers, checked for accuracy by the first author, and subsequently imported into NVivo 12 for analysis. All participants were given pseudonyms to protect their privacy. Next, subject analysis was performed on the interview data (Braun & Clarke, 2006), including transcribed, simplified, and categorized data, dividing them into themes. This was independently carried out by the two authors (the first author and the corresponding author). Specifically, in the first step, the two authors thoroughly read the interview text many times to familiarize themselves with the data and then named the phenomena in the data to form initial codes to complete open coding. In the second step, based on the above work, the two researchers revisited the material and categorized the initial codes into subthemes through an iterative process. Finally, the connections between subthemes were determined, and the key themes that governed all subthemes were extracted. All authors then consulted with each other, reviewed their analysis, made necessary changes to

the coding scheme or interpretation, and reached a consensus on themes and subthemes.

After interviews with eight participants, no new topics emerged, and the data reached saturation (Strauss & Corbin, 1998). Interviews with the final two participants were used to confirm and validate themes extracted from previous interviews. After the themes were established, two bilingual authors translated the quotes included in the themes from Chinese to English.

The trustworthiness of the findings

In this research, the trustworthiness of data was enhanced through the following steps. First, this study improved the reliability of the data through the diversity of samples (Graneheim & Lundman, 2004). The participants had different educational backgrounds, occupations, and children with different types of disabilities (which determined their varying educational experiences). Second, member checking, also known as participant or respondent validation, was carried out to ensure the confirmability of the results (Stahl & King, 2020). After initial collation, we returned the data to the participants for confirmation that our transcripts truly and faithfully represented their experiences. Additionally, all four researchers had rich experience in handling interview data, two of whom had participated in the entire data analysis process; the third and fourth researchers were asked to check and verify the data. Third, the researchers continuously and critically reflected on their prejudices and positions to reduce potential subjective bias in data interpretation during the research process, thus determining the confirmability of the qualitative outcomes (Berger, 2015).

Ethical considerations

Several steps were taken to ensure the participants' safety and confidentiality. First, recruitment did not begin until institutional review board (IRB) approval was received. To ensure that all participants understood their rights as well as the study's goals, the first author verbally explained the consent and demographic forms to each participant in their preferred language. For parents with low literacy, she offered to read the questions on both forms, as well as to write down the parents' answers. To protect confidentiality, pseudonyms were used for the research site, neighborhood, and individual participants.

Table 3 Interview themes

Themes	Subthemes
1. Theme 1: Aggressive involvement	1.1 Views on disability and identity: "Difficult to accept" 1.2 Educational expectations: "To be a normal child and transition to a regular school" 1.3 An intense transition schedule: "Train as fast as you can" 1.4 Authoritarian parenting: "I can't stand when he/she disobeys me"
2. Theme 2: Factors in transforming parental involvement	2.1 Setbacks to children's development 2.2 Self-adjustment 2.3 Social support
2. Theme 3: Rational involvement	3.1A change in parents' attitude: "Accept him/her as a child with a disability" 3.2A change in educational expectations: "Reach your ceiling as you can" 3.3A change of educational scheme: The step-by-step approach 3.4 Democratic parenting: Treat him/her with respect and pay attention to his/her interests and hobbies 3.5 Active home-school interactions

Results

During parental involvement in the transition to primary school, parents' views on disability identity, parenting attitude, and parenting behavior would change with children's development and external and internal factors related with parents. Accordingly, parental involvement showed different characteristics. With thematic analysis, we classified the results into three key themes: (1) "aggressive" involvement; (2) "rational" involvement; and (3) factors in transforming parental involvement. Each theme was divided into several subthemes, as shown in Table 3. Specifically, corresponding to the two different stages of parental involvement, the first two themes reflect parents' psychological state and parenting behavior during parental involvement. The third theme encompasses factors that promote the transformation from aggressive involvement to rational involvement. Notably, we defined "aggressive" and "rational" as unique characteristics of parental involvement. However, we found that the transformation was not linear and unidirectional; instead different stages were characterized by twists and turns, and even stagnation.

Theme 1: Aggressive involvement

Aggressive involvement generally occurred in the early stage of school readiness for the transition to primary school. Parents blindly took a series of radical actions to participate in their children's education, regardless of their children's actual development. Based on an analysis of interview data with 10 participants, aggressive involvement could even be traced back to when the children had been

diagnosed with IDD. This theme was supported by the following subthemes:

Subtheme (1–1): Views on disability identity: “Difficult to accept”

Views on disability identity were directly correlated with parenting attitudes and behaviors in parental involvement in their children’s transition to primary school. Participants proposed that their views on children’s disability identity went back to when their child was just diagnosed. Almost every participant had good wishes for their children and hoped they would grow up healthy and safe. However, a diagnosis of ASD or developmental delay shattered their dreams. Nine parents said that after their children’s diagnosis, they struggled with the fact that their children had developmental disabilities for a long time. For example, one participant recalled when her daughter was first diagnosed: “I was on the verge of collapse and immediately became depressed. It was hard to accept the fact that my lovely daughter had ASD” (Gong). Another participant also expressed frustration after her child was diagnosed with Angelman syndrome: “It was overwhelming. I knew his performance was worse than other children, but I never thought he was a child with disability” (An).

When suffering setbacks, psychological pressure caused by an unexpected incident can make an individual feel tense, anxious, and unpleasant. In response to these negative emotional experiences, individuals usually activate “psychological defense mechanisms” to reduce the harm done to themselves (Brody et al., 2010). Denial—meaning an attempt to avoid the blow of reality by refusing to admit it—is a psychological defense mechanism. Most participants refused to acknowledge their children’s disability status at the time of diagnosis, as one participant said:

“If you had a child, you would feel this way. My son has all his limbs and looks normal, but the psychiatrist said he was sick [autism]. Instead, I thought it was the psychiatrist who was sick, not my son... It was hard for me to accept what the psychiatrist had said. You could say my son is not good enough, but you could not say he was sick. I denied it.” (Jiao).

Subtheme (1–2): Educational expectations: “To be a normal child and transition to a regular school”

Due to their denial of their children’s disability, most participants tried their best to eliminate the label of “children with disabilities.” They firmly believed that one day their children would develop typically. These participants

thought their children were just suffering from a temporary illness that could be cured. As soon as they discovered “a dose of good medicine” for their children, their children could become normal, like typically developing children. One participant raising a child with severe autism expressed hopes for her child to become normal:

“When my daughter was first diagnosed, she was able to talk. The doctor said that her language skills were relatively good. At that time, we had great expectations that she could be cured, and she could get better over time. So, I asked her to study like other ordinary children in daily life. How I long for her to become a normal child!” (Zhou).

With the expectation that their children would become normal, almost all participants hoped their children would transition to regular primary schools, following an educational path similar to that of typically developing children. There are multiple educational placements for children with IDD in China, such as inclusive classrooms and special classes in regular schools, as well as special schools. The participants believed that if their children attended regular primary schools, then the transition would be a success. As stated by one participant:

“At that time, we thought that when our child became normal, we would let him go to regular schools no matter what... Although he developed slowly and lagged behind other children, we still hoped that he could make good progress in his studies. The goal of our early intervention was to successfully transfer to a regular primary school.” (Jia).

However, the majority of participants expressed resistance to letting their children transition to special schools, even though nearly half of children with IDD in China—especially those with moderate and severe disabilities—attend special schools (Ministry of Education of China, 2021). These participants believed that children in special schools would weaken their children, even if their children were already severely disabled. One participant said:

“We don’t want him [the child] to go to a special school. The kids in the special schools are severely disabled. Although my child has many problems, attending a special school will make her learn more bad habits and bad behaviors. Who wouldn’t want their child to go to a regular school?” (Liu).

Subtheme (1–3): An intense transition schedule: “Train as fast as you can”

Almost all participants believed that the period between 3 and 6 years old was a critical time for the transition of children with IDD, during which children have to be trained as quickly as possible to develop school readiness. Due to the lag in children development, all participants were under great psychological stress to improve their children’s school readiness. To help their children successfully transition to primary school, several participants arranged an intense schedule for their children, including full-time kindergarten classes and after-school learning activities.

One mother admitted that from the age of three, when her child started rehabilitation, she had been committed to improving his school readiness through various means: “I have been preparing for him to go to a regular school. Since he was very young, we have taken him to various rehabilitation programs and learning remedial classes” (An). Before her child went to primary school, in addition to receiving full-time kindergarten education, this mother also arranged a two-hour rehabilitation training course for him. She would find a full-time institution for her child to study, even on holidays and weekends. She described this intense schedule as “seamless.” Another participant said she had made similar arrangements for her child:

“It made me anxious to think that my child would not be able to study in regular schools like normal children. So, I took her to early rehabilitation institutions when she was 3 years old. I also trained her at home... She was under high pressure for a long time, with classes during the day and studying at night. She wasn’t even six at the time.” (Zhou).

In their intense transition schedule, the participants focused particularly on the cognitive and skill development of children with IDD. To help their children better adapt to regular primary schools, the participants emphasized children’s acquisition of knowledge and skills (e.g., math, reading, writing), which are the main standards to measure children’s level of school readiness. One participant described her feelings at the time:

“When choosing a training institution, for me, the most important thing is whether the institution will teach children the knowledge and skills they need in primary school. There was not much attention paid to social communication. The regular primary schools placed particular emphasis on gaining knowledge, so I hope my children will not lag behind in this.” (Zhang).

Subtheme (1–4): Authoritarian parenting: “I can’t stand when he/she disobeys me”

As for parent-child interactions, parents are the absolute authority at this stage. Most participants mentioned that they often use coercive means to make their children obey them unconditionally due to their parenting stress. For example, one participant recalled how she treated her child and expressed regret:

“If I had it to do over again, I would not have done that to him. I thought I was so hard on him. Other parents might spoil their children, but I did not. At that time, I felt his ability was poor, so I was very strict with him. He had to do everything I asked of him. I barely thought about his feelings. Like, does he like it? Or can he accept it?” (Yan).

Similarly, another participant mentioned that when her child had emotional and behavioral problems, she did not compromise and did not do anything about her child’s crying. Furthermore, she often used coercive means to get her child to complete tasks she did not like. For instance, “She did not like coloring. But I ordered her to do it. She cried a lot. Even if I held her hand, I would make her finish [the drawing]” (Liu).

Another mother described her daughter with a developmental delay as “learning things slowly” and “careless.” When her daughter made errors in math calculations—a foundational skill for transitioning to regular primary school—the mother could not control her anger:

“I have taught her some pinyin and arithmetic many times, but she still makes the same mistakes. If it went on like this, no regular school would admit her, and she would have to go to a special school. Think about it: I am very angry. I really have no idea. I tore up her homework several times. I even wanted to beat her.” (Jia).

Theme 2: Factors in transforming parental involvement

Despite the participants’ efforts in the stage of aggressive involvement, their children did not develop as expected. However, many participants were able to overcome the crisis through self-reflection and social support. In terms of this theme, we now elaborate on the factors driving parental involvement for change.

Subtheme (2–1): Setbacks to children's development

Most participants mentioned that their past involvement approach had been characterized by a high-pressure parenting style that led to a variety of unexpected consequences, such as more severe emotional and behavioral problems, hostile parent-child relationships, and learning fatigue. For example, one mother said:

“During that time, for school readiness, we made his learning schedule too difficult. There’s too much pressure on him. When he took classes, we couldn’t point out any of his mistakes. Otherwise, he would fall apart emotionally. He cried and lay down and rolled on the ground.” (Yan).

Another participant mentioned that her daughter was afraid of her and often deliberately avoided her at that time. In her words, “being away from me was like being liberated from slavery...” (Liu). One participant also said: “My child is particularly afraid of me. Some time ago, he had just learned the word ‘fierce’ in the book. He said to me: ‘Mother, you are fierce, I am so afraid of you’” (Yang). Most of the participants stated that the high intensity of learning made children more tired of it. One mother said: “When my son heard that he was going to a class, he began to rebel and made all kinds of excuses not to go” (Jiao).

Subtheme (2–2): Self-adjustment

The participants reported that they often made self-psychological adjustments to reduce parenting stress, which resulted in a significant improvement in their emotional state.

“I always talk to myself and comfort myself. I admitted I’ve been impatient with my daughter.” (Gong).

“Anyway, I have been doing psychological construction for myself. I hinted to myself that my child is not bad.” (Zhou).

“I think I should be thankful that I did not end up getting worse. Now I do what I can do, and for what I cannot control, I let it go.” (Jiao).

Except for psychological comfort, the participants were also learning regarding their children’s education and rehabilitation in various ways. With the accumulation of knowledge, the parents began to understand the characteristics of their children’s physical and mental development. One parent recalled:

“Since my daughter was diagnosed with autism, I have been learning. I bought a lot of books on children with special educational needs. I have also attended

parent training, open classes, and lectures on taking care of children with autism.” (Zhou).

Several participants said they were greatly inspired by learning from previous ignorance about children with developmental disorders and understanding their fundamental characteristics. As stated by a mother:

“I gradually found out that these children are like this. They sometimes progress a lot, sometimes go backward significantly, sometimes learn something but forget quickly. It is a very normal thing. I’m not as anxious as I used to be.” (Liu).

Subtheme (2–3): Social support

In addition to self-adjustment, social support also promotes changes in parental involvement in the kindergarten-primary school transition stage. The participants reported that they receive social support from other family members, like-minded parents who also have children with IDD, and teachers.

In this study, most mothers took on the responsibility of looking after their children. Social support from other family members, such as the husband and children’s grandparents, could provide the mother with great emotional support in life.

“No pressure from my family. My husband and parents always told me, ‘Take it easy, do not get too tired, do not get too rushed.’” (An).

“My family always told me to go with the flow and be positive.” (Gong).

“I feel so relieved when my family gives me a hand. It’s just motivation. It feels like I’m not the only one struggling.” (Liu).

In interviews with parents of children with IDDs, they also frequently mentioned the concept of “people in the same boat,” which refers to other parents of children with developmental disorders. They believed that like-minded parents had empathy for them and felt a strong sense of belonging with them.

“I prefer to talk to parents of children with autism. We emphasize with each other, and our ideas are more integrated. We understand each other without having to say much.” (Liu).

“We can communicate our common concerns, and we can easily empathize. Especially for parents in this transition stage, they can understand some things that bother me.” (Pei).

Theme 3: The “rational” involvement stage

This theme describes parental involvement experiences after the transformation with self-adjustment and social support. At this stage, parents’ cognition, attitude, and parenting behavior shift toward a rational approach.

Subtheme (3–1): A change in parents’ attitude: “Accept him/her as a child with a disability”

As participants spent more time with their children and got to know them better, they recovered from the shock of the initial diagnosis. Their attitude toward their children’s disability gradually changed from denial to acceptance, which laid the foundation for them to exhibit more rational involvement behaviors. One participant regretted that she had been very intolerant of her child because of her child’s disability. When her child had severe emotional and behavioral problems in the past, she saw her daughter crying, angrily moving away from her hand, and she felt great sadness. She admitted that being so cruel to her daughter had made her forget that a child strongly needed maternal love:

“I probably did not accept it [autism] before. She often murmured to herself or yelled on the subway. I would get angry, and I just thought, you cannot do that. But now I think it does not matter if she does it because she is a child. That’s something she couldn’t change as a child with autism. I accept this.” (Zhou).

Another participant’s attitude toward her son had also changed a lot. She believed that her son was a gift from God, even though he was different from others:

“I feel happy now. I think this is another kind of happiness. In other words, even if my son with autism is not that good, I would not say he is terrible. We only expect him to be better, but it does not affect my love for him. When I look at my son now, I feel he is sweet, and I want to hug him and kiss him a lot of the time.” (Jiao).

Subtheme (3–2): A change in educational expectations: “Reach your ‘ceiling’ as you can”

The participants reported that their expectations of their children had changed from the initial hope that their children would become like their typically developing peers to the hope that their children would reach the highest level of development possible for them. One mother said that since

accepting her daughter as a child with ASD, her expectations had shifted to become more realistic:

“After taking care of her for some time, I came to realize what the child actually was. Then my expectations for her changed to be more realistic. I think it all depends on the child’s ability. Although her ability is not good enough, as long as she can maximize her potential to reach her own ceiling, I think it is a success.” (Zhou).

More than half of the participants reported that they were currently more concerned about their children’s future well-being than their academic achievements. Several participants remarked:

“It became clear that he is unusual, and we lowered our expectations. I hope that he can take care of himself and adapt to society and integrate into society a little bit in the future. I think that’s enough.” (An).

“Later, I think that a high degree does not necessarily mean anything. I think it is OK that a child has a good personality and loves life, and he can get that kind of happiness from his life and work in the future.” (Zhang).

Subtheme (3–3): A change in educational scheme: The step-by-step approach

Several parents gradually recognized that their previous intensive transition scheme did not promote their children’s development, but rather caused regression, such as more emotional and behavioral problems and learning fatigue. After learning about special education, they explored the step-by-step approach, which they found to be suitable for their children. They emphasized the importance of making educational schemes for children with IDD’s step-by-step, rather than expecting their children to make progress overnight:

“She has her growth curve. I used to have an intensive intervention program for her, but she didn’t make much progress. So now I have stopped forcing her to learn what everyone else learns. Anyway, I’m just following her foundation and helping her improve gradually. Sometimes, understanding her or empathizing with her may be better than suppressing her and intervening all the time.” (Zhou).

“Now it’s just a slow exercise, starting with the basics and teaching her step-by-step. You have to go at her pace, and if you push her or force her, it may end in misery.” (Liu).

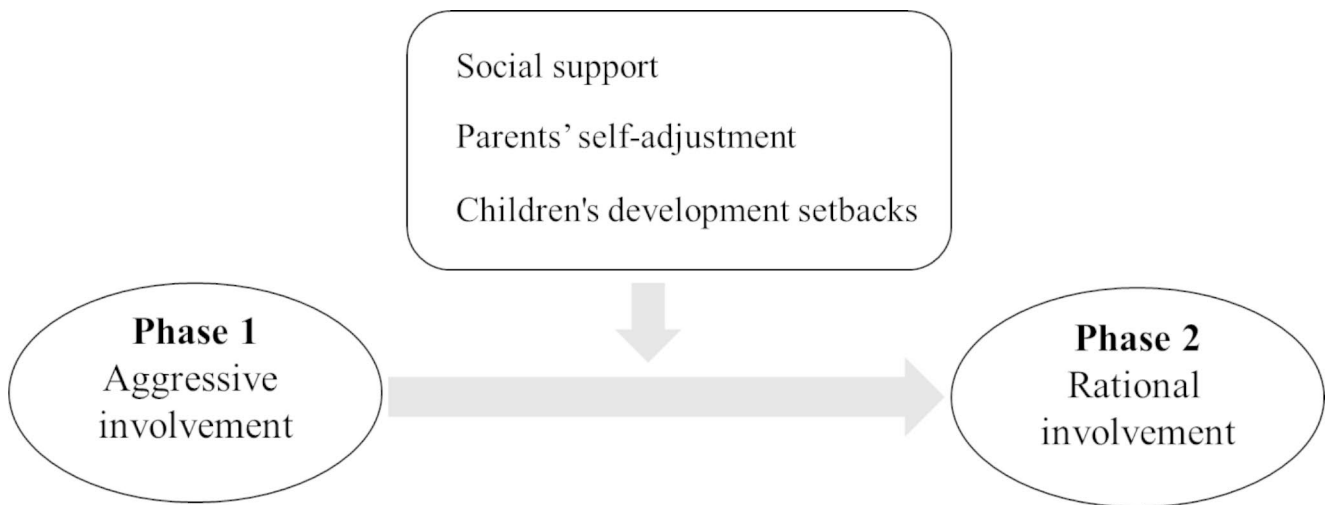


Fig. 1 A Two-phase Transformation Framework on Parental Involvement among Children with IDD

Subtheme (3–4): Democratic parenting: Treat him/her with respect and pay attention to his/her interests and hobbies

The majority of the participants reported that instead of absolute obedience, parental use of positive emotional expressions such as praise, understanding, and encouragement could contribute to a harmonious parent-child relationship. One participant said:

“I try to change myself. I am afraid that my strict demands on my child will leave a psychological mark on her. Now I often praise her. When I disagree with her, I will patiently listen to her ideas and explain things to her.” (Gong).

Another participant described her relationship with her child as “daggers drawn” because she was indifferent to her child and had either ignored him or forced him to respond to emotional and behavioral problems. However, later on, she tried to change her parenting behavior:

“I read a suggestion on the forum that parents should be patient and gentle with their children who are developmentally delayed. This was a great inspiration to me. So, I tried to change myself. For example, when my son cried, if he allowed me, I would wipe away his tears. If he did not accept this, I would stay with him and try to calm him down. At least I would not add fuel to the fire when he was in a particularly emotional state. And then, when he stopped crying, I tried to talk to him again.” (Zhang).

Most of the participants no longer only stressed the development of their children’s knowledge and skills, blindly

preparing for further study in primary school. Instead, they focused on cultivating their children’s interests:

“His academic performance may be quite different from that of other children, but I think as long as he does his best, I will not blame him.” (P-Zhang).

“My child likes to play in the water, so I took her swimming. I also think that in the future, when she is free, she can spend her spare time by herself, cultivate more hobbies, and have things she likes to do.” (Zhou).

Discussion

Parents can help children with IDD develop good school readiness, which plays an irreplaceable role in promoting the transition from kindergarten to primary school (Pears et al., 2015). This study aimed to explore experiences of parental involvement for children with IDD, focusing specifically on the change in parental involvement experiences during the transition from kindergarten to primary school and the factors leading to this change. The current study identified a two-phase transformation framework for parental involvement (Fig. 1), which is influential as parents shifted from aggressive involvement to rational involvement through self-adjustment and social support. The study provides initial insight into the dynamic process of parental involvement in the kindergarten-primary school transition among Chinese parents of children with IDD.

This two-phase transformation framework for parental involvement among children with IDD is partially consistent with the Triple-E framework on parental involvement of children with ASD in early intervention proposed by

Chua (2015). In the Triple-E framework, Chua divided the three phases of parental involvement in terms of the support that schools provide to parents, including parent enablement, parent engagement, and parent empowerment (Chua, 2015), which are different from the two phases of parental involvement in the current study. Chua acknowledged that it was hard for parents to accept the reality of the diagnosis of ASD and that they were usually at a loss regarding whom to seek help from and how. They even used many non-evidence-based practices (e.g., diet therapy, chelation therapy, herbal treatment, homeopathy) to “cure” autism in the phase of parent enablement, which corresponds to the aggressive involvement found in the present study. Parents feel hopeless when they do not have enough information (e.g., a place to enroll, the child’s educational path, available support) provided by schools or support systems. Conversely, if parents are given enough information and resources on their children’s disabilities, they can form a collaborative partnership with the school and undertake all activities that help their children achieve learning outcomes, which are reflected in the phase of parent engagement. Rational involvement in the current study shows certain aspects of parent engagement proposed by Chua, both of which emphasize parenting support and learning support at home (Chua, 2015). Notably, the participants in this study rarely mentioned their involvement in decision-making on the transition policy and related services provided by the school and kindergarten, which are highlighted by parent empowerment in the Triple-E framework. Previous studies have suggested that Chinese parents practice more home-based than school-based involvement (Acar et al., 2021). Chinese parents tend to conform to school requirements and supervise their children’s learning at home, resulting in less involvement in the transition in the school context.

As a contextualized concept in this qualitative study, aggressive involvement means that parents blindly took a series of radical actions to participate in their children’s education, regardless of their children’s actual condition. In the early stage of school readiness for the transition to primary school, most participants were unwilling to accept the reality of their children’s physical and psychological developmental delay and still had extreme academic expectations for their children. For this, these participants authoritatively arranged an intense learning schedule for their children, regardless of the children’s ideas, interests, or abilities, which inevitably resulted in aggressive involvement. These findings are consistent with previous studies showing that parents’ extremely high expectations for their children may lead to blind and aggressive behavior in participating in their children’s learning, which in turn hinders social development and academic achievement (Branjerdporn et al., 2021; Sun et al., 2020). This outcome seems to apparently

contradict the “Pygmalion effect,” a psychological phenomenon in which high expectations lead to better performance in a given area (Rosenthal, 2010); however, the potential explanation may be closely related to the elitism in the Chinese education system (Ma, 2020). Almost all Chinese parents, even those of children with IDD, have incredibly high expectations for their children, which encourages parents to overinvest in their children’s school readiness at any cost, particularly when it comes to academic achievement (Acar et al., 2021).

Furthermore, the psychological stress caused by improving children’s school readiness also encouraged parents to recklessly adopt more radical measures to enhance their children’s academic achievement to demonstrate their children’s abilities. This finding is consistent with previous research indicating that parents’ psychological status is an essential factor affecting parental involvement (Paulson et al., 2011; Schiltz et al., 2018). According to the spillover hypothesis theory, certain emotions or behaviors (positive or negative) of family members in a family system are transferred from one situation to another (Wang et al., 2020). Stressful events throughout life have spillover effects that reduce the motivation, frequency, duration, and quality of parental involvement in their children’s education (Yao & Liu, 2018). In current study, the higher parenting stress and greater psychological burden of parents of children with IDDs transferred to their participation actions (intense transition schedule and authoritarian parenting), leading to setbacks of children’s development and ineffective parenting behaviors of involvement in the transition to primary school.

These findings highlight that social support from family members and like-minded parents who also have children with disabilities could be a driving force in the transformation of parental involvement. This has been described in other studies on the critical impact of social support on parental involvement (Sharabi & Marom-Golan, 2018; Hamme et al., 2010). According to the convoy model of social relations, support from family members, friends, and significant others provides people with a protective base during various life stages, thus potentially enabling individuals to overcome pressures smoothly and promoting positive parenting behaviors (Antonucci et al., 2014). In the current study, social support improved participants’ sense of self-efficacy and alleviated their psychological burden, thus facilitating their rational involvement in their children’s educational activities, which echoes the convoy model of social relations. Additionally, participants mentioned that the emotional support they received from their partners and other relatives, and the empathic support from like-minded parents, changed their psychological state and participating behavior in different ways. These findings provide fresh

support to the conclusion in a quantitative study that various sources of social support have different effects on parental involvement (Yan et al., 2022).

This study indicates that most participants used rational involvement with internal psychological adjustment and social support. As another contextualized concept in this qualitative study, rational involvement means that parents make and implement transition schedules for their children with IDD according to their children's interests and abilities. Specifically, parents can accept their child's disability status and limitations and, based on that, set reasonable educational expectations and achieve them step-by-step, rather than expecting their children to make progress overnight. This rational involvement reflects the positive approach in parenting psychology as parents of children with IDD overcome early anxiety and depression (Sun, 2011). In Chinese family and relationship culture, with the strength of the whole family and social bonds, parents of children with IDD improve their resilience to achieve the adaptation of parenting involvement (Zhao, 2017). For example, Sun et al., (2020) reported that Chinese parents of children with developmental disorders gradually adjusted their negative emotions and eventually accepted their children as the parenting process progressed. This further confirms that Chinese parental involvement is a process of continuous rationalization through self-reflection and social support.

Conclusion and implications

This study described experiences of parental involvement in the transition from kindergarten to primary school for Chinese parents of children with IDD and the transformation factors they encountered in the process of parental involvement. By self-adjusting and receiving social support from the external environment, they underwent a dynamic shift from aggressive to rational involvement. This study identified these interpretive processes from the parent-centered voice, adding to the currently limited research on parental involvement in the kindergarten-primary school transition in China. In addition, the study also echoes conflicting results with periodic changes in Chinese parental involvement.

Our findings have potential implications for future research and educational practice directed at increasing parental involvement among parents of children with IDD. Social support from family members and like-minded parents who also have children with disabilities could be a driving force in the transformation of parental involvement. In particular, since Chinese parents of children with IDD are inclined to communicate less with their family and friends (He & Lin, 2013), intervention practitioners can encourage their family and friends to provide instrumental and emotional assistance to parents of children with IDD

to relieve parenting stress, ultimately promoting parental involvement. Additionally, interventions should focus on decreasing parenting stress, given that the parents in this study blindly took radical actions to participate in their children's education under high pressure. In this regard, research has identified different avenues to improve support for families of children with IDD, including individual and family, interventions, and service-related interventions (Desmarais et al., 2018). For example, mindfulness-based interventions, acceptance and commitment therapy, and emotionally-focused therapy have all been found to change how parents experience negative situations by teaching them to accept the sensations they encounter, thus enhancing parental well-being (Rayan & Ahmad, 2017; Lunskey et al., 2018; Lee et al., 2017). Finally, given the lack of systematic support for parental involvement in the transition for children with IDD in China (Xu et al., 2014; Guan et al., 2022), programs for social workers, teachers and decision-makers in government departments need to be conducted to build a supportive environment that secures a smooth school transition for children with IDD. For example, social workers need to provide psychological counseling services to alleviate parents' anxiety and helplessness during the transition phase, and conduct a series of advocacy activities to promote parents' active involvement in the transition. Teachers need to provide guidance strategies for parents to facilitate their children's readiness for school. More importantly, the government needs to empower parents of children with IDD to participate in decisions about their children's transition to primary school.

This study has several limitations. First, there may be recall bias because participants were asked to recall their past involvement experiences. Second, as with most qualitative research, generalization of the results is not the goal, but rather to increase understanding of the views of a particular population. Since this study is based on a small sample of Chinese parents of children with IDD, more research is needed before their involvement experiences can be generalized to all parents of children with IDD in China or other countries. Lastly, the study invited as many fathers as possible to take part in the interviews, but most participants were mothers. While this provides more information from primary caregivers, it may increase the potential gender bias of the responses. Moreover, it is difficult to examine the differences in involvement experiences between fathers and mothers for children with developmental disorders transitioning from kindergarten to primary school. Therefore, future studies should include a broader gender perspective and analyze potential gender differences by comparing the involvement experiences of different caregivers who raise children with IDD.

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Declarations

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Consent to participate: Informed consent was obtained from all participants included in the study.

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