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Barriers and facilitators to participation in everyday activities for children with intellectual disabilities in China

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Abstract

Background: Children with intellectual disabilities (IDs) are vulnerable and participate less in everyday activities compared to their peers with typical development. This study aimed to identify barriers and facilitators related to the participation in everyday activities of children with IDs in China.

Methods: Twenty semi-structured interviews were conducted with primary caregivers of children with IDs from special schools in Tianjin, China. The data were transcribed and analysed using inductive qualitative content analysis.

Results: Four categories of barriers to participation in everyday activities for children with IDs were identified: insufficient knowledge, attitudes and skills in primary caregivers; ID-related characteristics of children; stigma and Chinese culture; and lack of support from society. Four categories describing facilitators of participation in everyday activities for children with IDs were also identified: the optimistic attitude of the primary caregiver; adequate family support; active environment in school and policy; and attractive characteristics of children with IDs.

Conclusions: The findings in this study add knowledge on important barriers and facilitators affecting the participation of children with IDs in everyday activities in China. The primary caregivers' voices need to be heard by government and society. Appropriate and effective changes in family-oriented services and the legal, social, political and economic context of the child welfare management system for the scale-up of improving participation should be implemented for children with IDs.

KEYWORDS

barrier, children, China, facilitator, intellectual disability, participation

1 | INTRODUCTION

Based on non-discrimination and equal opportunities according to a human rights approach to disability as presented in the United

Nations Convention on the Rights of the Child, children with intellectual disabilities (IDs) have equal right as their peers with typical development (TD) to fully engage in everyday activities (Huus et al., 2016; Sutherland, 2019). In China, children with IDs account for 70% of all disabilities among children (Zheng et al., 2012). Studies have shown that children with IDs participate less in everyday activities compared to their peers with TD (Samuels et al., 2020; Shields et al., 2014). The

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restrictions are related to the interaction between the children's impairments and the physical or social environment (Boström et al., 2018; Imms et al., 2017; King et al., 2013; Samuels et al., 2020). Investigations of barriers and facilitators have mainly been conducted in developed countries (Robertson et al., 2015). There are still no studies about barriers and facilitators affecting the participation in everyday activities of children with IDs in China.

Disability is a complex phenomenon, covering impairments, activity limitations and participation restrictions (WHO, 2001). Participation, highlighted in The International Classification of Functioning, Disability and Health (ICF) (2007), is an indicator of health and well-being and reflects the interaction in everyday activities between body impairments and societal barriers for children with IDs (Imms et al., 2017; WHO, 2001, 2007). Based on ICF and participation, the Family of Participation-Related Constructs (fPRC) framework presents participation as including two dimensions: attendance and involvement (Imms et al., 2017). Attendance relates to how often children engage in an activity, while involvement may be seen as the subjective feeling of having participated related to motivation, engagement, perseverance, social connection and level of affect (Arvidsson et al., 2021; Balton et al., 2020; Eriksson et al., 2007; Maxwell et al., 2012). In ICF, environmental and personal factors are referred to as important for performing everyday activities and for participation (WHO, 2001). Everyday activities are those that 'occur frequently in the natural environments where children spend time' (Adolfsson et al., 2011).

Previous studies report that the lower levels of participation in everyday activities among children with IDs have multiple causes and may vary between cultures (Dada, Bastable, Schlebusch, & Halder, 2020; Earde et al., 2018; Huus, Schlebusch, et al., 2021; Samuels et al., 2020). Barriers are seen as factors that hinder an individual from participating in activities (WHO, 2007), such as financial burdens, over-protection by family and a child's own personal insecurities and fears (Earde et al., 2018; Hansen et al., 2014). Facilitators are factors that support functioning and increase the opportunity for a child to participate in everyday activities (WHO, 2007), such as resource-ready environments, peer acceptance and a child's own self-acceptance and sense of success (Earde et al., 2018; Hansen et al., 2014; Shields & Synnot, 2016). To enhance participation, it is important to understand and overcome barriers and utilize facilitators in the child's environment (Shields & Synnot, 2016). Studies of facilitators and barriers are warranted in the Chinese culture context (Kang et al., 2017). Primary caregivers face children with IDs every day and can provide valuable insight into the barriers and facilitators to participation experienced in the current Chinese context (Dada, Bastable, & Halder, 2020). The aim of this study was to gain an understanding of contextual factors that were perceived by primary caregivers as barriers and facilitators when encountered in relation to the participation in everyday life of children with IDs in China.

2 | METHODS

A descriptive and explorative design with a qualitative semi-structured interview was used to understand primary caregivers' perceptions of

Key messages

- The barriers and facilitators affecting the participation of child with IDs in everyday activities as perceived by primary caregivers in China were related and complex and can be translated into actions.
- The importance of participation for the development of children with IDs needs to be further promoted and recognized through education and public awareness in China.
- Developing the strategies to give full play to the positive function of a multi-faceted service model that integrates economic support, spiritual support, social integration support and respite care or child-sitter service for the primary caregivers, may encourage children with IDs to participate more frequently in everyday activities.

barriers and facilitators to participation for children with IDs. The inductive qualitative content analysis approach was implemented.

2.1 | Ethical considerations

Ethical approval was obtained from the local ethics committee of Tianjin Medical University, People's Republic of China (TMUHEMEC2016017), and the study was conducted in accordance with the Declaration of Helsinki (World medical association declaration of helsinki, 2001). The participants took part voluntarily and were informed of their right to withdraw from the interviews without giving any reason. Assurance of confidentiality was given by coding the participants' interviews with numbers at the transcription stage, and ensuring no individual was identifiable in the results. All the data were stored on a password-protected hard drive and used only for this project.

2.2 | Participants

The participants were part of an ongoing study which aims to obtain cross-cultural validation and psychometric evaluation of the simplified Chinese version of 'Picture My Participation' (PMP-C; Simplified) (Shi et al., 2021). Primary caregivers from four special schools in Tianjin, urban area, located in the north part of mainland China (2019 to 2020) were invited to participate. The inclusion criteria were that the primary caregiver provided most of the care and support for his/her child with IDs and had lived with the child for at least 1 year, had completed the PMP-C (Simplified) questionnaire (Shi et al., 2021) and was able to speak and understand Mandarin. Potential participants among primary caregivers to children that were diagnosed at a hospital as IDs ($n = 106$) were selected at the respective special schools. A purposeful sampling method was used. Teachers were asked to strategically

select primary caregivers varying in age, gender, relationship to child, educational level, occupation representatively and the child's age, gender and severity of IDs as defined by the Chinese Wechsler Intelligence Scale (C-WISC) and the Infant-Junior Middle School Students' Social Life Ability Scale (revised version of the Japanese S-M Social Life ability test), the disability is considered mild or moderate (Barbour, 2001) (If IQ and adaptive behaviour were both indicated as under threshold, the child was diagnosed as having ID). On the basis of these principles, the teacher was instructed to select the primary caregivers who usually communicated with her in a functional manner. A total of 22 primary caregivers were invited to participate, where of two primary caregivers declined. Semi-structured interviews with primary caregivers were completed until data saturation was reached by the twentieth interview (Creswell & Creswell, 2013). The characteristics of the 20 primary caregivers and their children with IDs are presented in Table 1.

2.3 | Data collection

Written informed consent information was sent out via the teachers to 22 participants at the respective special schools and 20 participants

agreed to take part in the study. The first author obtained the primary caregivers' phone numbers from the teachers and made an appointment directly for the interviews. Two pilot interviews were done by the first author to test the interview guide. It had predetermined topics and a topic guide mapped to the domains of the PMP-C (Simplified). Participants were asked: (1) Recall your feelings or experiences about your child's activity 'participation' during the PMP-C (Simplified) interview (the frequency of participation and the intensity of engagement while participating). (2) What factors made it (a) easier (facilitators) or (b) harder (barriers) for your child to participate in everyday activities? The primary caregivers were encouraged to choose particular activities in the PMP-C (Simplified) that were important to discuss, and probing questions were used to obtain more detailed information, such as 'Did your child experience any problems in participating in these activities? If yes, can you explain more about it?' and 'How did you deal with these problems?' After the pilot study, one guiding introduction 'Tell me about your child, what he/she like to do' was added to the interview outline which helped to establish the topic of interest. As no important changes were made in the interview guide, these two interviews were later included in the data analysis. All the participants were interviewed and audio-recorded by the first author face to face for between 30 and 60 min in a room at special school.

TABLE 1 Characteristics of the primary caregivers and children

No.	Primary caregivers				Children with IDs		
	Age	Relationship to child with ID	Educational level ^a	Employment status	Age	Diagnose	Impairment ^b
N1	38	Mother	High	Full-time job	12	ID with asthma	Mild
N2	64	Aunt	Low	Unemployed	14	ID	Mild
N3	43	Father	Medium	Full-time job	12	ID	Moderate
N4	35	Mother	Medium	Unemployed	10	ID	Moderate
N5	44	Aunt	Medium	Part-time job	9	ID	Mild
N6	50	Mother	Low	Unemployed	16	ID with diabetes	Mild
N7	37	Mother	Medium	Unemployed	11	ID with autism	Moderate
N8	43	Mother	Medium	Unemployed	15	ID	Mild
N9	33	Mother	High	Unemployed	10	ID	Moderate
N10	44	Mother	High	Unemployed	17	ID	Mild
N11	35	Mother	Medium	Full-time job	11	ID	Mild
N12	41	Mother	High	Full-time job	17	ID with cerebral palsy	Mild
N13	70	Grandmother	Low	Unemployed	14	ID	Mild
N14	47	Father	Medium	Full-time job	17	ID	Mild
N15	68	Grandmother	Low	Unemployed	12	ID with congenital heart disease	Mild
N16	40	Father	High	Full-time job	11	ID with autism	Moderate
N17	42	Father	Medium	Full-time job	13	ID	Moderate
N18	36	Mother	High	Full-time job	9	ID	Mild
N19	39	Mother	Medium	Full-time job	10	ID with epilepsy	Mild
N20	58	Aunt	Low	Unemployed	13	ID	Mild

^aLow: elementary school or low vocational education. Medium: secondary school or intermediate vocational education. High: higher vocational education or university education.

^bID (moderate): IQ 35–49, moderate deficits in the adaptive behavioural level; ID (mild): IQ 50–69, mild deficits in the adaptive behavioural level.

2.4 | Data analysis

All the interviews were audiotape-recorded and transcribed verbatim. The data were analysed with qualitative inductive content analysis (Elo & Kyngäs, 2008). There were three main procedures in the analysis: preparation, organizing and reporting (Elo & Kyngäs, 2008). To prepare the unit of analysis, the transcripts were read to obtain a sense of the whole. Data was organized through open coding to create abstractions. In the open coding, the transcripts were read and coded inductively. Then, the notes were transferred to a coding sheet where similar notes were grouped together. Similar codes were then collected on a separate sheet for analysis, subcategories were identified. By further abstraction, similar factors in the subcategories were grouped together on a separate sheet, categories were generated. The transcripts analysis was primarily conducted by the first author (LJS), the emerging codes, subcategories and categories were critically discussed and analysed by the other authors until consensus was reached. All the authors are familiar with the research field.

3 | RESULTS

There were 20 primary caregivers who consented to participate in an interview: Sixteen were women and four were men. The average age of the participants was 45 (range 33–70). Four participants lived alone with child because they were unmarried or divorced.

Four main categories of barrier and facilitator emerged from the data to display the full range of primary caregivers' perspectives.

3.1 | Barriers to participation for children with IDs

Four categories were identified as barriers: Insufficient knowledge, attitudes and skills in primary caregivers; ID-related characteristics of children; stigma and Chinese culture and lack of support from society (Table 2).

3.2 | Barrier 1: Insufficient knowledge, attitudes and skills in primary caregivers

The most prominent barriers to participation described by the primary caregivers were 'Insufficient knowledge, attitude and skills' of the primary caregivers themselves. Some primary caregivers said they did not realize that having adequate knowledge, skills and an optimistic attitude was crucial before taking part in this study.

3.2.1 | Knowledge deficiency

The primary caregivers said there were gaps in their knowledge about what 'participation' meant and why it was important for children. They also described their lack of knowledge about how to help the children with IDs to develop.

I spend a lot of money on buying health products for my son to improve his intelligence ... I'll be satisfied if he eats and drinks well, I do not know how to make him develop and I did not notice the 'participation' in his everyday activities, no one tell me. (N 11, mother)

3.2.2 | Negative attitudes

Primary caregivers of children with IDs expressed different degrees of frustration and loss of confidence about their daily life. They did not trust children with IDs to look after themselves and were less inclined to create any opportunities to facilitate the children's contact with social activities. On the contrary, to let their children stay at home was a protective mechanism.

I have slim hopes for my child's future. I feel sorry for giving birth to him so I want to give him the best care

TABLE 2 Barriers of participation in everyday activities for children with IDs

Subcategories	Categories
Knowledge deficient	Insufficient knowledge, attitudes and skills in primary caregivers
Negative attitudes	
Lack of caregiving skills	
Children have limited physical functions to perform the activity	ID-related characteristics of children
Children have limited mental functions that require environmental adaptations	
Public stigma and Chinese culture	Stigma and Chinese culture
Self-stigma and Chinese culture	
Stigma by association and Chinese culture	
Lack of support from family	Lack of support from society
Lack of financial support	
Inadequate inclusion policies	

... if someone calls him Sha zi (fool), I cannot stand it, I have to let him stay at home ... if I die in the future, I'll take him with me (N7, mother)

She cannot understand the instructions of the game and sometimes she shouts, so children with TD do not want her to play with them. (N18, mother)

3.2.3 | Lack of caregiving skills

The participants described difficulties in educating the children with IDs. They were confused and claimed that they lacked caregiving skills and did not know how to act when a child was easily provoked and unable to control his emotions.

His father always beats him, the child's stubbornness may be irritating him, he does not know how to deal with it except by beating (N6, mother)

3.3 | Barrier 2: ID-related characteristics of children

Primary caregivers said that professionals have told them that their children's impairment and comorbid behavioural and/or psychological problems could reduce their participation in everyday activities. They had realized that the barriers for children with IDs to play with peers with TD included their limited ability in physical, understanding and communicating skills.

3.3.1 | Children have limited physical functions to perform the activity

Some identified barriers to participation in everyday activity were related to the child's characteristics and the consequences of ID-related vulnerability. Children with IDs may have more risks for conditions with complications (i.e., epilepsy, obesity, asthma and congenital heart defects), which further hindered their participation in everyday activities.

Because she had a congenital heart defect, she cannot run, jump, chase and fight like other kids. She spends most of time on watching TV or playing with toys at home. (N15, grandmother)

3.3.2 | Children have limited mental functions that require environmental adaptation

Many primary caregivers said that it was hard to know children's preferences when there was limited communication and children with IDs are at high risk of acquiring challenging behaviours that puts the children and others at risk. This made it impossible for the children with IDs to be able to be involved in playing with peers.

3.4 | Barrier 3: Stigma and Chinese culture

Some primary caregivers claimed that a very important reason to that children with IDs have poorer participation in everyday activities is discrimination from the family members, relatives and those around in society. As a set of prejudicial attitudes and discriminatory behaviours still exist in Chinese culture, the children with IDs are generally regarded as a disadvantaged group.

3.4.1 | Public stigma and Chinese culture

The primary caregivers described how the children with IDs were still called 'retarded children' in Chinese culture; it was a public stigma. As children with TD and their parents refuse to have a classmate with IDs, there is no interest in training institution that is willing to enrol children with IDs. The primary caregivers said that public stigma denied their child full social acceptance and reduced the opportunities to attend activities.

People in the neighbourhood seem scared of the IDs and thought it was neurosis or an infectious disease. Sometimes we go to the park, they all stay far away from us ... my child likes to sing, but no teacher accepts him (N13, grandmother)

3.4.2 | Self-stigma and Chinese culture

The primary caregivers of children with IDs reported that self-stigma led them to try to conceal their child's illness and face it negatively. The primary caregivers also described 'mian zi (face-saving)' as a traditional idea in society in China; if you were known to have a child with IDs, it was shameful for you. The primary caregivers also said that a boy does not need to do household chores following the traditional notions of male superiority in Chinese culture.

I do not want my colleagues to know that my son has an intellectual disability. I could not accept him in the beginning ... I did not want to take him to attend a party. I feel a deep sense of shame ... A boy does not need to learn to do housework, his sister would do it. (N19, Mother)

3.4.3 | Stigma by association and Chinese culture

In China, the words 'handicap' or 'retard' are still used to describe persons with physical or mental disorders. The primary caregivers said

that they did not feel comfortable when others used the word 'handicap' or 'retard', and they automatically generated negative attitudes towards taking their children to participate in any activities.

This is my secret trouble, I cannot find relief from anxiety, his grandfather cannot accept his grandson, similarly, relatives do not invite us to their home, they fear their child will learn bad habits from my son. (N4, mother)

3.5 | Barrier 4: Lack of support from society

The primary caregivers said that lack of support from family, insufficient financial resources and an inadequate inclusion policy acted as barriers, and they could not get enough support from the professionals, for example, physicians, nurses and teachers. They believed that long-term isolation from society has burst the bubble of their self-confidence, which leads to less participation.

3.5.1 | Lack of support from family

Many primary caregivers said that children's disability can lead to family conflicts and divorce. They understood the benefits of attending more activities, but some children with IDs required one-on-one supervision to participate in activities. Most of the time, playing with their children was not prioritized when balancing this with the other needs of the family.

It's hard to have a child with IDs by myself alone (divorced), I feel so stressed that there is no time to attend any activity. Teaching him to do something will make me more tired, so I seldom did. (N8, mother)

A lack of support was more of a concern in single-parent family or when the parents themselves had disabilities. Other family members had to take on the parents' responsibilities.

I'm helpless. Because taking care of this child takes up all my time and energy, I do not have time to think about my own life and I'm not married yet. (N5, aunt)

3.5.2 | Lack of financial support

The primary caregivers stated that it cost 10 times as much to raise a child with IDs as it did to raise a child with typical functioning. Insufficient financial resources often meant that their child's activity needs were not a priority. This was a potential limitation to participation in some activities.

My family's economic condition is poor, I have to work. I do not have time to take him to the park and I do not have money for travelling The state grants are not available until the child's graduation. (N1, mother)

3.5.3 | Inadequate inclusion policies

Many primary caregivers said that it is difficult to access government support and IDs are different from other disabilities, such as physical disabilities. Unemployment is the main problem for the intellectual disability population. However, there is no special policy for families having a member with IDs.

I do not know any other policy support except that children's disability tickets are free ... you have to buy a school district house and then you are eligible to go to the special education school ... I cannot imagine what he will do after graduation. (N10, mother)

3.6 | Facilitators of participation

Four main categories of facilitator were identified: the optimistic attitude of the primary caregiver; adequate family support; attractive characteristics of children with IDs and active environment in school and policy (Table 3).

3.7 | Facilitator 1: An optimistic attitude of the primary caregiver

The primary caregivers thought that the most salient facilitators of participation for children with IDs were themselves, who recognized that their own internal characteristics (e.g., knowledge, motivation, attitude and habits) had an impact on promoting the child's participation in everyday activities. The primary caregivers were aware of the importance of participation for children with IDs to strengthen social connections. They were willing to put in time and effort in relation to their child's well-being.

3.7.1 | Family commitment

The primary caregivers said that they had the total responsibility to take care of the child and make the child better. Having clear goals encouraged them to make a big move in providing opportunities for the child with IDs.

I have to take full responsibility to make him better. I do not care about the discrimination from others when

TABLE 3 Facilitators of participation in everyday activities for children with IDs

Subcategories	Categories
Family commitment Positive motivation	The optimistic attitude of the primary caregiver
Having enough 'hands' Social interaction with siblings and peers	Adequate family support
Cheerful personality and self-acceptance Well-mannered appearance	Attractive characteristics of children with IDs
Rich and colourful curriculums and activities Integration of vocational education and enterprise development Free ticket policies	Active environment in school and policy

we go out together; my child enjoys his life is the most important thing (N3, father)

support; otherwise I do not know what I would have done ... and they gave me money to raise the child ... (N9, mother)

3.7.2 | Positive motivation

The primary caregivers said that they accepted that the child was not perfect and they were the best teacher for their children. The different level of positive motivation resulted in a different situation for the whole family. It was a very important factor, providing a positive attitude towards life for children with IDs.

This is my first time to be a mother, God gave me a more difficult task, so I have to do my best to do it ... I always learn by myself from the internet about how to take care of the children with IDs. I think the more I learn, the better my child will be (N12, mother)

3.8 | Facilitator 2: Adequate family support

The primary caregivers said that family and peer support was very important for the participation of children with IDs. The interaction with siblings and peers was a particularly powerful facilitator for the children with IDs.

3.8.1 | Having enough 'hands'

The primary caregivers said that with the grandparents' help, all kinds of burdens (financial, living care and housing) seem to be relieved. A family structure in China called '4-2-1 or 4-2-2' means that four grandparents and one adult couple care for one or two kids. In this situation, the primary caregiver can have the time and energy to engage in social interaction with children.

I am very grateful to my parents for helping me to take care of my child and for giving me psychological

3.8.2 | Social interaction with siblings and peers

The primary caregiver explained that the aim of having the second child was to give the child with IDs support, especially when they were old and died. They knew playing with peers made their child with IDs more engaged in activities and made these activities feel more meaningful and enjoyable. They also provided examples of how their children tried to emulate their peers to improve their child's ongoing participation.

His younger sister is very helpful to him. He enjoys doing what his sister does. If you tell him, he will not learn, but if he sees his sister do it once, he will do it. The younger sister always takes him with her to dancing, performing, singing and so on. (N18, mother)

3.9 | Facilitator 3: Attractive characteristics of children with IDs

3.9.1 | Cheerful personality and self-acceptance

The primary caregivers said their children had an open and frank disposition, were enthusiastic and sincere to others. They were simple and happy every day, and if they enjoyed an activity, they were more likely to have autonomous motivation for the activity.

The child has learned to be polite, he says 'hello' and smiles at everyone He plays basketball every day. When he wins, he is excited (N20, aunt)

3.9.2 | Well-mannered appearance

The primary caregivers said that if the child was cute and well dressed, it was relatively easy for them to attend games or audition classes, and people may not realize she had IDs at first glance.

She is a good-looking girl, clean and agreeable at first sight. We went on a trip last year and she had a great time talking to a grandmother on the coach (N14, aunt)

3.10 | Facilitator 4: Active environment in school and policy

In China, there are an increasing number of government policy, education or skilled service providers to help children with IDs. Based on the implementation of the colourful curriculum, the primary caregivers believed that the school improved the level of participation of children with IDs, and free ticket policies also play an important role.

3.10.1 | Rich and colourful curriculums and activities

The primary caregivers said there are many courses and activities in the school. Some primary caregivers highlighted that individual activities were more appropriate for their child to develop skills, such as a course with local characteristics called 'carving porcelain', 'kneading clay figures' and 'calligraphy', while other primary caregivers said that a team environment facilitated their child's social interaction.

Since the child has been to the school, she has learned a lot. She likes to go to school and enjoys learning the waist drum dance (a kind of dance in China). (N2, aunt)

We've heard of various activities held by the school, for example, going to nursing homes for volunteer service, Disabled children's sports meet, parent-child games and so on. (N17, father)

3.10.2 | Integration of vocational education and enterprise development

The primary caregivers said that the government tried to encourage some special companies to hire disabled people, such as cleaning companies and some small handicraft factories. However, the resources of supports and services for children with IDs were still limited; not all schools and companies can provide such cooperation opportunities; some professional partnerships had been developed between the school and the companies; it also need to expand the social attention and help to these children.

We've heard of the activity held by the school and company, playing dress-up games to experience the different occupations. I know a kid who graduated last year went to a factory belonging to the disability agency, I hope that there are more and more factories like this (N10, mother)

3.10.3 | Free ticket policies

The primary caregivers said that having free transportation and free admission to scenic spots was the best policy for children with IDs.

As transportation is free, I can take her on fun trips to some places, such as museums, aquariums, science museums, zoos, etc. If it was not free, I could not afford it. (N16, father)

4 | DISCUSSION

Primary caregivers reported on barriers and facilitators of participation for children with IDs in everyday activities that seem to be each other's opposites, but in fact, they are related and complex. The categories were comparable to self-report based studies involving children with IDs from Sweden and South Africa (Huus, Morwane, et al., 2021) and expand our current knowledge about the environmental challenges for children in China. The similarity suggests that a child's personal functioning, social exclusion and lack of support are universally related to barriers, while personal capability, being included and having access to resources are identified facilitators (Huus, Schlebusch, et al., 2021). Interventions that are aimed at improving participation in everyday activities for children with IDs need to take account of these factors.

The knowledge, attitudes and skills of primary caregivers were both barriers and facilitators for the participation in everyday activities for children with IDs. Primary caregivers' insufficient knowledge, attitude and skills were key barriers while the optimistic attitude of the primary caregiver promoted the child's participation in everyday activities. The findings are consistent with previous reports (Barr & Shields, 2011). Since the living environments of a majority of children with IDs in China are arranged and managed by their primary caregivers (Coussens et al., 2020; Zheng et al., 2012), the family circumstances are crucial determinants of children's participation. Family circumstances are represented by the context- and environment-related constructs of the fPRC model (Imms et al., 2017) and the knowledge-attitude-practice model (KAP) (Kwol et al., 2020; Li et al., 2020). In these models, primary caregivers, as a key component of the child's context, can regulate their child's participation opportunities (Raval & Walker, 2019). It is likely that good knowledge and positive attitudes in caregivers influence child behaviours that enhance child engagement in 'practices' (Conchar et al., 2016; Downs et al., 2013; McGarty & Melville, 2018). The results suggest that the

concept of participation should be further promoted, at the same time, educating the primary caregivers about entitlement of service for their children with IDs. The interviews revealed that the primary caregivers seemed to unsure where to seek help. The primary caregivers' voices must be listened to by the healthcare authorities and professionals to further identify their difficulties and needs. An important issue for healthcare professionals as well as administrative institutions for special education is to offer rehabilitation training curricula and series of lectures regarding caring and education of children with IDs, especially about how to respond to challenging behaviour and mental health problems of children with IDs. Family support provisions can be embraced and enhanced in China. Offering and implementing appropriate support adapted to the Chinese culture, such as family-centred service and support, inclusion policies and volunteer services for children with IDs should be prioritised to enhance the participation of children with IDs.

The characteristics of children with IDs have been reported as being both a barrier and a facilitator for participation in everyday activities (Barr & Shields, 2011). This was also found in the present study. According to primary caregivers, children with IDs experienced difficulties in their participation due to cognitive difficulties and having multiple chronic conditions that affect energy level (e.g., obesity, congenital heart disease, diabetes, epilepsy and asthma). Therefore, one task for health professionals is to educate primary caregivers and children with IDs about health as a prerequisite for participation. Another task is to properly design and implement abundant programs aimed at accessibility, safety and enjoyment for children with IDs. On the other hand, our study reveals that if children expressed a positive perception of themselves and had a well-mannered appearance, it facilitated participation. It is likely that children with IDs that are perceived as natural and have a great motivation to communicate with other people are also included (Barr & Shields, 2011; Mahy et al., 2010).

Social support is a process that 'arises from formal support (policy and government organisation) and informal sources (family, friends and neighbours) around the children with IDs' (Mantri-Langeveldt et al., 2019). Such support processes were sometimes perceived as barriers to participation in the present study. Many primary caregivers experienced difficulties in obtaining support from family, financial institutions and policy-makers. The limited development of the primary healthcare system and medical insurance system highlighted this barrier within a Chinese context (Chiu et al., 2013). A lack of formal provision of services and support probably puts a heavy burden on families (Chiu et al., 2013). Thus, appropriate and effective support promoting participation of children with IDs should consider how responsibility is shared between the habilitation services, special school and other health services. In this study as well as in a previous scoping review, family support can be perceived as a facilitator of participation (Anaby et al., 2013). In this study, family support was seen as both a facilitator and a barrier. The '4-2-1' or '4-2-2' family structure in China is complicated and changing, which means that four grandparents and one couple care for one or two children. If the grandparents are healthy and helpful, satisfaction with sharing the caring responsibility of the child with IDs was evident. However, the

system can also result in one couple caring for four grandparents and one or two children, which actually can make the situation worse. Another forceful facilitator of participation found in this study as well as in earlier studies was peers (Iacono et al., 2016). Positive peer interaction can enhance family functioning and the influence of social support on improving the participation of children with IDs (McGarty & Melville, 2018).

Primary caregivers of children with IDs not only face the economic and caring burden but also have to deal with the stigma imposed by society in China (Chiu et al., 2013; Papadopoulos et al., 2019). Chinese mothers internalize the stigma of having a child with IDs, attributing it to inadequate care or a gene. Children with IDs can be seen as 'bad seeds' leading to a loss of face for the whole family (Yang, 2015). Primary caregivers of children with IDs perceived themselves as marginalized by their community, which led to concealment of the child with IDs, and withdrawal from social relations (Chiu et al., 2013). Additionally, findings from the present study indicate that male gender may be a barrier to participation in housework, due to traditional notions of male superiority in Chinese culture (Xu et al., 2005). Based on these results, the government and society should pay more attention to primary caregivers and their children with IDs and call for the people of the whole society to treat them equally and kindly. At the same time, appropriate and effective support should be planned and implemented for primary caregivers to relieve them from caring for children with IDs and contribute to improving their children's participation in everyday activities, for example, respite care, child-sitter service, provide tax breaks for families of children with IDs and paid leave for primary caregivers who care for their children.

In the present study, the active involvement of school is a strong facilitator for participation of children with IDs from the primary caregivers' perspective. They were satisfied with the curriculums and activities in school for meeting the needs of children with IDs (Simeonsson et al., 2001). Even though great progress has been made in Chinese social policy for children with IDs, there is a long way to go (He et al., 2018). The result of this study indicates that primary caregivers are confident with the Chinese government's policies for vulnerable groups, under the positive atmosphere of the school, grassroots efforts by caregivers also should be encouraged (Zheng et al., 2012), several grassroots initiatives have been launched to share information and resources of caring children with IDs, provide parent-to-parent support and take their children to participate in more parent-child activities together. These efforts will give full play to the positive function of the family and establish self-rational support and promote the development of national policies related to disability in family-oriented services.

5 | CONCLUSION

The results of this study highlight the importance of eliminating barriers and utilize facilitators to improve the participation in everyday activities for children with IDs. In order to help children with IDs,

societal recommendations for developing appropriate and effective strategies to shape public policy in China are needed. In addition, the family-centred service plans can be used to empower primary caregivers in China to encourage their children with IDs to participate more frequently and enhance their engagement in everyday activities.

6 | STRENGTH AND LIMITATIONS

As part of the effort to help present the primary caregivers' voices, this is the first study to consider Chinese cultural factors and it provides a comprehensive description of barriers and facilitators to participation in everyday activities of children with IDs in China. However, the participants who participated in this study only included primary caregivers of children with mild to moderate IDs from special schools in urban areas, so the results may lack representativity of primary caregivers of children with IDs from other settings.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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