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Participation in Outside Home Activities in China: A comparison of Typically Developing Children and Children with Developmental Disabilities

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ABSTRACT

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Background: There are personal factors and environmental factors playing impacts on the participation of children with developmental disabilities in China. **Aim:** The aim of this study is to investigate the participation of children with developmental disabilities in outside home activities compared to typically developing children. **Method:** A quantitative cross-sectional method was used in this study. Participants were children with developmental disabilities (autism spectrum disorder and intellectual disabilities) and typically developing children between the age of 5 to 13. An instrument called 'Picture My Participation' (Simplified Chinese version) was used for data collection. **Results:** In general, typically developing children attended more frequently and felt more involved than children with developmental disabilities in outside home activities. There were many similarities in attendance between the two groups of children. They both attended more frequently in formal learning at school, shopping and playing with others, and less frequently in spiritual activities, social activities, and trips. Some differences were found in the activities with lower levels of involvement. Apart from the spiritual activity with the lowest mean score of involvement in both groups, typically developing children felt less involved in organized leisure and trips. However, children with developmental disabilities had lower levels of involvement in health center visits and social activities. There was no significant association between age, gender, place of residence, and participation in neither the attendance nor involvement aspect. **Conclusion:** Both intrinsic and extrinsic factors play essential parts in the participation of children with developmental disabilities. More support should be provided to children with DD.

Keywords: participation, developmental disabilities, Autism Spectrum Disorder, Intellectual Disabilities, China

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1. Introduction

Participation in various kinds of activities can promote children's mental and physical health (Mahoney, Larson, & Eccles, 2005; Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001). For typically developing (TD) children, the activities they participate in may take place on many occasions, such as at home, in the community, and at school (WHO, 2001).

However, it is not the same for children with developmental disabilities (DD). Children with DD are more likely to attend leisure activities inside the home, in other words, the passive activities that they do alone or with their family members or assistants, rather than their peers (Solish et al., 2010). There are many outside home activities that include physical, recreational, and social activities conducted outside the home context and involve people other than family members. Children with DD are often excluded from these outside home activities (Solish, Perry, & Minnes, 2010).

Some previous research reported the difference between genders and age groups in participation (Badia et al., 2011). To children with DD, the limitations in communication, social interactions, and adaptive behaviors may also be potential barriers to participation (American Psychiatric Association, 2013). The environmental factors also play important impacts on restricting children with DD in the outside home context. It is even more critical for children with DD in China. Apart from the large number of populations in China, there are limited supportive facilities in the public areas, insufficient health care professionals working for children with DD, developmental gap between rural and urban areas, as well as some people's negative attitude against disability (Campbell & Uren, 2011; Hu & West, 2015; McCabe, 2008).

This study analyzed the participation regarding attendance and involvement in outside home activities in China. Comparisons were made between TD children and children with DD. Instead of from the perspectives of parents, teachers, and other professionals, this study took the perspectives of children themselves.

2. Background

2.1 Participation

Participation is defined as “involvement in a life situation,” which plays a vital role in children’s health and well-being (WHO, 2001). It is “a feeling of belonging and engagement experienced by the individual in relation to being active in a certain context” (Eriksson & Granlund, 2004). According to the United Nations Convention on the Rights of the Child [UNCRC] (1989), children with disabilities have the right to enjoy the best possible life and participate actively in the community, including getting access to education and different kinds of activities.

There are many studies showing the benefits of participation in various activities for children with disabilities. Previous research shows that participation in social, recreational, and physical activities is beneficial to individuals with and without disabilities to their physical, emotional, and social development (Murphy & Carbone, 2008). Meanwhile, the activities are of great importance to the ones with disabilities. Because these activities increase their chances of interacting with others and making friends (Kampert & Goreczny, 2007). The activities also let them present with another identity, such as football players or artists, instead of just individuals with disabilities (Devine, 2004; Høiseth, 2012). Besides, their self-efficacy and social competence will develop during these experiences (Hutzler & Korsensky, 2010).

The International Classification of Functioning, Disability and Health (ICF) is a biopsychosocial framework that provides a global standard for defining and measuring health-related conditions from three perspectives of health, including biological, individual, and social (WHO, 2001). According to ICF, functioning is defined by body functions and structure, activities, and participation. Correspondingly, disability is a concept that should be considered in relevant aspects, including impairments in body functioning and structure, limitations in activities, and restrictions in participation. The levels of functioning of individuals with disabilities are the outcome of interactions between health conditions and contextual factors. Among the contextual factors, there are both environmental factors and personal factors. Thus, it is essential to consider both personal factors and external barriers when investigating the participation of children with DD in outside home activities (Badia et al., 2011; WHO, 2001).

2.2 Personal factors

First of all, the features of DD can limit their participation in outside home activities. Autism Spectrum Disorder (ASD) and Intellectual disability (ID) are two major types of DD that account for a high proportion of children with DD (American Psychiatric Association, 2013). ASD is an enduring condition, and the symptoms vary between individuals. There are three types of common symptoms of ASD, which include limitations in communication, difficulties in social interaction, as well as repetitive and restricted behaviors (American Psychiatric Association, 2013). The characteristics of ID are limited intellectual functioning and difficulties with adaptive behaviors in many kinds of social and practical skills, as defined by the American Association on Intellectual and Developmental Disabilities in 2017. Both kinds of DD affect children's social skills, and many children with DD are dependent on their family members and professionals, limiting their opportunities to make their own decisions on the choice of activities (Hawkins & Freeman, 1993; Zijlstra & Vlaskamp, 2005).

Researchers have different findings on the relationship between participation and age (Askari et al., 2015). Research by Badia et al. (2011) shows that compared to the influence of disabilities, personal factors have a more significant effect on participation in leisure activities. The first personal factor is age. Comparing to the elder ones, the younger participants with DD have stronger preferences to participate in recreational, social, and physical activities. Similarly, Zijlstra and Vlaskamp (2005) found that the number of activities that the older participants with ID participated is less than the younger ones. However, a study also reported that there was no significant association between age and levels of participation in social activities among children with ASD (Shattuck et al., 2011).

The other personal factor that showed inconsistent results among studies in the participation of children with DD is gender (Askari et al., 2015). Badia et al. (2011) found that different genders do make differences in participation. Comparing to women with DD, men with DD are more likely to participate in physical activities. Besides, research by Melbøe and Ytterhus (2017) also highlighted the differences in participation between genders. Both boys and girls with ID participate in many informal activities at home, such as using the computer. However, boys spend more time playing computer games, and girls prefer to use computers for other activities, such as searching for information in their interested field. Nevertheless, some other studies came up with different findings regarding gender. Even though the female participants with DD participate at a higher level than male participants in some activities, there is no significant difference between genders in general (Draheim,

Williams, & McCubbin, 2002; Robertson et al., 2000; Umb-Carlsson & Sonnander, 2006). The research of Zijlstra and Vlaskamp (2005) also reported that no associations were found between participation and gender.

2.3 Environmental Factors

Environmental factors are another aspect that determines the outcome of an individual's participation in activities (WHO, 2001). Children with DD face more restrictive factors in participation in community and school environments than at home (Chien et al., 2017). This is consistent with various research in children with mild to severe levels of limitations of DD in different age groups (i.e., Chien et al., 2017; Poon, 2011; Rosenberg et al., 2012).

The environment of residence is one of the worth-noting environmental factors, which can influence the choice of activities (Chambers et al., 2007). There are negative environmental factors in community such as faraway distance between home, school and friends' home that limit the accessibility of children with DD to participate in activities (Chien et al., 2017). Living in rural or urban areas can also make a difference. There are both advantages and disadvantages in living in rural areas and urban areas. In the rural areas, people are more likely to know each other, which increases the possibility for children with DD to communicate with their neighbors. Nevertheless, compared to the more developed urban areas, there are limited activities that can be organized in a rural environment (Melbøe & Ytterhus, 2017). Urban areas where there are more developed cities with better facilities. However, heavy traffic and safety in big cities are two major concerns of parents that hinder children with DD from going out of their home (Chien et al., 2017; Rosenberg et al., 2012). Attitude of other people is another notable environmental factor in participation (WHO, 2001). One example is that TD children do not seem so willing to interact with children with ID, since they seldom initiate activities and contact children with ID (Melbøe & Ytterhus, 2017).

2.4 Children with developmental disabilities in China

The vast population of children with disabilities is raising broad concern in China. In approximately every forty seconds in China, a new baby with disabilities comes to this world (Zhou, 1994). This means that there will be about 2000 more children with disabilities daily, in other words, over 700,000 to 800,000 annually (Wang & Michaels, 2009). According to the Second National Sampling Survey on Disability, China Statistical Yearbook (2008), there

were 3.87 million children between 0 to 14 years old with disabilities nationwide (Campbell & Uren, 2011). Among the vast number of children with disabilities in China, the proportion of DD is worth noting. Approximately 70% of children with disabilities are with ID, and approximately 12,000 to 500,000 are with ASD (Siperstein et al., 2011).

However, despite the large number of children with DD, they seem to be relatively invisible in China since they rarely appear in public areas. Previous research shows that the lack of support in the construction of public facilities is one of the obstacles that hindered them from going out from their home (Campbell & Uren, 2011). Meanwhile, there is a lack of social awareness, insufficient support from the health care system, barriers in the implementation of inclusive education, and different attitudes on children with DD in China.

Social awareness

There is a lack of social awareness of DD, especially for ASD. ASD had not raised much attention until 2007, when it was included in the official list of disabilities (Clark, Zhou & Du, 2019). No policies or regulations were made specifically for individuals with ASD (McCabe, 2008). Even though it varies between areas (Tao et al., 2011), according to China Disabled Persons' Federation (2011), 75.6% of the parents do not have a specific understanding about ASD before receiving their child's diagnosis. Almost one-quarter of the parents refuse to accept the fact that their child is diagnosed with ASD, and they take the child to other hospitals to be rechecked (Ming et al., 2007). After receiving the diagnosis of ASD, the way these parents learn about ASD is mainly from the internet and other parents who have children with disabilities. Only a few of them learn directly from professionals (The Chinese Autism Society, 2003). Sometimes, these parents have a more profound understanding of ASD than the professionals (Guo, 2012).

Health centers

Instead of taking their children to psychiatric or neurological hospitals, more than half of the parents prefer to take their children to women's and children's hospitals for diagnoses (China Disabled Persons' Federation, 2011). After receiving the diagnosis, 65% of them start planning for interventions in a year (The Chinese Autism Society, 2003). These children can get interventions in government-funded hospitals and private rehabilitation centers (McCabe, 2008). However, there are various problems in both kinds of organizations. The insufficient financial support from the government is one of the main reasons. As a result, parents have to pay for the increasing fees of interventions and treatment themselves (Xiong et al., 2011).

Meanwhile, due to the shortage of funds, the hospitals and rehabilitation centers can hardly upgrade their technologies and provide their staff with enough training (McCabe, 2008). In addition, some professionals in private organizations often quit one job in an organization and go to another organization. This issue makes it hard for children, parents, and professionals to cooperate smoothly (Xiong, 2010). More importantly, no detailed guidelines and requirements for the professionals and interventions were issued by the government (Sun et al., 2013).

'Learning in Regular Classrooms'

In China, the idea of inclusive education was put into practice by the initiative of 'Learning in Regular Classrooms' (Ministry of Education and the China Disabled Persons Federation, 1996). However, it is mainly for students without difficulties in learning. Children with difficulties in learning and social contact are likely to be transferred to separate classes for students with disabilities or special schools (Xu, Cooper & Sin, 2018). One previous research interviewed high school students between 12 to 15, and only 11% had schoolmates with ID, and 9% had classmates with ID (Siperstein et al., 2011).

There are insufficient adaptations for students with disabilities in regular classrooms. Furthermore, there is a limited number of qualified teachers and other professionals with sufficient knowledge about how to support children with disabilities (McBrayer, 2016; Xu, Cooper & Sin, 2018). There are usually more than 40 students in one classroom with only one teacher, which requires the teacher to work fast. Students with disabilities will take more of their attention in the classroom. It is difficult for teachers to provide them with enough support (Su et al., 2020).

Attitude

Parents of children with disabilities held complicated attitudes towards them. Some parents consider having children with disabilities as a shame of the family, and they are not willing to show their children with disabilities to others (McCabe, 2007). In China, the exam-oriented education system is in the dominant position, which assesses students mainly on their academic performance (Xu, Cooper & Sin, 2018). This can become extra stress for parents of children with DD and leads to a low expectation of those children (Wang et al., 2011; Xiong, 2010). But the majority of parents of children with ASD expressed their strong willingness to have their children in mainstream schools since it will provide these children with a better social environment (Xiong, 2010).

Some TD children are holding different kinds of attitudes toward children with DD. In the research of Siperstein et al. (2011), most of the high school students have learned about ID from television, websites, and books, and 86% of them think that it is possible to become friends with children with ID. However, only around one-third of them have the experience of talking to someone with ID, and only 4% of the students actually have a friend with ID. Half of the TD students think children with ID can hardly handle complex tasks like using money and mobile phones, and some of them prefer not to communicate with children with ID at school. Around half of these TD students are willing to have students with ID in their activities with friends (Siperstein et al., 2011).

For children with DD who study in mainstream schools, some of them are facing difficulties. Many children with ASD have mentioned their problems interacting with others in mainstream schools (Wu, 2011; Tao et al., 2011). The attitude of their peers matters. Comparing to academic-related activities such as discussing homework and working as a group, TD students are more willing to have some simple interactions at school with students with ID, such as greeting and borrowing things from each other (Siperstein et al., 2011).

Some adults hold a negative attitude towards individuals with disabilities. In their opinion, the ones with ID should stay at home. They also think people with ID can only get jobs like workers in specific workshops (Siperstein et al., 2003). Thus, as parents of typically developing children, some adults are against inclusive education for children with ID (Siperstein et al., 2003; Siperstein et al., 2011). In another research, six out of seven parents of TD children are against the idea of having students with ASD in the same classroom with their TD children (Xiong, 2010). Researches about children with ASD and ID, parents of TD children think those children with ASD or ID will cause trouble and bring adverse effects to the class (Siperstein et al., 2011; Xiong, 2010).

Urban areas and rural areas

Except for the lack of supportive facilities and complex attitude toward children with disabilities, the Hukou system is another environmental factor worth noting in China. It is a household registration system that has existed for a long time in China. It divides Chinese households into two categories, agricultural hukou for rural citizens and non-agricultural for urban citizens. This bifurcation system registers households by their place of birth (Hu & West, 2015; Lu, 2012). It was made during the planned economy era, which was used to calculate and distribute funds for resources, as well as the requirement for receiving services

and welfare in the place of residence (Jianwen & Jiawei, 2010). It was until the year of 1985 that new regulations about the hukou system were carried out with relaxation of migration inside China (National People's Congress, 1985). The new regulations allowed citizens to migrate freely between rural and urban areas. Although the new policies stated that migrate citizens should have equal access to social services, they were not receiving all kinds of services as local rural citizens in practice. For example, even regulations encouraged public mainstream schools to accept all migrant children, but the available spots for them are not enough, and sometimes they are placed in separate classes (Hu & West, 2015).

At that time, with the process of economic globalization and reform of the economy in China, the higher employment opportunity and salaries in urban areas attracted young or middle-aged laborers from rural areas to migrate to urban areas. With the relaxation of migration regulations between rural and urban areas, a growing number of people migrated to urban areas for jobs. The gap of economic and social development areas was gradually widened between rural and urban (Hu & West, 2015). The imbalanced development between areas was not only reflected in the economy, but also health services, education, and the construction of public facilities.

All of these factors mentioned above may become barriers or facilitators for children with DD to participate in outside home activities, which are activities conducting in the contexts away from where they live, such as social activities, shopping, organized leisure activities, formal learning at school, and traveling.

3. Theoretical framework

The Family of Participation-Related Constructs (fPRC) is a framework that can be used to describe the participation of children or adults with disabilities or long-term health conditions (Imms et al., 2017). It discusses the factors affected by the previous experiences, which also play an impact on the participation in the future (Imms et al., 2017; Imms et al., 2016).

According to fPRC, participation can be measured while considering two aspects, including attendance and involvement. Attendance, which is defined as 'being there,' represents the frequency of attending and diversity of activities. However, attendance cannot predict the level of participation. It is a necessary but insufficient condition for involvement (Imms et al., 2017). In other words, individuals might attend certain activities frequently, but the involvement in these activities may be in low levels. Involvement is defined as the experience while attending, which contains "engagement, motivation, persistence, social

connection and level of affect” (Imms et al., 2016). The context of activities is essential when measuring involvement, since different persons have their own goals, enjoying different aspects while attending the same activity (Imms et al., 2017).

Meanwhile, both intrinsic and extrinsic factors can influence participation. There are three person-related intrinsic concepts as intrinsic factors that influence participation, including activity competence, sense of self, and preferences. Activity competence is the ability to conduct the activity, measures from three aspects: capacity, capability, and performance. Activity competence is formed by what the child has learned from past participation, and it can predict the participation in the future. Sense of self represents the perception of oneself, such as self-esteem. It is influenced by past experiences and self-efficacy, which is related to future participation. Preference is the interest to participate in the activities that are meaningful to the child. It can be used both as an explanation of complying and a prediction of choosing in participation (Imms et al., 2017). Context and environment are external factors. They provide and regulate participation. Environment refers to the factors that influence individuals’ participation directly or indirectly in a broad level. Context is related to how the individual perceive the details of participation, such as the place, activities and other people involving in the activity. These external factors can also be influenced by the participation of children depending on the level of their participation (Imms et al., 2017).

To achieve a holistic view in participation of children with DD in outside home activities in China, the investigation of this topic was guided by the fPRC framework. Accordingly, measurement of participation was from the aspect of attendance and involvement. The characteristics of DD as intrinsic factors and the features of outside home context in China as extrinsic factors was analyzed when describing the participation in outside home activities of children with DD in China (Imms et al., 2017).

4. Rationale

Participation of children, especially children with DD, has not been frequently studied in research in China. The previous research about the participation of children with DD mentioned in the background is mainly conducted in European countries. Considering the vast differences from the immediate surroundings to policies and cultural level, the situation of Chinese TD children and children with DD may differ from the result of those studies.

The majority of relevant studies on children with DD in China focused on everyday activities at home. However, the activities that take place outside the home, such as in the

community, at school, and in other public areas, account for a large proportion of children (King et al., 2013). There is a lack of attention toward the outside home activities, which are the activities that are conducted in the context outside children's home or involving people other than family members. Children with DD may experience more challenges in the outside home context and the presence of other people in the activities, which makes this topic worth further investigating.

Meanwhile, previous relevant studies mainly examined from the perspectives of their parents, teachers, and peers in China (e.g., Siperstein et al., 2011; Wang et al., 2011). However, children probably do not have the same point of view (Garth & Aroni, 2003). Therefore, studies focusing on the perceptions of TD children and children with DD themselves are necessary. Regarding children's developmental stages, deficits in language comprehension, and difficulties in expressing themselves, suitable instruments and adaptations were applied to the research participants.

5. Aim

The aim of this study is to investigate the participation in outside home activities for children with developmental disabilities (DD), comparing to typically developing (TD) children in China. This aim will be guided by the following research questions:

1. What are the levels of attendance of children with DD and TD in outside home activities?
2. What are the levels of involvement of children with DD and TD in outside home activities?
3. What are the differences and similarities regarding attendance and involvement of participation in activities outside home between children with DD and TD?
4. What are the relationships between participation and age, gender and place of residence of children with DD?

6. Method

This study used two existing datasets from researchers in the CHILD project at Jönköping University. A quantitative cross-sectional design was adopted in this study to compare the two groups of participants (Kazdin, 2002).

6.1 Participants

The participants were children between 5 to 13 years old from China. One group of the participants were children with DD, and the other group were TD children. Instead of discussing the differences between different kinds of DD, this study will analyze their participation as a whole group.

Two existing datasets were combined in the analysis. Dataset One contains 163 participants between 5 to 13 years old. Among these participants, there were 57 children between age 5 to 13 with ID from both rural and urban areas. There were also 105 TD children between 8 to 13 in this dataset. All of them were from rural areas in China. As mentioned before, individuals with ID and ASD account for the majority proportion of the population with DD in China (Siperstein et al., 2011; Wang & Michaels, 2009). Therefore, Dataset Two of 63 children between 5 to 9 years old with ASD and 63 TD children of the same age was combined with Dataset One. These children are from both rural and urban areas in China.

The participation of all the children from the two datasets was measured by the same instrument, which is the PMP-C (Simplified) instrument. All of them have the ability to understand the interview questions and to express themselves in Mandarin. And they had passed three trial questions in the PMP-C (Simplified) questionnaire, which indicated that they could understand the questions, the symbols, and pictures, as well as the scales in PMP-C (Simplified). No participants among these two datasets had severe medical conditions, visual or hearing impairments. The descriptions of the two datasets are as follows.

Dataset One was collected from May 2017 to January 2019 in Tianjin and Hebei province in China (Shi et al., 2020). These participants were recruited by a convenience sampling strategy from hospitals, special schools, and mainstream schools. The participants with ID had received a diagnosis from the hospital, based on the Chinese Wechsler Intelligence Scale (C-WISC) or the Infant-Junior Middle School Students' Social Life Ability Scale. All of the participants with ID have mild or moderate levels of impairment.

The participants with ASD in Dataset Two were collected by another researcher from November 2018 to August 2019 in Tianjin, China. Sixty-three children between 5 and 9 years old with ASD were recruited using a convenience sampling strategy as well. All of these participants were recruited from a rehabilitation institution. These participants were diagnosed

with ASD according to the criteria of the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5).

6.2 Instrument

The choice of instrument is vital for data collection in this study. Comparing to adults, children see things differently (Garth & Aroni, 2003). In order to investigate the perspective of children instead of their caregivers and professionals, the instrument for data collection should be easy for children to complete. Meanwhile, considering some of the participants in this study are children with DD, the instrument itself should be supportive of those children's understanding and communication.

There are a variety of instruments measuring participation, however, some of them actually measure activity competence, enjoyment, and attendance while participating in activities, and few instruments measure the involvement of participation (Adair et al., 2018). Thus, it is essential to use an instrument that measures participation in both attendance and involvement. Besides, the instruments designed for high-income countries might not be valid enough in low and middle-income settings. For instance, compares to children from high-income contexts, children from low and middle-income areas have lower literacy skills (UNESCO, 2012; Uwezo, 2012). Moreover, the variety of activities some instruments aim to measure are not representative of children from low- and middle-income countries (Rainey et al., 2014). Considering the differences between cultures, the activities that the instrument aims to assess should be culturally related to the everyday life of the participants (Imms et al., 2017; Arvidsson et al., 2019).

In this study, the participation of all the participants was measured by the 'Picture My Participation' (PMP) instrument. PMP measures the participation in 20 kinds of activities at home, school, and community in four aspects; the frequency and attendance of the 20 activities (always, sometimes, not really or never), levels of involvement in the activities (very, somewhat, or not), three priority activities chosen by the participant independently, and evaluation of perceived barriers to and facilitators of participation (Imms, Granlund, Bornman & Elliott, 2014). PMP instrument supports the participants with an approach named 'Talking Mats,' which can help individuals with or without disabilities to achieve better understanding and communication (Liao et al., 2019). All the questions were presented with visual scales using pictures and symbols on the 'Talking Mats'. It was placed in front of the participant

during interviews. For example, the four-point Likert scale of attendance was represented by the number of apples in a basket. The basket with no apples represented ‘Never’, the basket with two apples represented ‘Not really’, the basket with five apples represented ‘Sometimes’, and the basket full of apples represented ‘Always’. The participants placed the card with a symbol of each activity below the basket of apples that matched their level of attendance. This instrument also measures involvement with a three-point Likert scale in the same way (Imms, Granlund, Bornman & Elliott, 2014). Previous research has also shown that the activities and measuring scales in the PMP instrument is suitable for low- and middle-income countries (Arvidsson et al., 2019). In addition, the instrument used in this study is the Simplified Chinese version of ‘Picture my participation’ [PMP-C (Simplified)]. Comparing to PMP, PMP-C (Simplified) made adaptations to local culture by revising five activities and eight pictures in the instrument (Shi et al., 2020).

Among the 20 activities that PMP measures, this study only included the results of the outside home activities. Outside home activities refer to activities primarily conducted in the context outside home or usually involving people other than family members. There were nine activities in PMP-C (Simplified) that met the criteria. The activities are family/community celebrations (celebrations), getting together with other children in the community (playing with others), organized leisure activities (organized leisure), religious and spiritual gatherings and activities (spiritual activities), shopping and errands (shopping), taking part in social activities in the community (social activities), visit to health center (health centre), formal learning at school (school), overnight visits and trips (trips and visits). Thus, data about the participants' attendance and involvement in these outside home activities in the PMP-C (Simplified) questionnaire were included in this study. Meanwhile, regarding the research questions, some demographic information of the participants, including age, gender, and place of residence, was also be used in this study.

6.2 Data collection

The data collection comprised two parts. One part was to let primary caregivers of the participants to complete a questionnaire. The questionnaire aimed to collect demographic information and their perspective on their children's participation. The questionnaire for caregivers can be found in Appendix A. The other part of data collection was conducted by interviewing participants with the support of the PMP-C (Simplified) instrument. It helped the participants to understand and to answer the same questions about participation and a few

questions about demographic information (Imms, Granlund, Bornman & Elliott, 2014). The questionnaire for children can be found in Appendix B.

Before the interviews, the participants and their primary caregivers was provided with an introduction to the PMP-C (Simplified) questionnaire and consent letters. Then, the parents were asked to complete the questionnaire. Afterward, the interviews with the participants were conducted. Each of the interviews lasted between ten to twenty minutes (Arvidsson et al., 2019; Shi et al., 2020). As a start, there were three trial items (see Appendix B) to check whether the participants could understand the questions and scales (Arvidsson et al., 2019). The ones who passed the three trial questions were further interviewed with the rest of the questions about participation (Imms, Granlund, Bornman & Elliott, 2014).

The interviews were conducted by researchers who were trained to use PMP-C (Simplified), and the researchers were familiar with working with persons with disabilities (Shi et al., 2020). During the interviews, contingent feedbacks such as ‘Good job’ should not be used (Arvidsson et al., 2019). The procedures in the DD group and TD group were the same.

6.4 Data analysis

There are three kinds of variables used in this study, including demographic information of the participants, attendance (never=1, not really=2, sometimes=3, always=4), and involvement (not=1, somewhat=2, very=3) of the nine kinds of outside home activities. The demographic information includes the age of the participants, gender, and place of residence (urban area, rural area). The participants were sorted into two groups, children with ID and ASD were put into DD Group, and the TD children from both datasets were put into TD Group. The descriptive information of all participants is shown in Table 1.

Table 1. Descriptive information on participation with DD and TD

Demographic Variables	TD Group	DD Group	All participants
Gender			
Male	88 (30.6%)	87 (30.2%)	175 (60.8%)
Female	80 (27.8%)	33 (11.5%)	113 (39.2%)
Age			
5	8 (2.8%)	8 (2.8%)	16 (5.6%)

6	23 (8.0%)	24 (8.3%)	47 (16.3%)
7	27 (9.4%)	30 (10.4%)	57 (19.8%)
8	6 (2.1%)	12 (4.2%)	18 (6.3%)
9	16 (5.6%)	10 (3.5%)	26 (9.0%)
10	38 (13.2%)	5 (1.7%)	43 (14.9%)
11	20 (6.9%)	7 (2.4%)	27 (9.4%)
12	25 (8.7%)	14 (4.9%)	39 (13.5%)
13	5 (1.7%)	10 (3.5%)	15 (5.2%)
Place of residence			
Urban	63 (21.9%)	80 (27.8%)	143 (49.7%)
Rural	105 (36.5%)	40 (13.9%)	145 (50.3%)
Total	168	120	288

The analysis of data was conducted by using SPSS Version 25. Research question one about attendance in outside home activities was answered with the mean score of the attendance in all of the outside home activities in each group of participants. Then, the mean scores of the attendance in each activity were calculated in each group. The same procedures were conducted to analyze the involvement in outside home activities for research question two. For research question three, the Mann-Whitney U Test was conducted. It is suitable for comparing two groups since involvement and attendance are ordinal variables with scores ranging from low to high (Field, 2009). For research question four, chi-square tests were performed since they are suitable for the analysis of the relationship between categorical variables (Field, 2009). Variables including ‘gender’ and ‘place of residence’ are categorical. Age as an interval variable was dichotomized before the tests before running the test. Age ‘5 to 9’ was dichotomized into ‘1’ (the ‘younger group’), and age ‘10 to 13’ into ‘2’ (the ‘elder group’). After running the test, the result showed that the frequencies of 25% of cells were less than 5. Chi-square tests should be used when it is more than 5. So, a Fisher’s Exact Test was used instead (Field, 2009).

7. Ethical Considerations

The Declaration of Helsinki is an ethical guideline for researchers on protecting their research subjects and making sure the outcome is beneficial to all (World Medical Association, 2013). It requires the researchers to respect the participants’ rights and interests and giving them the opportunities to make decisions. The welfare of the participants should be put in the first

place. The vulnerability of the participants should be taken care of cautiously. Researchers should also protect the privacy of their studying subjects (World Medical Association, 2013).

Ethical issues should be pondered through the whole process of conducting research when the target group is children (Alderson, 1995; Alderson & Morrow, 2011; Hill, 2005; Lindsay, 2000; Morrow & Richards, 1996). Gaining consent is an essential process during the research for ethical issues. Researchers should let the participants and their caregivers know what will happen if they participate in the research and the use of the information that the participants provide (Hill, 2005; Powell et al., 2012). Assents are also necessary to be asked from children, too. They allow children to express their own opinions and to understand the research more. The assent-gaining process also provides researchers opportunities to examine the child's competence regarding the research (Kumpunen, Shipway, Taylor, Aldiss & Gibson, 2012). It is of significance to avoid causing harm to children during the research (Powell et al., 2012). The confidentiality of the participants should also be protected in the presentation and reports of the research. No information of the participants should be revealed to the participants' social network or any third party (Hill, 2005).

Both of the datasets used in this study are part of the 'Picture mu Participation' project in the CHILD research group at Jönköping University. During the data collection process, the researchers followed the principles of the Declaration of Helsinki. The data collections were approved by the local ethics committee in China. For instance, they were approved by Tianjin Medical University Ethics Committee and the schools and hospitals the participants were attending. Written and oral informed assents from the participants and consents from their caregivers were asked in advance. Meanwhile, detailed information and procedures about the research were provided to the participants and their primary caregivers. All of the participants were offered the freedom to stop participating in the research without informing the reason at any time (Shi et al., 2020). Names of the participants were replaced with codes. No personal information that can be used to trace back to the participants was gathered during the data collection process.

8. Result

8.1 Levels of attendance of children with DD and TD in outside home activities

The scale of attendance ranges from ‘1’ to ‘4’, representing ‘never’ to ‘always.’ Descriptive results of attendance for the group of children with DD and the TD group are presented in Table 2. Means of scores of the attendance in each outside home activity of the two groups are presented in Table 3, along with the valid number of participants and the standard deviations.

Table 2. Descriptive results of attendance

	N	Mean	Minimum	Maximum	Std. Deviation
DD group	115	2.3053	1.44	3.44	.41933
TD group	167	2.6673	1.44	3.78	.44536

Table 3. Attendance of outside home activities

Activities	N		Mean		Std. Deviation	
	DD	TD	DD	TD	DD	TD
Celebrations	120	167	2.28	2.86	.898	.996
Playing with others	120	168	2.58	3.36	.922	.784
Organized leisure	120	167	2.19	2.68	.981	1.059
Spiritual activities	116	168	1.35	1.64	.676	.857
Shopping	120	168	2.78	2.89	.948	.925
Social activities	119	168	1.75	2.27	.815	1.013
Health centre	120	168	2.29	2.42	.760	.858
School	120	168	3.60	3.73	.803	.530
Trips and Visits	120	168	1.99	2.16	.722	1.057

The mean score of attendance in DD group is 2.3053 ($SD = 0.41933$). There are 6 activities that score lower than average, including Health centre, Celebrations, Organized leisure, trips and visits, Social activities and Spiritual activities. The activities that children with DD attend the most are ‘formal learning at school (school)’ ($M = 3.60$, $SD = 0.803$). That is the only activity above ‘3’, which can estimate that most of the children with DD ‘always’

go to school in this group. The second and third most frequently attended activities are the ‘shopping and errand activities (shopping)’ ($M = 2.78, SD = 0.948$) and ‘Getting together with other children in the community (playing with others)’ ($M = 2.58, SD = 0.922$). Most of the other activities score around ‘2’, which means children with DD ‘sometimes’ or ‘not really’ attend these activities. In this group, children attend ‘religious and spiritual gatherings and activities (spiritual activities)’ least frequently ($M = 1.35, SD = 0.676$). That infers that most children with DD almost never attend ‘spiritual activities’ in this group. The other two activities these children attend less are ‘Overnights visits and trips’ and ‘Social activities’.

In the group of TD children, the mean score of attendance is 2.6673 ($SD = 0.44536$). There are 4 activities score lower than the mean score of all activities, including Health centre, Social activities, Overnights visits and trips and Spiritual activities. Two activities including formal ‘learning at school (school)’ ($M = 3.73, SD = 0.530$) and ‘playing with other children in the community (playing with others)’ ($M = 3.36, SD = 0.784$), are above the level of attending ‘sometimes (3)’. And the mean scores of all the other activities except for ‘religious activities’ ($M = 1.64, SD = 0.857$) are above ‘not really (2)’.

8.2 Levels of involvement of children with DD and TD in outside home activities

The scale of involvement ranges from ‘1(minimally involved)’, ‘2 (somewhat involved)’ to ‘3 (very involved)’. Table 4 presents the descriptive data of involvement for the group of children with DD and the TD group. Results of each outside home activity of the two groups are presented in Table 5.

Table 4. Descriptive results of involvement

	N	Mean	Minimum	Maximum	Std. Deviation
DD group	115	2.1246	1.00	3.00	.48836
TD group	104	2.4081	1.44	3.00	.37749

Table 5. Involvement of outside home activities

Activities	N		Mean		Std. Deviation	
	DD	TD	DD	TD	DD	TD
Celebrations	120	168	2.2500	2.4226	.81220	1.15555

Playing with others	120	168	2.2583	2.6429	.81474	.62182
Organized leisure	120	167	2.2000	2.2083	.79494	.88130
Spiritual activities	116	168	1.3966	1.3393	.63079	.61742
Shopping	120	168	2.3750	2.4286	.71081	.79347
Social activities	119	104	1.8067	2.2596	.83643	.85894
Health centre	120	104	2.1583	2.3750	.79912	.76561
School	120	104	2.5167	2.8269	.60784	.45029
Trips and Visits	120	104	2.1667	2.1346	.87287	.93536

The overall mean score of involvement in group of children with DD is 2.1246 ($SD = 0.48836$). ‘School’ ($M = 2.5167$, $SD = 0.60784$) and ‘shopping’ ($M = 2.3750$, $SD = 0.71081$) are the first and second mostly involved activities in this group. On the other hand, ‘social activities’ ($M = 1.8067$, $SD = 0.83643$) and ‘spiritual activities’ ($M = 1.3966$, $SD = 0.63079$) score the lowest among these outside home activities. These represent children with DD are ‘very or somewhat’ involved in activities such as formal learning at school, but ‘minimally involved’ in religious and spiritual gatherings and activities.

In the TD group, the average score of all the outside home activities is 2.4081 ($SD = 0.37749$). ‘School’ ($M = 2.8269$, $SD = 0.45029$), ‘playing with others’ ($M = 2.6429$, $SD = 0.62182$) and ‘shopping’ ($M = 2.4286$, $SD = 0.79347$) score higher than the other activities. ‘Organized activities’ ($M = 2.2083$, $SD = 0.88130$), ‘trips and visits’ ($M = 2.1346$, $SD = 0.93536$), and ‘spiritual activities’ ($M = 1.3393$, $SD = 0.61742$) are with the lower mean scores in this group.

8.3 Differences and similarities between children with DD and TD

On a group level, TD children ($M = 2.6673$, $SD = 0.44536$) have a higher level of attendance in these outside home activities than the group of children with DD ($M = 2.3053$, $SD = 0.41933$). TD children score higher than children with DD in attendance in all of the outside home activities. When looking into the activities, ‘formal learning at school’ is the activity that children attend the most frequently in both groups. ‘Shopping’ and ‘playing with others’ are also the activities that children frequently in both groups. On the contrary, ‘spiritual activities’ is the item that they both attend the least frequently, as well as ‘social activities’ and ‘trips and visits’.

The overall involvement in outside home activities of TD children ($M = 2.4081$, $SD = 0.37749$) is higher than children with DD ($M = 2.1246$, $SD = 0.48836$). Children in both groups feel more involved in activities including ‘school’, ‘shopping’ and ‘playing with others’.

‘Spiritual activities’ are the item that children in both groups felt least involved. The other activities that children with DD reported with lower levels of involvement are ‘visit to health centre’ and ‘social activities’. However, TD children felt less involved in ‘organized leisure’ and ‘trips and visits’.

Further comparisons of attendance and involvement in outside home activities between groups were analyzed by Mann-Whitney U Test. The results of overall difference in attendance and involvement between groups are shown in Table 6. The comparisons between each activity are shown in Table 7 and 8.

Table 6. Overall similarities and differences in participation between two groups

	Group	N	Mean rank	Mann-Whitney	Z	Asymp. Sig. (2-tailed)
Attendance	DD	115	103.37	5217.000	-6.533	0.000
	TD	167	167.76			
Involvement	DD	115	92.61	3980.000	-4.286	0.000
	TD	104	129.23			

Table 7. Similarities and differences in attendance of each activity between two groups

Activities	Group	Mean rank	Mann-Whitney	Z	Asymp. Sig. (2-tailed)
Celebrations	DD	116.75	6750.000	-4.906	0.000*
	TD	163.58			
Playing with others	DD	105.87	5444.000	-7.041	0.000*
	TD	172.10			
Organized leisure	DD	122.24	7408.500	-3.906	0.000*
	TD	159.64			
Spiritual activities	DD	127.42	7995.000	-3.027	0.002*
	TD	152.91			
Shopping	DD	138.65	9378.000	-1.063	0.288
	TD	148.68			
Social activities	DD	119.42	7070.500	-4.447	0.000*
	TD	161.41			
Health centre	DD	138.98	9417.500	-1.021	0.307
	TD	148.44			

School	DD	141.30	9696.000	-0.744	0.457
	TD	146.79			
Trips and Visits	DD	139.46	9475.000	-0.911	0,362
	TD	148.10			

Table 8. Similarities and differences in involvement of each activity between two groups

Activities	Group	Mean rank	Mann-Whitney	Z	Asymp. Sig. (2-tailed)
Celebrations	DD	137.38	9225.000	-1.353	0.176
	TD	149.59			
Playing with others	DD	123.12	7514.500	-4.279	0.000*
	TD	159.77			
Organized leisure	DD	142.78	9874.000	-0.320	0.749
	TD	145.73			
Spiritual activities	DD	146.93	9230.500	-0.954	0.340
	TD	139.44			
Shopping	DD	138.80	9396.000	-1.105	0.269
	TD	148.57			
Social activities	DD	97.39	4450.000	-3.864	0.000*
	TD	128.71			
Health centre	DD	104.68	5302.000	-2.099	0.036*
	TD	121.52			
School	DD	98.10	4512.000	-4.489	0.000*
	TD	129.12			
Trips and Visits	DD	113.08	6171.000	-0.156	0.876
	TD	111.84			

$P < 0.05^*$

In general, there are significant differences in both attendance ($p = 0.000$) and involvement ($p = 0.000$) between groups. To be specific, comparing to TD children, children with DD participated significantly less frequent in ‘celebrations’ ($p = 0.000$), ‘playing with others’ ($p = 0.000$), ‘organized leisure’ ($p = 0.000$), ‘spiritual activities’ ($p = 0.002$) and ‘social activities’ ($p = 0.000$). Significant differences in involvement of participation were identified in activities including ‘playing with others’ ($p = 0.000$), ‘social activities’ ($p = 0.000$), ‘visit to health centre’ ($p = 0.036$) and ‘formal learning at school’ ($p = 0.000$).

8.4 Relationships between participation and age, gender and place of residence of children with DD

The result of Chi-Square tests of the relationship between participation and demographic factors are shown in Table 9 and 10. The Chi-square analysis showed that the level of attendance did not differ by age, gender, nor their place of residence. Similarly, there is no statistical association between involvement and age, gender and place of residence.

Table 9. Chi-square analysis for attendance and age, gender and place of residence

	Age	Gender	Place of residence
Chi-Square Value	0.007	0.956	0.434
df	1	1	1
Asymp. Sig.	0.933	0.328	0.510

Table 10. Fisher's Exact Test result for involvement and age, gender and place of residence

	Age	Gender	Place of residence
Exact. Sig. (2 - sided)	0.739	0.700	0.493
Exact. Sig. (1 - sided)	0.480	0.456	0.334

9. Discussion

This study described the participation of outside home activities for children with DD between 5 to 13 in China. A group of TD children of the same age range was included to make comparisons. In general, it was shown that children with DD attended less frequently and felt less involved in outside home activities than TD children. The relationship between gender, age, place of residence, and participation was also investigated in this study. However, there was no significant association between them.

9.1 Participation in outside home activities

The result showed that the outside home activities that both TD children and children with DD attend the most frequently and felt most involved are formal learning at school. This is probably related to the implementation of the nine-year compulsory education system for all children with and without disabilities and the 'Learning in Regular Classrooms' as inclusive

education regulation in China (Hu & West, 2015; Ministry of Education and the China Disabled Persons Federation, 1996). However, there is a significant difference in the involvement in learning at school between TD children and children with DD. This may be caused by the negative attitude towards inclusive education of some teachers, the TD classmates, and the parents of the TD classmates in the mainstream schools, and the lack of relevant knowledge of the professionals in special schools (Siperstein et al., 2011; Xiong, 2010). These are the reflections of how extrinsic factors within the fPRC framework restricted the participation of children with DD in the environment of the school (Imms et al., 2017).

Social activities got one of the lowest mean scores in both attendance and involvement of participation to children with DD. They also score significantly lower than TD children in playing with others in the aspect of attendance and involvement. However, this kind of activity scores one of the highest in both aspects of participation. These two kinds of activities usually take place with the presence of many other people, and they need to have active interactions with each other. Due to the features of DD, their activity competence may be lower than TD children. As a result, their participation in this kind of activity was restricted by the intrinsic factor. Moreover, other people's attitudes may also make an impact on their participation. As mentioned by previous studies, children with disabilities might bring some parents a sense of shame, and parents somehow prefer to have them at home (McCabe, 2007). It is also in line with the previous study that although most of the TD children have a positive attitude toward building friendships with children with ID, but very few TD children actually have made friends with them (Siperstein et al., 2011). These are the extrinsic factors that impacted their participation (Imms et al., 2017).

Trips and visits are another kind of outside home activity that children with DD attend less frequently in this study. This is related to the extrinsic factors of participation. One extrinsic factor can be the influence of other people's attitudes, and the other one can be related to the insufficient public facilities, which makes it inconvenient for children with DD to travel (Campbell & Uren, 2011).

The attendance and involvement of spiritual activities both scored the lowest among two groups of children, apart from the impact of the attitude about DD of their parents and other people. There is another possible explanation for this result. To most Chinese people, religion is not considered as an essential thing (World Values Survey Association, 2014). It was reported that 77% of Chinese were without religious beliefs (WIN-Gallup International, 2016). Meanwhile, it is forbidden to combine education and religion at school (Education

Law of the People's Republic of China, 2015). Thus, children were not encouraged to participate in spiritual activities in general.

Visits to health centers also have one of the lowest mean scores in involvement among children with DD. Moreover, there is a significant difference between the two groups of children. This can be explained from both intrinsic and extrinsic levels (Imms et al., 2017). One possible explanation is the lack of qualified professionals and advanced intervention programs in the health centers, as mentioned by previous research (McCabe, 2008; Xiong, 2010). This may also relate to the features of children with DD having restrictions in communication (American Psychiatric Association, 2013). Thus, parents may need to take over the role of communicating with the professionals.

Another worth-noting point is the attendance of 'visits to health centers, which is higher than five other outside home activities, although this kind of activity scored quite low in the involvement of children with DD. On the contrary, compared to the level of attendance, the involvement of activities including 'trips and visits', 'celebrations' and 'organized leisure' of children with DD were slightly higher. These can be explained by how the fPRC describe the relationship between factors and participation. Attendance is not a sufficient condition of involvement, which means the high level of attendance cannot guarantee a correspondingly high level of involvement (Imms et al., 2017). Attendance may increase according to the preference of children. However, as mentioned before, children with DD are often dependent on other people, such as their caregivers or assistants. Usually, these people are the ones who make decisions for children with DD (Hawkins & Freeman, 1993; Zijlstra & Vlaskamp, 2005).

Even though previous research by Melbøe and Ytterhus (2017) has mentioned that boys and girls with ID participate in activities in different ways, and living in urban and rural areas both have their advantages and disadvantages. Askari et al. (2015) and Badia et al. (2011) have also reported differences in participation between genders and different age groups. However, no statistical associations were found between participation and age, gender and place of residence in this study. This finding is in line with the other studies, such as the ones by Shattuck et al. (2011) and Zijlstra and Vlaskamp (2005). One explanation for the inconsistent finding among the studies can be the different contexts and environments, which influence individuals' participation (Imms et al., 2017). The result in this study may also infer that the impact of genders and age as personal factors are not big enough to restrict the participation in outside home activities of children with DD. The insignificant association

between place of residence and participation may indicate the fact that, despite the gap of economic development between rural and urban areas, the supportive facilities and services for children with DD or even individuals with disabilities, in general, were not developed correspondingly in both areas.

As mentioned in the background, the hukou system can be a restriction for rural-to-urban migrants in gaining social services such as education and health care. But it was not specified whether there were participants residing in urban areas but with agricultural hukou or in the opposite way. If there are migrant participants in the DD group, the lower level of attendance and involvement may be influenced by the hukou system since they do not have equal access to public mainstream school and health care with the same quality as a local inhabitant.

9.2 Practical implications and suggested future research

This study adopted a quantitative methodology, which attempted to map the participation of children with DD in outside home activities in China. The data were collected by the first and second sections of the PMP-C (Simplified) instrument, which can be used to investigate the levels of participation in various kinds of activities. The result is helpful to identify the preferences and experiences of children with DD of participation. Accordingly, practitioners can be more prepared to provide those children with appropriate support during the activities they reported attending less frequently or feeling less involved. They can also initiate more outside home activities that children with DD felt more involved in but attending less frequently.

The third and fourth sections of the PMP-C (Simplified) instrument will ask the participants to choose three activities that are of importance to themselves and to describe the barriers to and facilitators of participation in these activities (Imms, Granlund, Bornman & Elliott, 2014). The data about these two sections can be a good resource for qualitative studies. Future research of qualitative or mixed-method design bases on data collected from these two sections can be helpful to explain further the participation of outside home activities of children with DD and potential reasons for the different levels of participation of the outside home activities. Related longitudinal research is also necessary in the future in order to look into the causal relationship between the factors of this topic.

9.3 Strength and limitations

The instrument used for data collection in this study was PMP-C (Simplified). As mentioned before, this instrument was designed for assessing participation, and it was suitable for participants from low- and middle-income countries (Arvidsson et al., 2019). It is an instrument that has been tested before. The usage of this instrument can increase the reliability of this study (Carrig & Hoyle, 2014). Previous research showed that the symbols and activities in this instrument were representative, which proved the face and construct validity of this instrument (Shi et al., 2020). Some professionals in that research evaluated PMP-C (Simplified) as very good and acceptable in content validity using two kinds of content validity scales (Shi et al., 2020). These can contribute to the construct validity of this study, which requires the appropriate choice of measurement for a study (Cook & Campbell, 1979).

External validity considers that to what extent the research results can be generalized and the representativeness of the sample (Cook & Campbell, 1979; Almqvist, 2019). However, the participants are from Tianjin and Hebei Province, that both located in northern China. It may not be representative of individuals from other areas in China. The places of residence of the participants are not evenly distributed. In general, more TD children are from urban areas rather than from rural areas. In addition, the younger TD children are mainly from urban areas, and the elder ones are primarily from rural areas. On the contrary, there are twice as many children with DD from rural areas than the ones from urban areas. There are four activities, including ‘Social activities’, ‘Health center’, ‘School’ and ‘Trips and Visits’, that 64 TD children did not score on the involvement. Meanwhile, developmental disabilities such as Cerebral Palsy and Attention-Deficit/Hyperactivity Disorder were not included in the participants. These can be threats to the external validity of this study. During the analysis of research question four, all children with DD were dichotomized into the younger ones and the elder ones. This is another possible limitation of the study because of the smaller number of participants in the elder group.

10. Conclusion

This study aimed to describe the participation of children with DD and TD children in the activities conducted outside the home context or involving people other than family members. The relationship between age, gender, place of residence, and participation was also investigated; however, no association was identified between them. The levels of participation

were compared between children with DD and TD children from the aspect of attendance and involvement in nine kinds of outside home activities. TD children were participating more frequently with higher levels of involvement than children with DD. They shared more similarities in attendance and more differences in involvement. The difference in attendance was significant in activities such as organized leisure and celebration, as well as the involvement in health center visits and formal learning at school. There were also significant differences in activities that require deeper interactions between each other, including social activities and playing with others in both attendance and involvement between groups. The findings are reflections of how intrinsic and extrinsic factors can both influence children's participation.

As stated by the UNCRC (1989), children with disabilities have the right to enjoy the best possible life and participate actively in society, including getting access to education and different kinds of activities. The finding indicated that there were still many barriers for children with DD to participate in outside home activities in China. They should be provided with more support in the public environment. More education about DD to others can help with increasing social awareness and reducing prejudice. In addition, relevant regulations such as guidelines for schools, hospitals, and rehabilitation centers should be carried out for children with DD.

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Appendix A

Picture my Participation questionnaire (Response score sheet -caregiver)

Section A: Demographic Information.

These questions are about your child and about you, the person filling in the survey.

Please fill out all of the questions below by making an X in the appropriate box or writing the answer in the space provided.

What is today's date? year / month / day

Participant study number:

.....

Questions about your child

1. Date of birth of child: year / month / day

2. What is the gender of your child? ☐ Male ☐ Female

3. What month and year did your child begin attending the current school? year / month

4. The following table has questions about your child's abilities.

Please mark either the 'Yes' or 'No' column with an X in relation to your child.

	Ten question questionnaire	Yes	No
1	Compared with other children, does or did your child have any serious delay in sitting, standing, or walking		
2	Compared with other children, does your child have difficulty seeing, either in the daytime or at night		
3	Does your child appear to have difficulty hearing? (Uses hearing aid, hears with difficulty, completely deaf?)		
4	When you tell your child to do something, does he/she seem to understand what you are saying		
5	Does your child have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?		
6	Does your child sometimes have fits, become rigid, or lose consciousness		
7	Does your child learn to do things like other children his/her age?		
8	Does your child speak at all (can he/she make him or herself understood in words; can say any recognizable words)?		
9	Is the child's speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family)?		
10	Compared with other children of the same age, does your child appear in any way mentally slow?		

Questions about you, the child's parent or primary care giver

5. Date of birth of person completing this form: year / month / day

6. What is your relationship with the child?

☐ Father ☐ Mother ☐ Grandmother [] Other (please specify).....

6. What is your current work status?

☐ Employed full time ☐ Employed part time ☐ Unemployed

7. Do you receive a disability grant or government funding for your child?

☐ Yes ☐ No

8. What is the highest educational qualification that you completed?

☐ Grade 10 or less ☐ Grade 12 ☐ Diploma ☐ Degree [] Post graduate degree

9. How many people are living in your house (including you)?

Adults Children

10. Are you receiving a social grant?

☐ Yes ☐ No

11. In your opinion, does your child have a learning difficulty/

☐ Yes ☐ No

If yes, what is the severity of your child's learning difficulty?

☐ Mild ☐ Moderate ☐ Severe

Section B: Participation in Home and Community Activities
--

The following questions ask about your child's attendance and involvement in home and community activities. The different home and community activities are listed below:

We are interested in the how often your child takes part in the listed activities, and in how involved your child is when he or she does take part.

The levels of *attendance* are described below:

Level	Definition of attendance
Always	The child attends all of the time
Sometimes	The child attends some of the time
Not really	The child occasionally/rarely attends
Never	The child does not attend

The levels of *involvement* are described below:

Level	Definition of Involvement
Very involved	Generally, the child is involved throughout the activity. He/ she shows a lot of initiative and/or interest in and attention to what he/ she and others are doing during the activity.
Somewhat involved	The child is involved in the activity some of the time. He/ she shows some initiative and/or interest in and attention to what he/she and others are doing during the activity.
Minimally involved	Child is involved in a small part of the activity. He/she only shows a little initiative and/or interest in and attention to what he/she and others are doing during the activity.

For each activity place an **X** in one of the boxes indicating the *level of attendance* of your child in the appropriate column.

For each activity your child attends, also place an **X** in the involvement section to indicate the *level of involvement* they usually show when attending this activity.

	Attendance				Involvement		
Home and Community Activities	Always	Some-times	Not really	Never	Very	Some-what	Minimal
1. Daily routines at home for personal care (dressing, choosing clothing, hair care, brushing teeth)							
2. Family mealtime (with usual family members)							
3. Looking after his/her own health (medication)							
4. Gathering daily necessities for the family (water, food, picking vegetables, fuel)							
5. Meal preparation with or for the family							
6. Cleaning up at home (clothing, house-hold objects, laundry, rubbish, yard work)							
7. Taking care of other family members							
8. Taking care of animals (pet, or domestic livestock)							
9. Interact with the family (family time)							
10. Family/community celebrations (birthdays, weddings, holiday gatherings)							
11. Getting together with other children in the community (playing with others)							
12. Organised leisure activities (sports, clubs, music, art, dance)							
13. Quiet leisure (listening to music, reading)							
14. Religious and spiritual gatherings and activities							
15. Shopping and errands (market)							
16. Taking part in social activities in the community (parties, play group, parades)							
17. Visit to health center (e.g. Doctor, dentist, other health care service)							
18. Formal learning at school							
19. Overnight visits and trips							
20. Paid and unpaid employment							
21. Does your child participate in any other activities? Please list:							
TOTAL (for office use only)							

Section C: Prioritisation

Of all of the activities listed above, what are the 3 activities that you think are the most important to your child? Please fill in these 3 chosen activities starting with the most important one.

Most important activities
1.
2.
3.

Section D: Barriers and Facilitators

We are now interested in what things help your child and what things make it harder for your child to participate in these activities. Please fill in the same 3 most important activities identified above into the table below. You will then need to think about what makes it easier or harder for your child to participate in the activity.

Please write the reasons in your own words.

Childs most important activities (List here)	Easier/Harder	Please write in your own words what's make it easier or harder for your child to do the activity
1	What make it <u>easier</u> to do?	
	What make it <u>harder</u> to do?	
2	What make it <u>easier</u> to do?	
	What make it <u>harder</u> to do?	
3	What make it <u>easier</u> to do?	
	What make it <u>harder</u> to do?	

This is the end of the questions.

Thank you for taking the time to tell us about your child's participation.

Appendix B

Picture my Participation questionnaire (Response score sheet - child)

Section A: Demographics (Interviewer to complete)
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What is today's date? *year / month / day*

Participant study number:

Administrator name:

Profession:.....

Where the interview was conducted:
(e.g., School playground, at home, at a library, at the soccer field)

Country:.....

City:

Child's Gender:

☐ Male

☐ Female

Child's date of birth: *year / month / day*

Section B: Participation in Home and Community Activities









TRIAL ITEMS










The trial items are to help the child understand the process of choosing symbols or pictures to describe their responses. The trial items relate to the *attendance* part of the assessment




Always =  Sometimes =  Not really =  Never = 

PCS Symbol	Questions	Always 	Sometimes 	Not really 	Never 
	Do you eat ice cream?				
	Do you watch TV?				
	Do you play with real snakes at home?				

RECORD ATTENDANCE AND INVOLVMENT IN EACH OF THE ACTIVITIES

Home Community Activities		Attendance				Involvement		
		Always	Some-times	Not really	Never	Very	Some-what	Minimal
1. Personal care Daily routines at home for personal care (dressing, choosing clothing, hair care, brushing teeth)								
		Notes:						
2. Family mealtime With usual family members								
		Notes:						
3. My own health Looking after his/her own health (medication)								
		Notes:						
4. Gathering supplies Gathering daily necessities for the family (water, food, picking vegetables, fuel)								
		Notes:						
5. Meal preparation Meal preparation with or for the family								
		Notes:						
6. Cleaning at home Cleaning up at home (clothing, house-hold objects, laundry, rubbish, yard work)								
		Notes:						
7. Caring for family Taking care of other family members								
		Notes:						
8. Caring for animals/pets Taking care of animals (pet, or domestic livestock)								
		Notes:						

Home Community Activities		Attendance				Involvement		
		Always	Some-times	Not really	Never	Very	Some-what	Minimal
9. Family time Interact with the family								
		Notes:						
10. Celebrations Family/community celebrations (birthdays, weddings, holiday gatherings)								
		Notes:						
11. Playing with others Getting together with other children in the community								
		Notes:						
12. Organised leisure Organised leisure activities (sports, clubs, music, art, dance)								
		Notes:						
13. Quiet leisure Quiet leisure (listening to music, reading)								
		Notes:						
14. Spiritual activities Religious and spiritual gatherings and activities								
		Notes:						
15. Shopping Shopping and errands (market) Shopping								
		Notes:						
16. Social activities Taking part in social activities in the community (parties, play group, parades)								
		Notes:						
17. Health centre Visit to health center (e.g. Doctor, dentist, other health care service)								
		Notes:						

Home Community Activities		Attendance				Involvement		
		Always	Sometimes	Not really	Never	Very	Somewhat	Minimal
18. School Formal learning at school								
		Notes:						
19. Trips and Visits Overnight visits and trips								
		Notes:						
20. Employment Paid and unpaid employment								
		Notes:						
Other (a)								
		Notes:						
Other (b)								
		Notes:						
TOTAL (for office use only)								

Note: Pictures are from Picture Exchange Communication

Sections C: Prioritisation

Of all of the activities listed above, what are the 3 activities that are the most important to the child?

Please fill in the 3 most important activities identified into the table in Section D. You will then need to talk with the child about what makes it easier or harder for him or her to participate in the activity.




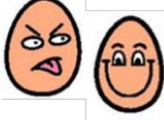

Sections D: Barriers and Facilitators

We are now interested in what things help the child and what things make it harder for the child to participate in these three activities.

- a. Place the Barriers and Facilitators Template in front of the child and explain the barriers and facilitators using clear plain and appropriate language.

For example "These pictures show what helps you (point to picture) and what makes things difficult for you to do the activity (point to picture). Ask the child about the first activity identified in the above step (prioritisation). Explain to the child that you are interested in knowing what makes it easier or makes it harder to do.

Barriers and Facilitators Template

Products and technology	Natural environment and human-made changes to the environment	Support and relationships	Attitudes	Services, systems and policies
				

- b. Example Thinking about [activity 1], are there things that make this hard to do? Can you tell me about them? Are there things that make it easier/help you to do this activity? Can you tell me about them?
- c. Repeat process for priority activity 2 & 3
- d. Transcribe what the child says on to the Table below. After the interview is finished with the child, assign a code to the child's descriptions.

Please write the reasons in the child's own words. Assign a code after the interview is completed by referring to definitions in the manual.

Childs most important activities (List here)	Easier/Harder	Please write in the child's own words what's make it easier or harder to do the activity	Interviewer assigned code					
			Product technology	Natural human environment	Support relationships	Attitudes	Service systems policies	
1	What makes it <u>easier</u> to do?							
	What makes it <u>harder</u> to do?							
2	What makes it <u>easier</u> to do?							
	What makes it <u>harder</u> to do?							
3	What makes it <u>easier</u> to do?							
	What makes it <u>harder</u> to do?							