

Intellectual and Developmental Disabilities

Being a "lay expert": A choice for Chinese parents of young children with autism

--Manuscript Draft--

Manuscript Number:	IDD-D-23-00001R1
Article Type:	Research
Keywords:	autism, rehabilitation, parents, belief, qualitative research
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Manuscript Region of Origin:	CHINA
Abstract:	<p>The lack of rehabilitation teachers for children with autism is common in lower-middle income countries. Designing programmes to train parents to become "para-rehabilitators", that is, "lay experts", is one of the ways to solve this problem. The purpose of this study was to explore the feelings, problems, and hopes of Chinese parents in the parent-implemented rehabilitation model. Semi-structured qualitative interviews with 19 parents of children with autism were conducted and analysed thematically. The study found positive changes in the parental understanding of and response to autism disorders, suggesting that the path of training parents to become "para-rehabilitators" to address the lack of rehabilitators is a useful attempt, and that improvement in training methods is needed.</p>

Being a “lay expert”: A choice for Chinese parents of young children with autism

Acknowledgments

The manuscript’s findings weren’t presented previously at a professional conference (oral or poster).

The authors thank the participating families to share their perspectives.

Conflict of Interest

No potential conflict of interest was reported by the authors.

Compliance with Ethical Standards

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee (Survey and Behavioral Research Ethics Reference no. 14600817) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent

all the participants were informed and consent to participate to the project.

Available of Data and Material

Due to the qualitative character of the study, the data and materials will not be deposited in a public repository.

Being a “lay expert”: A choice for Chinese parents of young children with autism**Abstract**

The lack of rehabilitation teachers for children with autism is common in **lower-middle income countries**. Designing programmes to train parents to become “para-rehabilitators”, that is, “lay experts”, is one of the ways to solve this problem. The purpose of this study was to explore the feelings, problems, and hopes of Chinese parents in the parent-implemented rehabilitation model. Semi-structured qualitative interviews with 19 parents of children with autism were conducted and analysed thematically. The study found positive changes in the parental understanding of and response to autism disorders, suggesting that the path of training parents to become “para-rehabilitators” to address the lack of rehabilitators is a useful attempt, and that improvement in training methods is needed.

Keywords: autism, rehabilitation, parents, belief, qualitative research

Being a “lay expert”: A choice for Chinese parents of young children with autism

Introduction

Autism spectrum disorder (ASD) is a pervasive developmental disorder characterized by impairments in social communication and interaction **and by** restrictive and repetitive behavior patterns (American Psychiatric Association, 2013). Children need be provided with intensive, consistent, and coherent **interventions, and parent training has been shown to yield gains in children’s social interactions (Ingersoll et al., 2016) and adaptive skills (Scahill et al., 2016), and to reduce their challenging behaviors (Bearss et al., 2015). Parental guidance is considered to be one of the most cost-effective, powerful, and useful strategies in the ASD field to address these problems,** which has led to more research on training and coaching parents (Wainer & Ingersoll, 2013). **However, barriers at the training provider and organizational levels have somewhat influenced the quality of parent training (Ingersoll et al., 2020).** Current training practices used in parent-mediated intervention studies include collaborative planning, modeling, guided practice, feedback, video review, and reflection (Sone et al., 2021; Tomeny et al., 2020). Available evidence suggests that adults learn better when (1) the learning material is relevant to their current needs; (2) practice and reflection are incorporated into the activity; and (3) the learning environment perceives their input as knowledgeable adults and experts appropriate to their situation (Merriam & Bierema, 2013).

Parental involvement in interventions and training is undoubtedly of greater importance for children in low-resource settings (LRS) that are unable to provide appropriate levels of care for people with disabilities (Blake et al., 2017). However, past research suggests that **racial, ethnic, and income disparities among children with autism and their families are part of long-standing systemic barriers to**

effective parent involvement (Stahmer et al., 2019). In lower-middle income countries, parents have few resources, including access to diagnosis and assessment, skilled professionals who can provide treatment, and inclusive environments to educate children with autism (Lee & Meadan, 2021).

Furthermore, it is important to consider cultural sensitivity, as the challenges that various developmental disabilities present to families may be culturally specific (Ha & Whittaker, 2022; Kong & Au, 2018; Xu et al., 2018). This means that specific research across cultural contexts is still necessary.

While China has made great strides economically, a country's success in treating children with disabilities appears to depend on a variety of factors. Lee and Meadan (2021) provide a framework for defining low-resource settings based not only on a country's income level, but also on the degree of accessibility of services, the degree of stigma, the financial burden on stakeholders, and the dissemination of level of treatment effort. The environment in which Chinese families of children with autism are located is undoubtedly an LRS. The recognition of childhood with autism in China was almost 40 years later than in advanced countries. There is a lack of understanding of children with autism throughout society, even among those with higher education (Su et al., 2021). A systematic and well-developed system for training teachers for autism education and rehabilitation has not been established (Wucailu Research Institute of Autism, 2022), and parents bear most of the responsibility for educating their children with autism (Liu & To, 2022), and also medical costs (Xiong et al., 2011). Moreover, most resources regarding autism interventions and services are located in large cities. The loss of income from remotely accompanying children to training in rehabilitation centers further adds to the financial burden on families (McCabe, 2010).

In such a context, enhancing parents' capacity for self-directed rehabilitation implementation

and making them more specialized and deeply involved in implementing rehabilitation as “lay experts” (Ho et al., 2014) may be extremely important for Chinese families with autism, who lack teachers and face high costs (Guo, 2012; McDevitt, 2021). In **high-income countries**, intensive parental involvement in rehabilitation has become a supplement. For many Chinese families of children with autism, it may be the only option to meet the condition that children with autism receive long term intensive intervention demand.

Institution A in China is one of the largest rehabilitation training education and research institutions for children with autism in mainland China. It advocates a model of intervention for children with autism that focuses on enhancing parents' rehabilitation skills. **Institution A is located in a four-story building, and its programmes include “fine”, “RDI”, “computer games”, “music games”, “sensory training”, “ABA individual training”, etc. It is a multi-faceted and integrated evidence-based intervention. From 8 a.m. to 12 p.m. and from 2 p.m. to 4:40 p.m., parents bring their children through the building and participate in modular rehabilitation sessions according to the Institution's assessment of their child's level of proficiency. Institution A requires parents to stay with their child throughout the entire programme, and asks them to carefully observe the behavior of the rehabilitator, take detailed observation notes and actively cooperate with the rehabilitator. There is usually a half day or day on the weekend for systematic rehabilitation implementation training and communication. Parents are taught to provide children with contextual learning in the home environment, especially “immediate, incidental, emotionally positive responses” during play (Ruble et al., 2008). Parents are encouraged to communicate in a natural, autonomy-inspiring, playful parent-child interaction, in this new way of parent-child interaction to perform interventions. The model aims to promote parents' deep**

involvement and ability to perform rehabilitation on their own so that they can become “lay experts” and perform better quality rehabilitation on their own when they leave the institution and return to an environment where teachers are not available. Parents go through the process of “observing the rehabilitator’s guidance - cooperating with the rehabilitator’s guidance – collaborating with the rehabilitator’s guidance - returning home to independent guidance”. However, there is little research examining the perspectives of Chinese parent groups in a rehabilitation training model that trains parents to become “lay experts”. **In-depth understanding of parents’ perspectives and experiences is needed, and feedback from parents is used to inform the adaptation of interventions in order to design services that are appropriate for parents to implement their rehabilitation needs. However, research related to PMI in China has focused more on the effectiveness of children’s rehabilitation and the psychological well-being of parents, and there is a lack of research focusing on the effectiveness and experience of parent training itself (Liu et al., 2020). Another well-known NGO in China, the Institute, focuses on improving parent rehabilitation implementation, and its model is to provide 4 to 11 weeks of ABA sessions per year. Approximately 40 families of young children are involved in each session (McCabe, 2008), a model that has limitations in terms of intervention approach in China, where there is a significant resource gap for rehabilitation. Although this Institution was established earlier, its experience is not informative for this study.**

To address this gap, an interpretive qualitative study was conducted. This qualitative study explored the perspectives of parents of children with autism in Institution A. The specific research objectives were to a) explore what these parents expect from rehabilitation for autism disorders; b) identify beneficial rehabilitation experiences gained by parents; and c) examine where training services

provided to parents could be improved.

Method

This study received ethical approval from the university ethics committee where the corresponding author works, and parents of children with autism were selected using a combination of purposive and convenience sampling. Semi-structured private interviews were conducted with parents of children with autism in the middle and late stages of parent implementation rehabilitation training. At the official start of the study, families were informed of the study description and signed a consent form. They were also informed of their rights, such as the freedom to refuse to answer specific questions and to withdraw from the study at any time.

Access to the site and selection of participants

Researchers entered the site as an ethnographic fieldworker. China is a late starter in this type of research, and some researchers may not have the capacity to provide comprehensive rehabilitation resources. This has left some families with the negative impression that “researchers are only there to benefit themselves, not to serve children with autism”. When parents are introduced to research through an Institution, they do not usually refuse, not because they are willing to participate, but because they may be concerned that offending the Institution may affect the child’s rehabilitation. Or it may be because of Eastern culture: they are embarrassed to refuse and have to give face to others. However, parents who participate in the study with such a negative mindset are bound to compromise the quality of the study. **Because of this, researchers did not contact institution A after arriving in the city where institution A is located, but stayed in a nearby hotel and sought opportunities for natural contact with parents with children with autism. A family with autism released a joint rental**

advertisement: the parents hoped to rent a room to reduce the family's financial burden. We went to explain our identity and purpose and the family agreed to share the rent but was not willing to participate in this study. However, we gained mutual trust in the shared residence after communicating, and the parents realized that parent feedback from the implementation of the intervention at Institution A was an extremely important direction that would be helpful to other families in the future. Therefore, we received support from the shared families, which was extended to other families with whom the family interacted, and then formally launched the recruitment of participants for this study.

The following inclusion criteria were used for the purposive sampling: the child had written evidence of a formal diagnosis of ASD without co-morbidities such as intellectual disability, epilepsy, etc. The reason for excluding co-morbidities such as intellectual disability and epilepsy is that children with autism with intellectual disability often require additional cognitive compensation. Children with autism with epilepsy must be treated with a combination of medications. There is also a qualitative difference in the degree of stigma associated with these disorders. This allows for significant variation in parental feelings and practices when implementing rehabilitation. Due to limited research effort and time, these samples were excluded from this study. Parents typically spend at least 6 months in rehabilitation at Institution A. Some may intervene for a year or several years, depending on various parental considerations, such as the child's intervention outcome, family financial burden, etc. In order to obtain fuller and more complete information about the parents' perceptions of the intervention effect, families that had not yet completed 6 months were excluded. A total of 19 families participated in this study, using a snowball sampling method that was stopped when information saturation was reached. Five of

the family participants were grandparents, but for consistency, the term “parents” is used in this paper.

(see **Table 1**). All participants speak Mandarin.

It is important to note that this study was conducted with families rehabilitated in Institution A. Parents from across the country compete for the few places available and have to wait in line for six months or more to join Institution A. Rehabilitation in Institution A means that families need to have good financial means for rehabilitation expenses because of being off-site. This leaves parents belonging to lower socioeconomic status often underrepresented, a situation that is prevalent in research on children with autism in China (Wucailu Research Institute of Autism, 2022). Moreover, there is usually one primary family member working full time with the child in Institution A and other family members working hard to earn money at the family’s original location, so each family member participating in this study is usually attending on their own.

Table 1. Demographic Information of Participants

Participant	Child’s Age	Diagnosis Age	Child’s Gender	Years of Parental Education		Family and Siblings
				Father	Mother	
P1(Mother)	51m	35m	M	16	16	Two-parent household, Older sister
P2(Mother)	73m	42m	M	16	16	Two-parent household, Younger brother
P3(Mother)	54m	39m	M	21	16	Two-parent household, Older brother
P4(Mother)	52m	40m	M	16	16	Two-parent household, Single Child
P5(Father)	55m	36m	M	16	15	Two-parent household, Single Child
P6(Mother)	68m	51m	F	16	16	Separated, Single Child
P7(Mother)	72m	48m	M	16	16	Two-parent household, Single Child
P8(Maternal)	51m	38m	M	18	15	Extended, Single Child

Grandmother)							
P9(Mother)	47m	35m	F	16	15	Two-parent household, Single Child	
P10(Mother)	49m	36m	M	18	18	Two-parent household, Single Child	
P11(Maternal Grandmother)	66m	40m	M	16	15	Two-parent household, Single Child	
P12(Mother)	66m	42m	M	18	15	Two-parent household, Older sister	
P13(Mother)	51m	36m	M	19	16	Two-parent household, Single Child	
P14 (Grandmother)	68m	43m	M	16	6	Extended, Single Child	
P15(Mother)	77m	45m	M	19	16	Two-parent household, Single Child	
P16(Mother)	67m	39m	M	16	15	Two-parent household, Single Child	
P17(Mother)	47m	33m	M	19	16	Extended, Single Child	
P18(Maternal Grandmother)	57m	42M	F	19	15	Living with Maternal Grandmother only, Single Child	
P19(Mother)	53m	37M	M	22	16	Two-parent household, Single Child	

Data generation

Data were obtained through semi-structured private interviews with the 19 parents. The interviews were guided by general questions, but also to some extent by the focus of the interviewees (Bogdan & Biklen, 2003). The general questions used were: Question 1: What do you hope your child's rehabilitation will be like? Question 2: What things do you feel have improved since attending the training? Question 3: What kind of help do you feel you need since attending the training?

To increase awareness of assumptions that may interact with the analysis process, a collaborative and reflective log was used. Each interview was conducted with two members, and upon

completion, their experiences during the interview were recorded and reviewed and compared to maintain awareness of personal biases, beliefs, and assumptions that may have influenced the study.

The choices of interview time and location for parents were based on their convenience. Some of the interviews with parents occurred while the children were waiting in rehabilitation or playing alone, and some occurred while walking to the supermarket. Every interview was conducted face to face with parents by the lead author and corresponding author. A tape recorder was used to record these interviews, and verbatim transcriptions were made as early as possible after their conclusion to allow for timely analysis. The length of each parent's interview ranged from 22-36 minutes. The researcher also paid special attention to the triangular argument of the materials: natural comments parents made about their children; field observations were conducted on the operating mode and course characteristics of Institution A; detailed browse was conducted on the internet forums commonly mentioned by parents as the forum contained many records uploaded by parents of children who were or had been rehabilitated at Institution A. These comments, observations and records confirmed the information stated by the participants, including the characteristics of the programme, the learning process, etc.

Data analysis

The analysis followed the procedures of IPA (Alase, 2017). An eight-person data analysis team was formed. Firstly, three authors repeatedly immersed themselves in the data by conducting keyword identification, clustering related concepts into themes, cross-referencing between transcripts and collation of initial and final emergent themes, which were then grouped into broader superordinate themes. Ongoing discussions of interpretation (debates and supporting responses) developed the final

interpretation through this process of confirming or refuting initial inferences. Five graduate students with experience in ASD research were then invited for consensus validation, and they analysed certain blocks of text to see if the categories they generated were consistent with those of the primary author. In addition, an independent researcher reviewed the process and materials of the study, including the manner of access to the site, the lead author's working notes, records of the analysis and discussion process, the consensus validation text, and the final text, to test whether the authors were highly self-aware and reflective (Smith et al., 2009). The three ASD rehabilitators presented the preliminary results of this study to the three participating parents and asked them if the labels and supportive concepts that measured the categories resonated with them. They found it to be the case.

Results

For "Question 1: What do you hope your child's rehabilitation will be like?" and "Question 2: What things do you feel have improved since attending the training?", two themes emerged from the participants' responses: "Parents' expectations of rehabilitation" and "Optimization of parental rehabilitation methods". For "Question 3: What kind of help do you feel you need since attending the training?", the participants' responses generated three themes: "Difficulties in rehabilitation implementation", "Mutual parental support", and "Mothers' responsibility", which revealed the main difficulties, the role of parents in solving the difficulties, and the responsibility of mothers in difficult situations. Transcript excerpts are used to illustrate the results.

Sub-theme 1: Parents' expectations of their children's rehabilitation

This sub-theme describes the expectations that participating parents have of their children with autism, both near-term and long-term. Concerning the near-term expectations, it was often described

“not wanting to be seen as abnormal” (P1). The point was emphasized by comparing the “smart” traits that Chinese parents generally value in their children:

“Tell him to look more natural, it’s okay to be stupid, there are other kids who are stupid.” (P1)

“It’s okay to be stupid, but if a child can’t speak, can’t play with others, ignores when people talk to him, loves to lie on the floor, it’s not a normal child, it’s not okay.” (P13)

The parents were worried about the reasons why their children were different from others, and the expressions flowing from the parents were not about the fear of losing parental face, but about the child’s mental health issues and future survival - fear of the child being alone, *“stuck in a rut with no one to save them”* (P2) and *“unhappy without friends”* (P7)

At the same time, parents also suggested that things get difficult when children reach school age, as they want children to be rehabilitated so that they can *“really study and work”* (P3), and that the immediate difficulty lies in *“the lack of support services for children with special needs”* (P4) and the deeper difficulty lies in the *“conflict between the characteristics of autism and the culture of Chinese society itself”* (P3). For example, as P3 and P4 said, *Autism is autism, and it can only be not eradicated. He cannot master the social scale that is most important for social beings, and in Chinese culture, this is an unthinkable obstacle.* Families with better financial means are hoping to migrate to a developed country (e.g., P10) or to find a private school to learn some skills (e.g., P15), while other parents hope that the government will provide better security, but at the same time express no hope for this.

Sub-theme 2: Optimization of the parental approach to rehabilitation

This theme describes important positive changes in parents’ perceptions and practices of rehabilitation when implementing rehabilitation.

Nine parents used a child-motivated, playful parent-child interaction approach to rehabilitation.

“Every day I let my child choose the game he most wants to play and then I play it with him, teaching him to talk in the process while playing” (P13), “Every day I ask my child to decide what to eat, go to the supermarket to buy something, talk about what she wants to say and do what she says” (P9), “He likes to draw; sometimes we sing together and he doesn’t understand the meaning of the lyrics, so I tell him first and encourage him to draw it himself; usually he understands it if he can draw it, then he tells the story and sings by himself looking at the picture he drew” (P10).

In the process of adjusting the parent-child interaction style, parents noticed the shortcomings of their original parent-child interaction style. Four parents described their changes. For example, *“I used to ask questions and let my child answer; now I chat, sometimes I say something wrong on purpose and my child happily corrects me” (P10) and “I used to talk a lot, five sentences from me and one from my child; now I wait” (P4).*

Three parents mentioned implementing a systematic approach to rehabilitation and how to do it in a layered and gradual manner. For example, P7 said to *“pick something similar in content that the child is already familiar with for training and slowly change the content when he gets it.”*

Almost all parents mentioned multiple, comprehensive use of rehabilitation resources, including not only internet resources, books, and school resources, which were commonly used by Chinese parents in the past, but also family resources (*asking friends and relatives to ask my child to help with something so that she can have a concept of “others”, P12*), community resources (*forming a playgroup in my neighborhood, P5*), research resources (*actively participating in academic topics related to autism, P3*), and other parent resources (*asking other mothers around to find out how to do better, P13*).

Sub-theme 3: Difficulties of parents in implementing rehabilitation

As many as twelve parents reported difficulties with understanding or application: some parents had problems with one aspect, and some had problems with both.

Seven parents mentioned difficulties in understanding the rehabilitation skills they had been taught. *"Sometimes I don't quite understand what the teacher says" (P1); "I seemed to understand it at the time, but I don't know how to apply it to my own child, so I still don't understand it" (P6).*

Eight parents mentioned that they understood the rehabilitation skills when they learned them, but had difficulty generalizing when applying them in a home context, partly because they could not think of applying them and partly because they had difficulty applying them in a rigorous and comprehensive manner. *I can't always think of generalizing life; I probably still don't understand it well enough (P2). I'm just the first two steps, change things and so on, you say really step by step to the end, I cannot do that (P4).*

From the participants' accounts, one of the reasons for the difficulty in understanding and application was that the separation in the learning process, including the separation between operation and theory, and the separation between operation and feedback. The parents hoped that: First, they hoped that the rehabilitators could explain the principles of each step while rehabilitating, instead of the rehabilitators only performing, while some principles were explained by other experts many days later. *"We would understand more deeply while performing" (P3).* Second, they hope that the theoretical lectures will be combined with examples, especially those that occur in life with high probability. *"There is no use in just talking about theory" (P9).* Third, they hope that everyday parents' performance confusion can be fed back during example observations and theory lectures. *"Occasionally some parents*

are invited to speak about their experiences; this would be particularly good, and those parents can always be approached to ask questions if they do not understand” (P12).

Another difficulty in understanding was the lack of opportunities for repeatable, self-paced learning, with participants repeatedly referring to the lack of videotaping, as described by P8:

I feel like the ones I understand, I still don't know how to do it myself, and I can't figure out what I'm doing wrong. I wish I had a video so I could watch it over and over again.

Sub-theme 4: Support from parents

In addition to parental involvement in rehabilitation training, Institution A has created an online forum for posting rehabilitation information and parent communication. Parents can ask questions about their problems, and parents who have encountered similar problems can give feedback on how they have dealt with the problem. Parents can also leave their contact information so that they can be contacted. Participants said that when they encountered problems, they would often search the forum first to see if there were similar situations. For example, P6 and P19 talked about the response to their children's education.

Our hometown is a small town and many parents of regular kids don't understand what autism means, and even the teachers can't figure it out. We wanted to write a letter to the teachers and parents explaining our child's situation before he or she started school; how would this letter be easy for others to understand? I searched the forum and found that parents had contributed various letters seeking understanding and help, from the school board to the principal, to the teachers. At the time, it was felt that it would be less difficult for us parents to move forward together as families with autism. (P6)

My child is starting primary school and I would like to chaperone as a shadow teacher, but the

teacher may not agree; after all, there is no such system. On the forum, I found the “step-by-step” method left by parents who have already “passed”: first, apply to accompany a field trip or prepare meals to give the teacher and the children a good impression; then apply to accompany the gym class; gym class needs someone to carry equipment, and more helpers make the teacher feel that the chaperone can help; then, pick up the children early and leave late. I wouldn’t have been able to think of these ideas on my own. (P19)

Several sections of the forum have a large number of exchanges. The first HELP section alone had 6,640 top threads as of December 20, 2022, and a top thread within the “HELP” section on the “Directory of Parents of Children with Autism” had been viewed 998,180 times.

Sub-theme 5: The responsibility of mothers

This theme shows the special nature of the role of mothers in the parent population of children with autism. The data show that mothers have full responsibility and accountability for the well-being of their children with autism. All of the nineteen parents interviewed were rehabilitating parents who were caring for their child’s life at home full time, of which only one was a father and fourteen were mothers. There were another four grandparents, three of whom were maternal grandmothers, who came out of a desire to share their daughters’ burdens.

The mothers had given up their former white-collar jobs to stay home, which they felt was necessary. Not only was it necessary for rehabilitation implementation, but also for their everyday life. Given the intensity and attentiveness required for rehabilitation implementation, the mothers felt that the only person who could take it on was themselves. As for life needs, the mothers also felt they knew their children best.

Almost all of the mothers expressed a desire to return to work in the future, but the employment they were considering was based on the premise that their children would be in their direct care. For example, working in an online shop where they could work from home, and some even:

I want to open a rehabilitation Institution in my hometown. My kid will still have a place to stay and have some company if they don't make it to elementary school. I can also earn some living expenses.

(P16)

Discussion

As found in our sample and in many other studies, parents of Chinese children with autism bear significant responsibility for the rehabilitation and development of their children. The present study also found that Chinese parents in the parent-implemented rehabilitation training model still have some difficulties in learning rehabilitation skills, but important positive changes are occurring in the quality of parents' implementation of rehabilitation skills.

The study found that, similar to existing research, participating parents emphasized that they wanted their children to look normal, but differed in that the reason for this hope was not because their child's disorder embarrassed and ashamed them and made them lose face (Su et al., 2021), but rather that they were worried about their children's future survival dilemmas, loneliness, and lack of help, considering the impact of the disorder on the children's own survival, development, and well-being in life. This shows that the traditional Chinese culture of valuing the dignity of parents and the family as a whole is receding in these parents' perceptions, and that love and attachment to children and the desire for children to have happy life experiences take a more important place. This change was even more evident when participants spoke of visionary hope. Unlike previous surveys, parents want to care not

only about their child's "basic survival," "basic inclusion," and "basic healing" (Marsack-Topolewski & Weisz, 2020), but also about whether the child can stand on their own feet. This is the pursuit of the child's happiness experience and the dignity of being an autonomous and self-sufficient human being. However, it is clear that parents' expectations go beyond what the Chinese government is currently able to do. While some parents have called for a government-led social system of support, there is a deep despair among some parents who believe that the situation is unlikely to fundamentally change because China is a relational culture (Qu & Wang, 2020). The traits of low socialization and low communication skills that children with autism possess have a natural dilemma in the face of this culture. **Such a conception adopts a form of the social model of disability. This all demonstrates the loving and respectful attitude of the participating parents toward their children.** One possible reason for such differences is the relatively good socioeconomic status of the participating families. Another optimistic speculation is that intensive parental specialization has provided parents with insight into their children's difficulties and the distress, allowing parents to shift their attention more from saving face to focusing on the child's own experience of well-being (He et al., 2015). There is also the possibility that parent-implemented rehabilitation has a more positive perception because parents are less stressed by being effective and empowered (Gentile et al., 2022). These need to be verified by further studies.

The study also found that in the present model, Chinese parents of children with autism showed an advancement in the level of rehabilitation instruction. It has been suggested that the parent-child relationship in Chinese families is more like an authoritative teacher-to-student relationship with an emphasis on imparting knowledge (Luo et al., 2013), whereas this study shows that some parents have begun to realize that they can improve by giving children more choices, and respecting children's

interests in their daily life. These new initiatives are more in line with the type of parent-child interaction needed to rehabilitate children with autism (Li et al., 2022). It has also been suggested that parents face generalization difficulties that are difficult to achieve or transfer in natural contexts (Patterson et al., 2012). For example, parents began to acquire more principles and skills of generalization, such as being aware of giving their children more independent choices to engage their children's autonomy and interest in participation, incorporating what they want to teach their children into things that they are interested in, focusing on applications in their lives, and attempting to generalize gradually.

However, the study also found that parents of children with autism still have great difficulties in implementing rehabilitation, including difficulties in deeply understanding and rigorously reproducing the rehabilitation behaviors of the rehabilitators. Parents not only need multiple learning approaches of "observe + listen + do", but also two adjustments to deepen their understanding of rehabilitation implementation skills in a multiple and integrated way, and to allow them to repeat and learn at their own pace by providing video materials. These directions of parental needs in China are consistent with the findings in the more **high-income countries** for the rehabilitation of children with autism (Merriam & Bierema, 2013; Rogers et al., 2019; Siller et al., 2018). Parents also have a strong need for parental support for their children, which is consistent with existing research (Chen & Li, 2011). In terms of parental support, even in developed Western countries where formal professionalized rehabilitation services exist, parents still feel the need for and benefit greatly from the support of other parents, parent support information channels and groups. In other words, for the training of Chinese parents in implementing rehabilitation and the construction of parental mutual support mechanisms, learning from international advanced experiences may be an important direction to improve the quality of

training of Chinese parents with autism in implementing rehabilitation.

The present study also shows the situation of mothers of children with autism. Consistent with existing research, mothers have an overwhelming sense of responsibility for their children, and it is not uncommon for a child's disability to have an impact on the mother's work and career, as has been seen in previous studies (Jones et al., 2013; McAuliffe et al., 2022; Nahar et al., 2022). Western research has shown that mothers with children with disabilities want to remain employed and seek work outside the home for a variety of reasons (Shearn & Todd, 2000); outside employment and the relationships that come with it make women feel that they are no longer "on the margins of wider society" (Shearn, 1998). In contrast, the sample of Chinese mothers in this study involved themselves more deeply in the lives of their children and had no intention of withdrawing from them. When considering re-employment, more consideration was given to working online and opening special agencies to still spend long hours with their children. However, this may place greater emotional stress on the mother (Zhou et al., 2018).

In addition, all families in this study were participants in a medium-term intervention programme in a large city, and there was lack of samples from low-income families. The underrepresentation of different populations may also hinder the replicability and generalizability of the findings. Therefore, ecological effectiveness needs to be considered when applying the results of this study. Bernal et al. (1995) first described an ecological validity framework to guide the cultural adaptation of existing evidence-based interventions. Lee and Meadan (2021) further developed the more refined Cultural Adaptation Checklist, including identifying intervention goals that are consistent with the target population's unique cultural values, building trusting relationships with community stakeholders, and so on. Institution A's parent training model, as well as the positive parent experiences

and reported needs identified in this study, need to be considered with equal caution when applied these aspects in other regions of China and other low-resource countries.

Limitations

This study used a qualitative approach in which a selected group of parents were interviewed for the survey. However, all of the families in this study were participants in medium-term intervention programmes in large cities, and with the cost of these programmes exceeding the income level of the average Chinese resident and the high level of parental education, the results of this study may not be representative of all families of children with autism in China. Another limitation of this study is that it was a project that lasted several months; a long-term longitudinal study would reveal the long-term decisions, feelings, and changes of families. Future research will need to track families who return home after implementing this programme to examine whether this type of assistance influenced participants' activities in their home regions. In addition to this, there is a need to include parents of Chinese children with autism in different situations to understand the actions and beliefs of families who cannot or choose not to participate in even short-term intervention programmes, and also seek quantitative studies to test hypotheses and reasonably assess the generalizable population of the study results.

Implications for practice

Data from the "Report on the Development of China's Autism Education and Rehabilitation Industry III", released in 2019, reveals a prominent contradiction between rehabilitation demand and service capacity (China Internet Information Center, 2019). This study suggests that if special teacher training programmes and rehabilitation personnel training programmes cannot meet the rehabilitation needs of children with autism in China in the short term, and given the fact that the rehabilitation of

children with autism is carried out by their parents, strengthening training in parent-implemented rehabilitation and enhancing parental rehabilitation executive capacity may be a more realistic solution.

Given the important positive changes in the rehabilitation perceptions, expertise and skills of Chinese parents who have improved their rehabilitation implementation, these measures to enhance parents' rehabilitation execution should be promoted. These initiatives to improve parental rehabilitation implementation should be promoted: parents directly observe and cooperate with the guidance of rehabilitation teachers in chaperoning, use their time each day to apply rehabilitation skills, and participate in training for systematic rehabilitation implementation. In response to the difficulties and problems mentioned by parents in the study, **the researchers also recommend that future treatment programmes pay special attention to: A. Repeatable hands-on materials, learning materials that help parents better understand difficult points and details, "hands-on with explanations" and "videos that can be watched again and again."** B. Hands-on instruction with feedback. Organize the sharing and exchange of experiences and lessons learned from rehabilitation among parents, both online and offline. C. Learning styles that can support each other rather than be isolated. Arrange lectures, observations, and hands-on exercises in a way that parents can easily understand. D. Support mothers in re-employment related to parent-implemented rehabilitation.

In addition, there are evidence-based strategies that have been identified as best practices in parent training curricula in high-income countries (e.g., modeling, role-playing, feedback coaching, practice planning). Introducing these international experiences within a framework of ecological validity may be an important direction for improving the quality of training for parents with autism to **implement rehabilitation in China.** As Wang (2008) perceptively pointed out, there is no need to spend

time and already scarce resources reinventing the wheel because most stakeholders of children with autism in the LRS cannot wait (Lee & Meadan, 2021).

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