Participation in everyday activities among children with intellectual disabilities in mainland China
– The development, verification, and application of the Picture My Participation instrument

Linjun Shi

Jönköping University
School of Health and Welfare
Dissertation Series No. 129 • 2023

Studies in Disability Research
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Abstract

**Background:** Participation in everyday activities is seen as a main outcome of rehabilitation for children. ‘Picture My Participation’ (PMP) is a validated questionnaire for assessing participation in everyday activities by children with disabilities in low- and middle-income countries, but it is not yet available in simplified Chinese.

**Aims:** The overall aims of this thesis were to validate a simplified Chinese version of Picture My Participation as a participation assessment tool, the PMP-C (simplified), and also to describe the attendance and involvement in everyday activities of children with IDs and their TD peers in rural and urban areas of mainland China as well as barriers and facilitators of participation from the perspectives of children and their primary caregivers.

**Methods:** This thesis reports four studies conducted to carry out these aims. Studies I and II used a quantitative method with a cross-sectional instrument validation design to cross-culturally adapt the PMP-C (simplified) and explored its validity and reliability. Based on this, Study III used a cross-sectional design to compare the frequency and involvement of children with IDs and TD in everyday activities in rural and urban areas of mainland China. Meanwhile, Study IV used a descriptive and explorative design with an inductive qualitative content analysis approach to describe primary caregivers’ perceptions of barriers and facilitators related to participation in everyday activities among children with IDs in mainland China.

**Results:** All items in the PMP-C (simplified) had excellent content and face validity. The internal consistency, reliability coefficient, and test-retest reliability of the subscale scores were excellent (Study I). The construct validity of the subscale scores extracted five subcomponents: organised activities, social activities, taking care of others, family life activities, and personal care and development activities (Study II). Children with IDs reported lower participation than children with TD in terms of their total scores for attendance and involvement but reported the same levels of involvement in the subcomponents taking care of others and family life activities as children with TD in urban areas. Concerning differences between...
urban and rural contexts, both children with TD and IDs in rural areas reported lower total scores for attendance and for all subcomponents except social activities than their urban counterparts. There was no significant difference in the total involvement score between rural and urban contexts for children with IDs; however, children with TD in urban areas reported higher involvement than their rural counterparts (Study III). 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 societal support. Four categories describing facilitators were identified: the optimistic attitude of the primary caregiver, adequate family support; active school and policy environments, and enjoyable characteristics of children with IDs (Study IV).

**Conclusion:** This thesis provides psychometric evidence that the PMP-C (simplified) is a valid and reliable measure of participation in mainland China and enable children with ID to have “a voice” and to report their own perspectives. The findings regarding ID–TD and urban–rural disparities in participation and the barriers and facilitators of participation among children with IDs offer important insights concerning environmental aspects when planning future intervention studies focused on promoting participation in mainland China.

**Keywords:** China, child, disability, ICF, participation, self-reported
Original papers

The following papers are enclosed as appendices.

Paper I


Paper II

Shi, L., Granlund, M., Zhao, Y., Huus, K. Construct validity of the simplified Chinese version of the instrument ‘Picture My Participation’. (Submitted)

Paper III

Shi, L., Granlund, M., Zhao, Y., Huus, K. Participation in everyday activities – a comparison of children with and without intellectual disability in rural and urban areas of mainland China. (Submitted)

Paper IV

## Abbreviations

The following abbreviations are used in this thesis and in the four sub-studies:

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>EST</td>
<td>Ecological systems theory</td>
</tr>
<tr>
<td>fPRC</td>
<td>The family of participation-related constructs</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>ID</td>
<td>Intellectual disability</td>
</tr>
<tr>
<td>LMICs</td>
<td>Low- and middle-income countries</td>
</tr>
<tr>
<td>PMP</td>
<td>Picture My Participation</td>
</tr>
<tr>
<td>PMP-C (simplified)</td>
<td>The simplified Chinese version of Picture My Participation for mainland China</td>
</tr>
<tr>
<td>PMP-C (traditional)</td>
<td>The traditional Chinese version of Picture My Participation for Taiwan</td>
</tr>
<tr>
<td>TD</td>
<td>Typical developed</td>
</tr>
<tr>
<td>UNCRC</td>
<td>United Nations’ Convention on the Rights of the Child</td>
</tr>
<tr>
<td>UNCRPD</td>
<td>United Nations’ Convention on the Rights of Persons with Disabilities</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
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</table>
Preface

Participation, which is defined as involvement in life situations, is beneficial for children’s health and well-being. Prior research has shown that the participation of children and youth with intellectual disabilities (IDs) is often restricted worldwide. My interest in this topic arose because ‘participation’ is a new concept for primary caregivers, teachers, and healthcare workers in mainland China. The lack of a well-validated self-reporting instrument for children’s participation has historically hampered its assessment in the region.

In 2016, I was given the opportunity to be part of the interdisciplinary CHILD research group. CHILD stands for Children, Health, Intervention, Learning and Development that focuses on the everyday life activities of children with disability or long-term health conditions. I became very interested in the Picture My Participation (PMP) instrument—a self-reported measure for participation and the environment that focuses on children and youth from low- and middle-income countries (LMICs). However, this tool has not been culturally or psychometrically validated in simplified Chinese. In addition, the outline of the Child Development Outline of China emphasises the need to ‘guarantee the right of participation and expression of children’. In this policy context, a scientifically effective tool for measuring the participation of Chinese children is urgently needed. It inspired me to focus on the development, verification, and application of the PMP instrument for evaluating the participation of children and youth with ID in mainland China.

While studying within the CHILD research environment, I learned methods for transcultural adaptation, psychometrically validating questionnaires, and measuring participation. My goal for the current study was to apply this knowledge to introduce a tool to evaluate the participation of children with ID in mainland China to establish a necessary foundation for determining how to improve their participation. Moving forward, my goal is to continue working to increase the participation and well-being of children and youths in everyday activities both within China and abroad.
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1. Introduction

The Convention on the Rights of the Child (UNCRC) and the Convention on the Rights of Persons with Disabilities (UNCRPD) state that children with disabilities have the same right to function fully in everyday life as everyone else (Sovig & Skivenes, 2019). The outline of the Child Development Outline of China emphasizes the need to ‘guarantee the right of participation and expression for children’ (Fisher & Shang, 2014). According to the integrative approach to disability provided by the WHO’s International Classification of Functioning, Disability, and Health (ICF), participation has been identified as an essential reflector of functioning, disability, and health in an everyday context (WHO 2001, 2007). Participation is therefore considered the ultimate outcome of interventions and services for children with intellectual disabilities (IDs) and is thus an important outcome for rehabilitation (Imms et al. 2017a). In step, participation has become an area of considerable international interest; today, participation-centred practices and participation goals for intervention are being widely recognised and implemented in the field of IDs (Granlund et al. 2021; Imms et al. 2017a).

According to China’s Second National Sampling Survey on Disability from 2006, there were 10,844,000 individuals with only IDs and 19,218,000 individuals with disabilities (including IDs and multiple disabilities) in the total surveyed population. The prevalence of IDs in China shows an uneven geographical distribution, with rates of 0.4% in urban areas and 1.02% in rural areas based on total national population in 2006 (Wu, Qiu, Wong, Hernandez, & Zhao, 2010). As of June 2012, 8.17 million children in China had been diagnosed with disabilities; notably, IDs have the highest prevalence, accounting for 34.47% of all disabilities among children. However, despite the large impact of intellectual impairment on child development, economics, and family life in China, little research has been done on the everyday lives of children with IDs. While limited studies have considered the status, rehabilitation, education, vocational development, social integration, and support services of adults with IDs in China (He, Chen, Liu, Zhang, & Zheng, 2018; Wu et al., 2010), there is a major gap in existing knowledge regarding the participation of children with IDs in everyday life activities in mainland...
China. Indeed, the concept of ‘participation’ is relatively new in this context; accordingly, research on this topic may enhance existing understandings of living with IDs among primary caregivers, teachers, and healthcare workers in mainland China.

Participation reflects how children function within their environments in activities that comprise their different roles in life. PMP is a new self-rating instrument used to assess participation. It was designed to help children with IDs self-report their participation in different everyday activities as well as the barriers and facilitators to participation they encounter in their environments.

China is a developing country with a huge population, and differences in the level of urban and rural development are important causes of inequality. The urban-rural difference in poverty is an important issue in China, particularly for people with disabilities. Moreover, there are major inequalities in the health statuses of people living in rural and urban areas because they have varying degrees of access to healthcare (Ying et al. 2020). Notably, urban–rural inequalities in healthcare services, rehabilitation services, and school education systems intensify for people with disabilities (He et al. 2018). Further, the extra costs of disability render this population susceptible to poverty, further exacerbating the inequalities they already face. Previous studies have shown that poverty is often tied to disability (Palmer, 2011) and that children from lower-income families participate less often in physical activities (Xu et al. 2020). Recently, the Chinese government has made concentrated efforts to reduce poverty, particularly in rural areas. However, little research has been devoted to urban–rural differences in children’s participation in everyday activities in mainland China. One basic reason for this gap is the lack of a validated questionnaire for effectively assessing the participation of children with IDs in everyday activities in mainland China.

To address this gap, this study aimed to validate an instrument to measure the participation of children with IDs and, further, to investigate the status of their participation ID in rural and urban areas as well as the underlying barriers and facilitators to their participation in everyday activities in mainland China. Validating the Simplified Chinese version of the PMP can provide professionals working with children with IDs with information about the
underlying factors influencing their participation. To the best of our knowledge, this is the first study to validate an instrument for and provide an up-to-date picture of participation in everyday activities among children with IDs in China.
2. Background

2.1. Disability

Based on the ICF framework, ‘disability’ covers impairments, activity limitations, and participation restrictions (WHO, 2001). An ‘impairment’ is a problem with a body function or structure, an ‘activity limitation’ is a difficulty encountered in executing a task or action, and a ‘participation restriction’ is a problem related to involvement in life situations (WHO, 2001; Alan, 2006). Given this study’s focus on participation, it is important to note that a participation restriction is viewed as a complex combination of problems within the features of a person’s body and living environment (Jette, 2006). Children with disabilities may find it difficult to integrate into society due to such difficulties related to participating in different everyday activities. The Classification of Disability in Mainland China (Purser et al. 2012) states that ‘disability’ refers to damage to bodily structures and functions that limit activity and participation. According to the UNCRPD, ‘disability’ results from a gap between the demands of society and individual abilities.

2.2. Intellectual disability

An ‘ID’ is a life-long neurodevelopmental condition that develops in childhood and is characterised by limitations in intellectual (i.e., learning, problem solving, and judgement) and adaptive functioning (i.e., communication and independent living) (Katz & Lazcano-Ponce, 2008). The 11th revision of the International Classification of Diseases and Related Health Problems (ICD-11) defines IDs as a group of developmental conditions characterised by the significant impairment of cognitive functions and related to limitations in learning, adaptive behaviour, and skills (Carulla et al., 2011). Children with ID suffer from physical and mental health problems (Emerson et al. 2016), are highly vulnerable, are often excluded from full participation in society, and experience discrimination (Ali, 2013).
The global prevalence of IDs in the general population is estimated to be 1% (He et al., 2018). In China, the estimated prevalence of IDs in the total national population was 0.75% in 2006, which implies that approximately 9.88 million people had IDs in China (Kwok, Cui, & Li, 2011). There are large differences in the prevalence of IDs between countries; this is mainly attributed to factors such as the definition of ID applied, study methods, demographic characteristics (e.g., sex, age, ethnicity), and geographical characteristics (level of economic, cultural, and scientific development; the physical environment; and the epidemiology of diseases). Overall, IDs have enormous social effects, not only for the people who experience them but also for their families and societies more broadly (Harris, 2006).

Rates of IDs vary across income and the economical standard of a country. The highest prevalence has been observed in LMICs, where the rate is almost twice those of high-income countries. This may be due to the lack of adequate antenatal screening methods in low-resource countries, which may result in more births with proportionately higher hereditary illnesses (Kwok et al., 2011). Other contributing factors include iodine deficiencies, birth-related infections, injuries due to poor maternal and child healthcare facilities, and intrauterine growth retardation (Kwok et al., 2011).

2.2.1. Diagnostic criteria and classification

To obtain a diagnosis of ID, scores for intellectual levels must be determined based on all available information, including clinical signs, adaptive behaviour in the cultural medium of the individual, and psychometric findings. In mainland China, the criteria for ID are as follows: intelligence quotient (IQ) score below 70, deficits in two or more adaptive behaviours, and age of onset under 18 years (Wu et al. 2010).

In children, IQ was evaluated using 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) revised for the Chinese context (Shi et al. 2021). The children with ID in this study were evaluated and diagnosed by the same tools. The severity of ID was classified as mild (IQ: 50–69), moderate (IQ: 35–49), severe (IQ: 20–34), or
extremely severe (IQ < 20) according to the *Criteria for Disability* issued by the State Council of the People’s Republic of China (Zheng et al. 2012). More specifically, based on this categorization, children with a mild ID can learn to read, write, and count but may have difficulty understanding abstract concepts, things that they do not perceive as concrete, and symbols for such things. Children with a moderate ID may only understand their own personal experiences, be able to learn to read single, easy words and write their own names, and communicate through speech and expand their understanding with graphic symbol support. Children with a severe ID can learn to recognise people, objects, and situations and associate words with certain actions and situations; however, they do not understand complex spoken languages, cannot speak, and communicate mostly through body language and gestures (Harris 2006).

2.2.2. *Causal factors*

Multiple causal factors are related to cognitive disability; generally, cognitive disability is associated with *genetic, acquired (congenital and developmental),* and *environmental and sociocultural* factors (Harris, 2006). First, *genetic factors* comprise chromosomal and hereditary factors. Regarding chromosomal factors, IDs most commonly occur among people with Down syndrome, an anomaly that occurs in 15 out of 10 000 births due to trisomy of chromosome 21 or the translocation of chromosomes 21 and 15. Meanwhile, hereditary factors include phenylketonuria, galactose, Mowat-Wilson syndrome, Tay-Sachs disease, and glycogen deposit disease, among others. Second, regarding *acquired factors*, congenital factors can include metabolic disorders (e.g., neonatal hypothyroidism), toxicity (e.g., lead poisoning, foetal alcohol syndrome, and prenatal exposure to substances), and infectious diseases (e.g., rubella, cytomegalic inclusion body disease, syphilis, toxoplasmosis, and herpes simplex virus II). Meanwhile, developmental factors can occur during the prenatal period (e.g., toxaemia and uncontrolled diabetes, intrauterine malnutrition, vaginal haemorrhages, placenta previa, umbilical cord prolapse), the perinatal period (e.g., prolonged foetal suffering with neonatal anoxia, asphyxia related with suffocation, inadequate application of high forceps or a poorly applied Kristelle manoeuvre), and the
postnatal period (e.g., encephalopathy from hyperbilirubinemia, encephalic traumatism and infections). Third, regarding *environmental and sociocultural factors*, epidemiological studies have consistently reported a notable link between poverty and intellectual disability. Evidence suggests that this connection reflects two distinct processes. The first establishes that a relationship exists between poverty and exposure to a wide range of environmental and psychosocial factors; the second indicates that relatives of people with IDs have an increased risk of high medical expenses that considerably affect poverty levels. These factors are the direct causes of the disproportionate increase in the incidence of IDs in developing countries. Interactions have been reported between scarcity and poor prenatal, perinatal, and postnatal healthcare; adolescent maternity; family instability; poor natal healthcare due to multiple and inadequate caregivers and health professionals; low levels of stimulation and education; and infant mistreatment (Harris, 2006).

As a developmental disorder, ID not curable. Treatment objectives should focus on the normalisation of behaviour in conformity with the rules determined by society; primary caregivers must use adequate childrearing methods that lead to optimal social integration (Sheerin, 2012). Children with ID living in developing countries require multiple social benefits that are not yet available. To date, the political, social, and economic agendas of developing countries have generally not prioritized such supports. Guaranteeing human development, education, family life, community life, work, health, security, optimal behavioural development, social integration, and protection and defence (Cluley, 2018) should be a priority in the legislative arena (Sanchez & Sanchez, 2021).

### 2.3. Children and Youth

The *UNCRC* (1989) defines a ‘child’ as a person below the age of 18, unless the laws of a particular country set the legal age for adulthood younger (Murphy-Berman & Weisz, 1996). However, the WHO (2003) defines a ‘child’ as a person aged 19 years or younger, unless national laws define a person as an adult at an earlier age. Likewise, the individuals between 19–24 years are
classified as ‘youth’ (Vale et al. 2017). Notably, participation can differ between children with disabilities and youths with disabilities. However, this thesis groups children and youth together based on the large number of issues and concerns they share. Both children and youth are expected to acquire skills, physically and psychologically mature, and assume social identities that enables them to fully participate as citizens in their communities.

2.4. Primary caregivers

A caregiver assumes care for another person who is unable to care for themselves (Matic Girard et al., 2023; Neary, 1990); a ‘primary’ caregiver is the caregiver bearing the most responsibility for the care. Primary caregivers are often parents (Shahrier, Islam, & Debroy, 2016) and are typically aged 18 years or older (Y. Liu & Guo, 2021). At various times in life, different people can become the primary caregivers of children with IDs.

Being a primary caregiver is an important responsibility. Duties can include personal care (e.g., meeting the basic needs of the person in need of care by managing their activities of daily living and preparing their meals), keeping appointments and facilitating social activities for the person in need of care when possible, monitoring health information to share with healthcare providers, housekeeping and household maintenance, and companionship (Y. Liu & Guo, 2021). At the same time, caregivers can face many challenges, including their own work schedules and demands, moving homes, physical and emotional exhaustion, and paying the bills of children with IDs (J. Hu et al., 2010; Shahrier et al., 2016).

2.5. Conceptualizing participation

The ICF (WHO, 2001, 2007) is based on a biopsychosocial model of health that emphasizes human functioning as a result of the interaction between health conditions (diseases or diagnoses) and contextual factors (environmental or personal factors). The three components of human functioning are classified and coded as body functions, structures and activities, and participation (WHO, 2001, 2007). As a multidimensional model
of functioning with participation as a key construct, the *ICF* provides a framework to describe the limitations of children’s functioning and identify their environmental factors (Imms et al., 2017a; WHO, 2001, 2007).

As established above, this model situates participation as one of the main areas of a child’s functioning; in particular, it figures ‘participation’ as engagement in the kinds of activities and experiences that children and youth are expected to share in their particular context (Wendy Coster & Khetani, 2008; WHO, 2007). Accordingly, participation reflects how a child functions within their environment in different life roles. Specifically, the *ICF* defines ‘participation’ as involvement in life situations (WHO, 2001).

The family of participation-related constructs (fPRC) framework further operationalises two key constructs associated with participation: attendance and involvement. Attendance relates to how often children participate, the duration of their participation, and the situations in which they participate. Meanwhile, involvement recalls that ‘participation’ not only refers to a child’s presence at an activity within a specific context but also to their subjective feeling of having participated in the activity (Imms et al. 2017a). More specifically, involvement represents the degree of engagement in an activity and may be related to motivation, an important aspect of perceived participation (P. Arvidsson et al., 2020; Imms et al., 2017a).

The ‘everyday life situations’ emphasized in the *ICF*’s definition of participation are situations that “occur frequently in the natural environments where children spend time, for example, eating dinner with the family, playing, going to school or sleeping” (Adolfsson, Malmqvist, Pless, & Granuld, 2011). Like all children, children with IDs have the right to fully participate in everyday activities. However, children with ID may experience participation restrictions in everyday life if they experience difficulties in performing their desired activities or are not given opportunities to participate (Shakila Dada, Bastable, Schlebusch, & Halder, 2020; Shields, King, Corbett, & Imms, 2014). These restrictions vary depending on the nature of children’s activities and interests as well as the contexts of their experiences (Shakila Dada, Kirsty Bastable, et al., 2020).
by their sex, age, community resources, particular impairment(s), family, and residential environment (Hu, Wang, and Fei, 2012).

2.6. Participation and child rights

Participation in everyday activities is particularly significant in promoting the health and well-being of children with ID; in particular, participation strongly influences their physical, social, and academic development; cultural understanding; and mental health (Granlund et al. 2021). A child’s right to participate is a core component of the UNCRC, frequently divides into three main areas: Protection, Participation, and Provision. The most relevant to this thesis is the right to Participation, which challenges children’s political and social exclusion (Superle, 2016), Therefore, to enjoy their human rights, children with ID must have the opportunity to fully and effectively participate in everyday activities (Andersen and Dolva 2015; Huus et al. 2015).

Additionally, every child has the right to voice their opinions and make choices based on their own personal values and beliefs (Andersen and Dolva, 2015). Thus, primary caregivers; childhood disability researchers; and professionals in healthcare, social services, and education have an ethical duty to include children with disabilities and provide opportunities for them to participate in various activities, even if they cannot do so independently.

2.7. ID in mainland China

2.7.1. Prevalence, distribution, and factors related to children with IDs in mainland China

Regarding the characteristics of children with disabilities in mainland China, the following information is helpful to note. ID is the most common type of disability; 34.47% of children with disabilities have IDs; meanwhile, 28.01% of children with disabilities have multiple disabilities and 17.93% have physical disabilities. Further, the prevalence of disability is higher among boys (compared to girls) and in rural areas (compared to urban areas) (Wu et al. 2010). The People’s Republic of China’s population census from the year
2000 revealed that approximately 954 000 children between 0–6 years of age had IDs in China (Xie et al. 2008). Meanwhile, a more focused study reported that the average detection rate of IDs in children aged 0–6 years was 1.33 per 1000 in 2000; this figure suggests that the number of children in this age group with IDs grows by approximately 136 000 every year (Xie et al. 2008). Additionally, this study observed geographical differences in the prevalence of IDs in children aged 0–6 years: the prevalence of ID in urban areas (0.83%) was lower than that in rural areas (1.03%)—these findings suggest that ID may be related to economic development and healthcare levels, parental awareness of disability, and access to early education (rural areas in mainland China are characterized by limited economic development and healthcare infrastructure, low parental awareness, and poor access to early education). Further, this earlier study showed that the prevalence of children with IDs is associated with several other factors, such as dwelling area, sex, age, number of children in the family, access to pre-school education, child-raising status, average annual household and personal income, and parental occupation and education; notably, these factors may be related to economic development, healthcare (especially perinatal care), and birth control policy in mainland China.

2.7.2. Current status and demands for the rehabilitation of children with IDs

While some studies in China have reported the utilisation of rehabilitation services for people with disabilities, researchers have not yet focused specifically on the use of such services by people with IDs (Guo et al. 2016). However, several studies have concluded that patients with IDs receive suboptimal care and are denied appropriate treatment (Fisher, Haagen, and Orkin, 2005)—this may be because health professionals frequently exhibit negative attitudes and behaviours towards individuals with IDs (Dinsmore, 2012). Meanwhile, although the number of children with disabilities in China is large, only 50% of these children receive a basic education.

Further, as suggested above, children with IDs in the Chinese mainland may face restrictions in participating in activities (He et al. 2018). Notably, children
with IDs participate less in all types of physical activities than children with typically developed (TD), which in turn renders them less active and increases their likelihood of living a sedentary lifestyle (Xu et al. 2020). Accordingly, studies have shown that children and youths with IDs prefer spending their time on a range of sedentary activities, such as watching TV and playing computer or mobile games (King et al. 2013).

All children with IDs require rehabilitation. Although relatively few children with disabilities have access to rehabilitative treatments, a previous survey stated that 64.11% of children with IDs aged 0–6 years received various treatments, with 57.50% of them receiving rehabilitation treatments at home. In-home and in-hospital are main forms of rehabilitation for children with disabilities; accounting for 52.32% and 25.36%, respectively, of all rehabilitation treatments for this group (Xie et al. 2008). It is worth noting that there was a significant divergence between the status of and demands for rehabilitation at specialized hospitals; home rehabilitation has been widely recognized as the main form of rehabilitation for children with IDs—the rehabilitation services provided by hospitals probably do not meet the needs of children with IDs or their families (Xie et al. 2008).

In recent years, the prevention of IDs and the QOL of children with IDs have improved due to the enactment and implementation of a series of national laws and regulations; however, these systems are still unable to fulfil all their needs. More needs to be done in the areas of education, vocational development, social integration, and support services to improve the QOL of individuals with IDs in China (He et al. 2018).

2.7.3. Urban–rural discrepancies in mainland China

China has hundreds of ethnic groups with diverse cultural traditions and considerable regional—particularly urban–rural—differences in social and economic development (Kwok et al. 2011). China’s economy has developed rapidly over the past few decades and well-being has risen accordingly; however, significant differences in prosperity persist between urban and rural areas. On the one hand, although the income of people with disabilities has increased year-over-year, the income gap between people with and without
disabilities is widening, and the incomes of urban households with children with IDs are much higher than their rural counterparts’ (Liao et al. 2022). Research on income-related inequality in the context of healthcare utilisation has shown that the use of medical services in China is also unequal (Wu et al. 2010). In China, the resources of supports and services in rural area for children with IDs are still very limited, all the challenges are likely to result in a less satisfactory of participation for children with IDs.

Some relevant factors, such as demographics, marital status, education level, socioeconomic status, and social support, may contribute to the large gap in development between urban and rural areas in China (Sicular et al. 2007). A range of studies on inequality in China have reported that the income gap between urban and rural households is large and contributes substantially to overall inequality (He et al. 2018; Zhang et al. 2017; Sicular et al. 2007). According to most estimates, the mean per capita income in urban China is more than three times that in rural areas. China’s vast rural populations not only endures a standard of living below that of its urban populations but is also denied access to many social welfare benefits and social mobility opportunities (Sicular et al. 2007). Meanwhile, ways of living also differ across urban and rural areas. Generally, people in cities lead intensive lives, live in comparatively smaller homes, and pay higher prices, but enjoy a higher QOL, in part because they have access to better living facilities, such as transportation, hospitals, education, and entertainment. People in rural areas can build large houses at a relatively low cost, usually live relatively easy and comfortable lives, and have access to fresh air and food.

2.7.4. Current research gap

Participation is a social-behavioural characteristic that is important for adjustment in a variety of areas and is likely to be affected by contextual factors. The influence of traditional culture on socialisation and child development is likely enduring and robust (Quintana et al. 2006). Urban–rural discrepancies in mainland China significantly inform understandings of the participation of children from different backgrounds and the role of the macro-level context in human development.
As suggested earlier, ID is a social problem that must be recognised in China (Sonnander and Claesson, 1997). There is an emerging sense that there is a need for supports to enable people with IDs to live a basic life and satisfy their objective material needs (Hu et al. 2012) in mainland China. Previous studies have focused on how the QOL of children with ID may be influenced by the family income, living conditions, safety, mental health status, educational level and/or employment, and physical activity levels of children with IDs (Hu, et al. 2012; Xu et al. 2020); however, less is known about the new concept of participation, including attendance and involvement. While researchers have highlighted the growing need for children with IDs to participate in everyday activities, existing studies have only considered how family characteristics are related to primary caregivers’ educational levels, knowledge-related IDs, and how behaviours associated with awareness affect the availability and accessibility of services in rural and urban areas of mainland China (He et al. 2018; Wu et al. 2010). To our knowledge, no studies have yet considered how to assess participation in everyday activities among children with IDs in both urban and rural areas of mainland China (Shi et al. 2021; Li et al. 2023).

2.8. Picture My Participation: An instrument for assessing participation

Participation assessment instruments are increasingly being considered as analytical tools when assessing the outcomes of well-being for children with IDs in high-income Western countries (Adair et al. 2018). Participation in measurements and practice rely on overall environmental as prerequisites (Imms et al. 2016). Existing instruments used to measure participation have been identified in previous reviews and include the Child and Adolescent Scale of Participation (CASP), School Function Assessment (SFA), Children’s Assessment of Participation and Enjoyment (CAPE), and Child Occupation Self-Assessment (COSA) (Potvin et al. 2013; Keller, Kafkes, and Kielhofner, 2005); however, these instruments do not involve environmental factors.

On the other hand, some instruments simultaneously assess both participation and environment, such as the Participation and Environment Measure for
Children and Youth (PEM-CY) (Coster et al. 2012) and the Young Children’s Participation and Environment Measure (YC-PEM) (Lim et al. 2018); however, these are caregiver-report questionnaires. While a small number of self-report instruments are available, including the CAPE (Potvin et al. 2013) and the Paediatric Community Participation Questionnaire, these instruments are based on Western culture. Prior studies on the properties of participation measures show that a limited number of measures were validated in LMICs and that these measures mainly focused on participation in clinical settings (e.g., hospital and physical therapy settings) rather than in everyday contexts (Linda et al. 2014).

Although many instruments claim to measure various aspects of participation and describe how each of these aspects is captured, there is currently no consensus on which participation instruments that give a voice to children themselves may be valid in LMICs (Li et al. 2023; Vlot-van Anrooij et al. 2018; Balton et al. 2022; Schlebusch et al. 2020). There is a shortage of locally validated instruments to measure participation in non-Western cultures, such as mainland China, and measures of participation and well-being should be contextualised by culture and informed by those being measured (Anaby, Anaby, and Granlund 2021; Frater 1995). Hence, it is necessary to develop valid, psychometrically sound self-report instruments to measure participation among children and youth with IDs in both urban and rural areas of mainland China (Moore & Kirk, 2010).

A new self-rating instrument, Picture My Participation (PMP) stands to serve as an appropriate tool for this task. PMP is a measure of participation and environment that focuses on children and youth aged 5–21 years from LMIC and has adequately simplified language, supportive visualisation, and helpful interviewer support (Arvidsson et al. 2019). It was founded in the ICF and was an adaption of the PEM-CY (Khetani et al. 2014) and Paediatric Activity Card Sort (Stoffel & Berg, 2008). Specifically, PMP is a paper-based questionnaire that contains 20 activity items based on the ICF and articles from the UNCRC and the UNCRPD as well as participation rating scales supported by pictures. PMP can also be used in a structured interview format. It aims to use clear, plain, culturally, and contextually appropriate language that children can understand; accordingly, it avoids jargon and technical
language. In addition, it does not require reading or writing skills and is ID-inclusive. The administration of PMP is intended to help others listen to children and other important members of their communities so that they can tell their stories about their participation in their homes, communities, and schools.

The administration procedure was inspired by the Talking Mats format (Bornman & Murphy, 2006b). It was used when conducting interviews with the simplified Chinese version of the PMP—the PMP-C (simplified)—during which pictures on a mat were used to help the participants visualise and respond to the questions by making them more concrete. These accessibility features can support more valid and reliable self-reporting (Kramer & Schwartz, 2017)—notably, clarifying the thought processes and struggles that children with IDs face when completing a self-report questionnaire is necessary to improve the resulting measures (Miller et al. 2011).

As a universal tool, PMP proved to be a reliable and valid self-report measure of participation for children with IDs in Sweden and South Africa (Arvidsson et al. 2019). Further, it was used in the local language (Lusoga) in rural Uganda to compare the participation of children and young people with cerebral palsy (CP) in activities of daily living and to capture important differences in attendance and involvement among children and young people with and without CP (Andrews et al. 2023). Additionally, the traditional Chinese version of PMP (PMP-C; traditional) was used to measure the cross-cultural adaptation of school-age children in Taiwan (Kuo, Kang, & Hwang 2019; Liao, A. W. Hwang, H. F. Liao, M. Granlund, & L. J. Kang, 2019). Traditional Chinese is mainly used in Taiwan, Hong Kong, and Macao; however, mainland China has only implemented simplified Chinese. Therefore, there is an urgent need for PMP to be available in simplified Chinese. As translations and culturally based adaptations of self-report instruments can change their measurement properties, there is also a need to evaluate a simplified Chinese version of PMP. Thus, a cross-cultural adaptation of PMP for mainland China and an evaluation of its psychometric properties are required.
2.9. Self-reporting and proxy-reporting

Self-reporting is a method used to ask children directly about their perspectives, feelings, attitudes, and beliefs (Creamer & Simmons 2019). Evidence suggests that self-reporting is superior to proxy-reporting for gaining insights into the personal experiences of children with IDs, (Scott & Havercamp, 2018)—the opinions, feelings, and thoughts of people with IDs may be more accurate and sensitive relative to proxy-reporting (Hulbert-Williams, Hastings, Crowe, & Pemberton, 2011). Apart from the importance of gaining an understanding of the child’s own perspective directly in decision making and research, self-reporting also addresses moral-ethical considerations (children’s rights to voice their opinions) and enables a person-centred perspective (Huus et al. 2015). However, collecting information directly from children with IDs can involve a series of challenges, including those related to problems with reasoning, verbal expression, reading, abstract thinking, and judgement that children with IDs may experience (Kooijmans, Mercer, Langdon, & Moonen, 2022). Beyond gathering data, these problems can make it difficult for children with IDs to voice their opinions and feelings and to participate in society (Kooijmans, Mercer, Langdon, & Moonen, 2022). A recent study compared self-ratings by children with IDs with their primary caregivers’ ratings (proxy raters) and found high inter-rater agreement between self-raters and proxy raters for ratings related to basic needs (e.g., food and water); however, lower inter-rater agreement was reported for ratings related to higher-order needs (e.g., social needs) (Huus et al. 2015). These results underscore the importance of promoting children’s right to express themselves by considering the opinions of children (as self-raters) and their primary those of their caregivers (as proxy raters). Notably, the results of the study discussed above indicated that it is especially important to include children’s voices when surveying their more complex needs (Huus et al. 2015). Therefore, children’s participation, especially involvement (Arvidsson et al. 2020) should be self-rated to obtain valid information. Children can best express their own needs related to participation and more accurately describe their involvement and engagement. Along these lines, children with IDs can offer important insights into the comprehensibility and acceptability of the wording, layout, and visual supports of items used in tools.
to measure participation. Therefore, children with IDs representative of the intended population should play an integral role in the construction of such self-reporting instruments (Kooijmans et al. 2022). Additionally, it is also important to include children’s voices in measurements for participation because the agreement between self- and proxy ratings can be affected by socioeconomic circumstances (Huus et al. 2015).

Proxy reporting occurs when someone else reports on behalf of someone from the intended sample population; in the case of this study, proxy reporting occurs when someone else reports on behalf of a child with an ID. Proxy reporting is necessary in circumstances in which self-reporting may be desirable but not possible; for example, a proxy may be necessary for a survey of a child with a serious ID who cannot understand the concepts being measured or a child with a communication impairment who is unable to communicate their own perspective (Varni et al. 2007). The advantage of proxy reporting is that data are collected from a person (the proxy) who knows the child well and regularly observes them in their natural environment (Marks, Yardley, L. 2003). The disadvantage is that children and their primary caregivers may not similarly perceive the same things (Jokovic, Locker, & Guyatt, 2004; Dada, Andersson, et al. 2020; Liao et al. 2019b); therefore, many researchers believe that it is necessary to ask children directly about their own experiences ("Introduction to Research Methods in Clinical and Health Psychology" 2004). In most situations, measuring the perspectives of children and primary caregivers is the most comprehensive approach. In traditional Chinese culture, limited supportive resources and primary healthcare services cause most children with IDs to depend on their families for their survival and development (Zheng et al. 2012). Accordingly, because primary family caregivers in China observe and engage children with IDs every day, they can provide valuable insights into their lives and the barriers and facilitators of participation they currently experience (Dada et al.2020). Notably, the primary caregiver’s perspective is multidimensional and dynamic because it responds to fluctuations in demand and context during the caregiving experience (Liu et al. 2020).
2.10. Barriers and facilitators

To enable children with IDs to participate in everyday activities, we must increase our understanding of the factors that directly affect their participation and develop effective methods to help them overcome barriers and increase their activity (McGarty & Melville, 2018). ‘Barriers’ are things that prevent an individual from participating in an everyday activity (Simpson, B. P. (2014). On the other hand, ‘facilitators’ are factors that—by their presence or absence—improve functioning and increase opportunities to participate in everyday activities (WHO, 2007). Identifying barriers and facilitators is necessary to determine effective methods for overcoming barriers, using facilitators, and turning barriers into facilitators. Some systematic reviews (McGarty & Melville, 2018; Shields et al. 2012) have reported that barriers to participation in physical activities for children with disabilities tend to be studied more often than facilitators. These barriers include a lack of knowledge and skills, personal preferences, stigmas associated with being disabled, parental behaviour, program challenges (e.g., lack of transport, facilities, staffing), and financial challenges. On the other hand, facilitators include a child’s desire to be active and to practice their skills, peer involvement, a supportive family, geographic location, and information (Shields et al. 2012). Existing studies have consistently shown that primary caregivers play an important role in supporting activities for children with IDs (McGarty & Melville 2018). In addition, a review notably divided barriers and facilitators into four categories in the high-income context: personal, social, environmental, and policy and programmes (Shields, Synnot, & Barr, 2012). Another review reported that most existing studies on barriers and facilitators are associated with children and family (Huus et al. 2021) and that there is a lack of research on barriers and facilitators in LMICs (Huus et al. 2021). Therefore, there is a need to identify the barriers to and facilitators of participation among children with IDs in mainland China.
3. Conceptual framework

3.1. Ecological systems theory

The ecological systems theory (EST), also known as the developmental theory or the bioecological systems theory, explains how a child’s environment affects their biological and psychological progress. This approach centres on the interrelated processes and structures within five environmental systems: micro-, meso-, exo-, macro-, and chronosystems (Figure 1). Bronfenbrenner’s ecological systems theory (Eriksson et al. 2018; Hayes et al. 2022) focuses on how children are affected by microsystems (e.g., primary caregivers, peers), mesosystems (e.g., the interaction between microsystems influencing the child), exosystems (e.g., community, economics), and macrosystems (e.g., government policies, ethics, and socioeconomic context). This study examined how the characteristics of children’s environments in mainland China are related to their participation in everyday activities and determines how their characteristics interact with their context in relation to participation.

The microsystem is the environment closest to the child and includes individuals with whom the child has close relationships and direct contact. This structure usually consists of primary caregivers, classmates, teachers, and neighbours. Relationships at this level are considered bidirectional, meaning that while such people in the child’s life can directly impact the child, the child may in turn also impact these people.

Effective human development requires regular interactions over extended periods. Such enduring interactions in the immediate environment are referred to as ‘proximal processes’ (Eriksson et al., 2018). Proximal processes function as the engines of development and a child’s involvement in a specific activity at a specific time may be seen as a snapshot of a proximal process. Children with IDs may experience recurrent difficulties in maintaining control and integrating their behaviours across situations and different domains of development. ‘Exposure’ refers to how long the developing child with IDs spends engaging in an activity involving proximal processes. Exposure varies according to the following factors (Hayes et al. 2022): duration (the average
duration of exposure), frequency (how often activities occur), interruption (are exposures often interrupted?), timing (the timing of interactions associated with participation in activities), and intensity (the extent of exposure). In the context of the fPRC framework, the first four points relate to attendance while the last point refers to involvement.

Mesosystems and exosystems are structures over which the child does not have a direct influence (Eriksson et al., 2018). A mesosystem reflects how a child with or without an ID is affected by interactions between members of diverse microsystems, for example, the interaction between a primary caregiver and a teacher in a special school. Exosystems are often the result of a much larger social system in which the child has no first-hand interactions, such as the primary caregiver’s place of employment and the parenting ways of the peers’ primary caregivers. The form, power, content, and direction of the proximal processes that produce development vary systematically as a joint function of the characteristics of the developing person and the processes that occur in direct and indirect environmental contexts. The macrosystem is
the outermost layer, it refers to the already established society and culture, such as socioeconomic status, cultural customs, values, and policies in which the child is developing in (Eriksson et al. 2018). This layer is far-reaching and may permeate all other aspects of children’s development. Last, the chronosystem deals with time—from time at a micro level, which focuses on a child in activities, to time at a macro level, which focuses on changes in society over decades or generations and all the environmental changes that occur over the lifetime that influence children's development, such as starting school, having to move to a new city or school or parents getting divorced (Eriksson et al. 2018).

3.2. The family of participation-related constructs (fPRC)

The family of participation-related constructs (fPRC) is a framework for conceptualising and measuring aspects of participation and variables related to participation. Participation can be seen as both an outcome and a process that leads to participation outcomes (Imms et al. 2017a). As established above, within the fPRC, participation has two essential components: attendance, defined as ‘being there’ and measured as the frequency of attending and/or the range or diversity of activities, and involvement, the experience of participation while attending (Figure 2). This construct of participation has interrelationships with the constructs within the activity and body-function components of the ICF (Imms et al. 2017a). The fPRC extends the ICF framework by discussing how phenomena, such as activity competence, sense of self, and context are linked (Imms et al. 2017a). Thus, the fPRC links EST and what Bronfenbrenner names ‘exposure’ (duration, frequency, and diversity) to proximal processes as well as to the intensity of being engaged in the process (Hayes et al. 2022). Participation can, therefore, be seen partly as a snapshot of a proximal process, as described by Bronfenbrenner (Merçon-Vargas, Lima, Rosa, & Tudge, 2020).
In addition, the fPRC includes intrinsic person-related and intrinsic factors that influence participation (Imms et al. 2017a). Intrinsic person-related concepts include activity competence, a sense of self, and preferences. Activity competence includes cognitive, physical, and affective skills. Sense of self refers to the personal perception of one’s confidence, satisfaction, self-esteem, and self-determination. Preferences are defined as interests or activities that hold meaning or are valued. Extrinsic factors include physical and social aspects of the environment that can affect a person’s functioning (all system levels) (Imms et al. 2017a). The environment is external and refers to the broader objective, social, and physical structures in which we live. The interaction between the person and the environment is found in the context (situated in the microsystem). Context is personal—that is, it is considered from the perspective of the participant—and relates to the people, place, activity, objects, and time in which participation is set. The context is co-constructed by the person and the environment; thus, the interaction constitutes the process itself.

The fPRC provides a useful framework for considering how personal aspects, environmental aspects, and contextual characteristics affect a person’s participation, both in relation to microsystems and macro time in a cultural context (Imms et al. 2017a). This is particularly important because most previous research has been based on empirical data collected from Western countries.
Figure 2. The family of participation-related constructs (Imms et al. 2017, p.16).

3.3. EST and fPRC: Relation to the four sub-studies

This thesis reports four studies. Studies I and II were rooted in a theoretical understanding of the instrument of participation, PMP, devoted to validating a simplified Chinese version of PMP for assessment of children’s participation in China. In EST, a child’s attendance and involvement in a specific activity at a specific time can be viewed as a snapshot of the proximal process (Merçon-Vargas, Lima, Rosa, & Tudge, 2020). Exposure is defined as the frequency of participation. Intensity refers to the strength of the exposure. The fPRC’s delineation of participation through attendance and involvement (Imms et al. 2017a) agrees with the definition of participation in PMP-C (simplified) (Shi et al. 2021). The PMP items were linked to ICF codes representative of the activity and participation chapters of the ICF. When performing the transcultural translation, the translators were told to consider the characteristics of the children (with and without IDs) and contextual
differences. Accordingly, the translation was conducted in light of the personal factors and environmental differences between urban and rural areas. Pretesting was also performed by children and youth with and without IDs in both urban and rural areas (Shi et al. 2021).

Study III compared participation in everyday activities by children with IDs and TD in rural and urban areas of mainland China. The theoretical basis and design of this study were anchored in a recognition that a fuller exposition of the features of the micro-, meso-, exo-, macrosystems and chronosystem within the culture influencing participation is needed. Notably, the design used for such a comparison may reflect the influence of intrinsic person-related conceptual factors. However, comparing the participation of children with IDs and TD across urban and rural areas may also indicate that the differences in children’s participation could be attributed to the differences in cultural and economic settings between these types of areas, i.e attributes of the macro system.

In Study IV, barriers to and facilitators of participation in everyday activities for children with IDs were explored using the microsystem, mesosystem/exosystem, macrosystem, and fPRC models. The primary point of departure was the microsystem, including the characteristics of children with IDs, the attitudes of their primary caregivers, family support, and the school environment. In addition, family and school systems and workplaces or healthcare services contact each other; these systems represent the mesosystem and include aspects of the exo- and macrosystems, such as narratives regarding socioeconomic status, culture, laws, and policies related to IDs. At the same time, the fPRC model also describes processes in which intrinsic factors influence participation, including preferences and activity competencies (e.g., children’s characteristics related to ID: limited physical functions to perform the activity and limited mental functions that require environmental adaptation) and sense of self (e.g., the self-stigma of the child with an ID) linked to the child’s participation in everyday activities, while extrinsic factors are associated with the context and environment of rural and urban areas of mainland China (Imms et al. 2017a).
4. Rationale

Participation is considered an important indicator of health and well-being and the ultimate goal of services for children with disabilities in everyday activities (International classification of functioning, disability and health (ICF) 2001; Imms et al. 2017b; Porta and Last, 2018; WHO, 2007); therefore, participation is a human right. Children and youths with IDs in mainland China, like all children and youths, have the right to engage fully in everyday activities. The lack of a well-validated self-report instrument has hampered the assessment of children’s participation in China.

PMP is a self-report measure of participation and environment. This measure focuses on children and youth aged 5–21 years from LMICs and was developed to be used with children and youth with IDs. However, this instrument has not been culturally or psychometrically validated in simplified Chinese.

In response to this gap in the research and the need to develop such an instrument, this study first cross-culturally adapted the PMP-C (simplified) and explored its validity and reliability for children with and without IDs in rural and urban area of mainland China (Studies I and II)—a verified PMP-C (simplified) can be used to provide more meaningful data on the effectiveness of health interventions and other services.

To the best of our knowledge, little is known about how children with IDs participate in everyday activities compared to their peers without IDs from the same background (e.g., rural, urban) in mainland China. To supply a gap, Studies III and IV focused on their level of participation and the factors affecting their participation. Personal (ID and TD) and environmental aspects (rural and urban areas) affect children’s participation and can be understood as different levels of ecological systems. Environmental factors are best investigated with an inductive qualitative content analysis, which can offer insights into what contextual factors primary caregivers may perceive as barriers to and facilitators of their child’s participation (Eriksson et al., 2018).
5. Aim

The overall aims of this thesis were to 1) validate a simplified Chinese version of PMP as a participation assessment tool and 2) to describe the attendance and involvement in everyday activities of children with IDs and their TD peers in rural and urban areas of mainland China as well as barriers and facilitators of participation from the perspectives of children and their primary caregivers.

This thesis sought to answer two overarching research questions:

- Is the PMP instrument a valid measure for children with and without IDs aged 5–21 years in urban and rural areas of mainland China?
- How do children and youths with IDs and their primary caregiver’s rate and perceive their level of participation in everyday activities and their barriers to and facilitators of participation?

The four sub-studies were driven by the following objectives:

- Study I: To describe the cross-cultural adaptation of PMP-C (simplified) and explore its face validity, content validity, and reliability.
- Study II: To explore the construct validity of the attendance scale in PMP-C (simplified).
- Study III: To compare the frequency and involvement of participation in everyday activities among children with IDs and TD in rural and urban areas of mainland China.
- Study IV: To identify primary caregivers’ perceptions of the barriers and facilitators related to participation in everyday activities among children with IDs in mainland China.
6. Methods

6.1. Study design and analysis

This thesis included three quantitative and one qualitative sub-studies, Studies I–IV. The combination of qualitative and quantitative techniques facilitates an understanding of the details of daily activity settings and yields more comprehensive, balanced, and significant research results (Abildgaard et al. 2016). Studies I and II comprised cross-sectional research to evaluate the reliability and validity of PMP-C (simplified). The findings of Studies I and II guided the design of the two subsequent studies on children with IDs in mainland China. Studies III and IV concurrently collected quantitative (Study III) and qualitative (Study IV) data. Table 1 presents an overview of the titles, samples, data collection methods, and analytical approaches used in the four studies.

Table 1. Overview of the four studies in the dissertation

<table>
<thead>
<tr>
<th>Study</th>
<th>Title</th>
<th>Sample</th>
<th>Data collection method and date</th>
<th>Analytical approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Transcultural adaptation, content validity, and reliability of the instrument ‘Picture My Participation’ for children and youth with and without IDs in mainland China</td>
<td>762, including 111 children and youth with IDs and 651 children and youth with TD</td>
<td>Picture-supported paper-based questionnaire (May 2017 to January 2019)</td>
<td>Quantitative, explorative</td>
</tr>
<tr>
<td>Study</td>
<td>Title</td>
<td>Sample</td>
<td>Data collection method and date</td>
<td>Analytical approach</td>
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<tr>
<td>II</td>
<td>Construct validity of the simplified Chinese version of the Picture My Participation instrument</td>
<td>290, including 96 children with IDs and 194 children with TD</td>
<td>Picture-supported paper-based questionnaire (September 2019 to May 2021)</td>
<td>Quantitative, explorative</td>
</tr>
<tr>
<td>III</td>
<td>Participation of children and youth with IDs and their typically developing peers in mainland China</td>
<td>312, including 153 children with IDs, (rural area: n=62; urban area: n=91) and 159 children with TD (rural area: n=65; urban area: n=94)</td>
<td>Picture-supported paper-based questionnaire (November 2019 to September 2022)</td>
<td>Quantitative, cross-sectional</td>
</tr>
<tr>
<td>IV</td>
<td>Barriers to and facilitators of participation in everyday activities among children with IDs in China</td>
<td>20 primary caregivers of a variety of ages and sexes participated in this study.</td>
<td>Interviews with primary caregivers over one year (November 2019 to May 2022)</td>
<td>Qualitative, explorative</td>
</tr>
</tbody>
</table>

6.2. Participants and setting

6.2.1. Study I

In Study I, a cross-sectional study was conducted using a convenience
sampling method for outpatients of children’s hospitals and students at special needs and mainstream schools in Tianjin, a city in Hebei Province in northern mainland China. When Study I began in 2017, Tianjin’s total population was 15.57 million, and the registered population of Hebei was 75.2 million. In total, 111 children and youths with IDs and 651 children and adolescents with TD (n=762) from Tianjin were recruited for this study. The inclusion criteria were as follows: (1) child or youth with either an ID or TD aged between 5 and 21 years—if the child or youth had an ID, they were included if they had been diagnosed with a mild or moderate ID according to the Chinese Wechsler Intelligence Scale (C-WISC) or the Infant-Junior Middle School Students’ Social Life Ability Scale (revised version of the Japanese S-M Social Life Ability Test), (2) able to understand Mandarin, (3) able to pass three trial items, (4) able express their thoughts verbally, and (5) willing to give informed consent and participate voluntarily. Children and youth with the following conditions were excluded from the study: (1) uncorrected visual or hearing impairments; (2) unstable health conditions, such as cancer, that required them to undergo surgery within the last 3 months; (3) infections or other active medical conditions that affect daily life; and (4) a progressive disease (e.g., neuromuscular disease) or a degenerative disorder (e.g., degenerative seizures).

6.2.2. Study II

For Study II, a prospective cross-sectional study was conducted at special needs schools and mainstream schools in Hebei Province, the Guangxi Zhuang Autonomous Region, and the Xinjiang Uygur Autonomous Region in mainland China. When Study II began in 2021, the registered population of Hebei Province was 74.48 million (Tianjin: 13.73 million); the permanent population of the Guangxi Zhuang Autonomous Region was 50.37 million; and the permanent population of the Xinjiang Uygur Autonomous Region was 25.89 million. A sample of 96 children and youths with IDs and 194 children and youths with TD aged 5 to 21 years were recruited, including children with IDs (n = 64) and children with TD (n = 49) from the urban area of Tianjin, children with IDs (n = 26) and children with TD (n = 55) from a rural area in Hebei, children with IDs (n = 3) and children with TD (n = 47)
from a rural area of Xinjiang Uygur Autonomous Region, and children with IDs (n = 3) and children with TD (n = 43) from a rural area of Guangxi Zhuang Autonomous Region. In total, 290 participants were recruited for this study. The inclusion and exclusion criteria were the same as those in Study I.

6.2.3. Study III

Study III involved a cross-sectional comparative survey of children and youths diagnosed with an ID and their sex- and age-matched TD peers in rural areas of Hebei Province and urban areas in Tianjin. Children and youth aged 5–21 years with IDs and TD were recruited by applying a convenience sampling method to students at special needs and mainstream schools. The participants were 312 children and youth, including 153 children and youth with IDs (rural area: n=62; urban area: n=91) and 159 children and youth with TD (rural area: n=65; urban area: n=94). The inclusion and exclusion criteria were the same as those in Study I.

6.2.4. Study IV

Study IV was conducted with participants from the same families included in Study III. Primary caregivers from four special schools in the urban area of Tianjin were invited to participate. The inclusion criteria were as follows: (1) provided most of the care and support for a child with a mild to moderate ID, (2) lived with the child for at least one year, (3) completed the PMP-C (simplified) questionnaire, and (4) able to speak and understand Mandarin. A purposeful sampling method was used. To increase the likelihood of identifying relevant categories, teachers in special schools were asked to strategically select primary caregivers to enable us to acquire diverse variations in caregiver age, sex, relationship to the child, educational level, and occupation and the child’s age and sex as well as the severity of their ID (Barbour, 2001). Semi-structured interviews with primary caregivers were conducted until saturation was reached (i.e., wherein no new themes were identified through further data collection); in total, 20 interviews were conducted (Creswell & Creswell 2013). The characteristics of the 20 primary caregivers and their children with IDs are shown in Table 2.
Table 2. The demographic characteristics of the primary caregivers and children with IDs in Study IV

<table>
<thead>
<tr>
<th>Age of child (years)</th>
<th>Level of impairment</th>
<th>Primary caregiver's relationship to child</th>
<th>Primary caregiver's age</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>mild</td>
<td>mother</td>
<td>38</td>
</tr>
<tr>
<td>14</td>
<td>mild</td>
<td>aunt</td>
<td>64</td>
</tr>
<tr>
<td>12</td>
<td>moderate</td>
<td>father</td>
<td>43</td>
</tr>
<tr>
<td>10</td>
<td>moderate</td>
<td>mother</td>
<td>35</td>
</tr>
<tr>
<td>9</td>
<td>mild</td>
<td>aunt</td>
<td>44</td>
</tr>
<tr>
<td>16</td>
<td>mild</td>
<td>mother</td>
<td>50</td>
</tr>
<tr>
<td>11</td>
<td>moderate</td>
<td>mother</td>
<td>37</td>
</tr>
<tr>
<td>15</td>
<td>mild</td>
<td>mother</td>
<td>43</td>
</tr>
<tr>
<td>10</td>
<td>moderate</td>
<td>mother</td>
<td>33</td>
</tr>
<tr>
<td>17</td>
<td>mild</td>
<td>mother</td>
<td>44</td>
</tr>
<tr>
<td>11</td>
<td>mild</td>
<td>mother</td>
<td>35</td>
</tr>
<tr>
<td>17</td>
<td>mild</td>
<td>mother</td>
<td>41</td>
</tr>
<tr>
<td>14</td>
<td>mild</td>
<td>grandmother</td>
<td>70</td>
</tr>
<tr>
<td>17</td>
<td>mild</td>
<td>father</td>
<td>47</td>
</tr>
<tr>
<td>12</td>
<td>mild</td>
<td>grandmother</td>
<td>68</td>
</tr>
<tr>
<td>11</td>
<td>moderate</td>
<td>father</td>
<td>40</td>
</tr>
<tr>
<td>13</td>
<td>moderate</td>
<td>father</td>
<td>42</td>
</tr>
<tr>
<td>9</td>
<td>mild</td>
<td>mother</td>
<td>36</td>
</tr>
<tr>
<td>10</td>
<td>mild</td>
<td>mother</td>
<td>39</td>
</tr>
<tr>
<td>13</td>
<td>mild</td>
<td>aunt</td>
<td>58</td>
</tr>
</tbody>
</table>
6.3. Instruments

The participation instrument, PMP, was translated from English into simplified Chinese (PMP-C; simplified) using the guidelines for the process of the cross-cultural adaptation of self-report measures (Mokkink et al. 2010b). This process consists of six phases: initial translation, synthesis, back-translation, expert committee, pretesting, and submission of documentation to the coordinating committee to appraise the adaptation process. First, two Chinese bilingual experts—a medical assistant professor and a native translator who had completed the Test for English Majors Band 8 (TEM-8)—translated the English PMP into the PMP-C (simplified). Differences in the translation results were discussed by the translators and a third expert familiar with the PMP project to synthesise the results and obtain the final translation. Second, back translation was conducted by two other bilingual translators who were native English speakers, who did not have medical backgrounds, and who had not seen the original English PMP. The back-translated version was then compared with the original version. Small modifications were made by an expert committee, including forward and back translators, a researcher on the PMP project, a child psychologist, and a special education teacher, to correct for cultural differences and preserve the equivalence of the translation to the English version of PMP. Third, children and youth (IDs and TD, n =20) were interviewed for pretesting to find out what they thought when they saw a particular picture and whether the picture was clear and relevant to their daily lives; they were not asked to propose revisions to improve the pictures. In this step, 20 children and youths provided key information that was applied to modify the pictures. Finally, all records were submitted to the developers of PMP to evaluate the cultural adaptation process. In the final accepted version of the PMP-C (simplified), five items from PMP were slightly modified and eight pictures were revised to improve their fit with the culture of mainland China.

The PMP-C (simplified) was designed for children and youths aged 5–21 years and measures their participation in 20 daily activities. Furthermore, it can be administered as a picture-supported one-on-one interview with a child
that unfolds across the following four sections (Figures 3–4), the first two of which were the focus of this study:

1. Rating the frequency of attendance for each item using a four-point Likert scale (never; seldom; sometimes; always).
2. Rating perceived involvement in activities using a three-point Likert scale (not involved, somewhat involved, and very involved).
3. Selecting the three most important activities.
4. Evaluating the perceived barriers to and facilitators of participation in these three activities most important to the child.

*Figure 3. Visual four-point Likert scale for the ratings of attendance. ‘How often do you participate in ...’*
Figure 4. Four examples (one from each subcomponent) of pictures/Symbols from Bildstod™ (www.bildstod.se).

6.4. Data collection

6.4.1. Quantitative studies: Studies I–III

All data were collected by the first author (LJS) and trained undergraduate and postgraduate students. These researchers were volunteers of The Association for the Disabled at Tianjin Medical University and were trained using a video on how to conduct an interview with PMP. All participants and their caregivers were introduced to the above definition of participation and the
purpose and procedures of this study. The quantitative studies were divided into the following three steps.

Step 1: Introduction to the child and their family. The researcher expressed the following to the child and their family: “We want to hear your story about who you are and what you do. Your story is important because we want to understand your involvement in your home, school, and community. We are interested in how often you perform activities, how involved you are in these activities, and what factors make it easier and more difficult for you to participate. There are no correct or incorrect answers. We will make sure that your story is kept confidential.”

Step 2: Measurement of frequency of participation. A specific picture-supported interview method inspired by the Talking Mats format was used to evaluate the children’s frequency of participation (Cameron & Murphy, 2002; Bornman & Murphy, 2006a); this method involves placing a mat in front of a child or youth. In this study, the mat was divided into four equal columns that visually represented the four-point Likert scale using pictures of baskets of apples; specifically, ‘never’ was represented by an empty basket, ‘seldom’ by a basket filled with two apples, ‘sometimes’ by a basket filled with five apples, and ‘always’ by a basket filled with apples (Figure 3). The children and youths were asked ‘How often do you participate in daily routine activities?’ and were shown a picture of a specific activity. They were then asked to place the picture on the mat in the column that they felt best represented the frequency of their participation (Arvidsson et al. 2019).

Step 3: Measurement of involvement. First, the researcher explained the ‘involvement’ component of participation. Next, as in Step 2, a visual scale was presented with pictures representing a three-point Likert scale for rating involvement, comprising ‘not involved’, ‘somewhat’, and ‘very involved’. Children and youths were asked, ‘When you attend celebration activities, how involved are you?’ They rated their involvement by placing a picture of a celebratory activity on the part of the visual scale that they felt most accurately represented their involvement in the activity. Three trial items were used to facilitate their understanding of the process and content of the PMP-C (simplified), for example “Do you eat ice cream?” Give the picture to the
child. “Could you put the ice cream picture under the basket that matches for you.” Items were presented individually, and response options were presented using corresponding pictures (Arvidsson et al. 2019) to enhance the participants’ understanding of the items. The researcher recorded responses to each item on separate score sheets until all 20 items were completed. The administration procedure was the same for children and youths with TD. To evaluate test-retest reliability, the participants were asked to complete the interview face-to-face a second time (two weeks after the first) using the same procedure. The researchers had experience in working with children with ID and were trained in interviewing (Arvidsson et al. 2019). Data related to the participants’ characteristics, including their date of birth, sex, and level of disability, were collected using a primary caregiver report survey.

### 6.4.2. Qualitative study: Study IV

Written informed consent letters were sent by teachers to 20 participants at their respective special schools, and all agreed to participate in the study. The first author (LJS) obtained the phone numbers of 20 primary caregivers from the teachers and made appointments directly for the interviews. The first author conducted two pilot interviews to test the guidance provided by the semi-structured interviews. The interviews were based on predetermined subjects and a topic guide mapped to the domains of the PMP-C (simplified).

Specifically, participants were asked: (1) ‘What were your feelings or experiences about your child’s participation during the PMP-C (simplified) interview (regarding the frequency of participation and involvement while participating) while taking care of your child with ID in daily life?’ and (2) ‘What factors make it (a) easier (facilitators) or (b) harder (barriers) for your child to participate in daily activities?’ Primary caregivers were also encouraged to choose a particular activity in the PMP-C (simplified) that they felt was important to talk about, and probes were used to obtain more detailed information (e.g., ‘What problems have you encountered while participating in these activities and how do you deal with these problems?’). After the pilot study, one guiding question—‘Tell me about your child: what do they like to do?’—was added to the interview outline, which helped establish the topic of interest. All participants were interviewed face-to-face by the first author (LJS)
at four special schools in Tianjin, China for between 30 and 60 minutes and the audios of these interviews were recorded.

6.5. Data analysis

6.5.1. Studies I and II: Instrument development and quality testing

In Study I, 16 children and youth with and without IDs were interviewed to test and verify the face validity of the PMP-C (simplified) attendance scale. Descriptive statistics were used to describe the population characteristics and the results of the scale. The content validity index (CVI), scale-level CVI/universal agreement (S-CVI/UA), scale-level CVI/average agreement (S-CVI/Ave), and kappa designating the agreement of relevance (K*) were calculated. S-CVI/UA > 0.8, S-CVI/Ave > 0.9, and K* > 0.74 indicate excellent content validity (Davies et al. 2018; Terwee et al. 2018). Internal consistency was assessed using the Cronbach’s alphas of the total score and four age groups (5–8 years, 9–12 years, 13–16 years, 17–21 years) of the PMP-C (Simplified) for children and youth with ID by comparing their responses to those of their peers with TD. Cronbach’s alphas greater than 0.7, 0.8, and 0.9 indicate that a scale has acceptable, good, and excellent internal consistency, respectively (Bland and Altman, 1997). Test-retest reliability with a two-week interval for participants with IDs (n=50) and those with TD (n=50) was measured by calculating the two-way random effects of average measures of the intra-class correlation coefficient (ICC) and their 95% confidence intervals. Based on the 95% confidence interval of the ICC estimate, values between 0.75 and 0.9 and greater than 0.9 indicate good and excellent reliability, respectively (Koo & Li, 2016).

In Study II, exploratory principal component analysis (PCA) was used as the extraction method to explore the dimensionality of the scale and investigate possible subcomponents of the PMP-C (simplified) attendance scale. An EFA performed using principal component analysis (PCA) and the varimax rotation method was used as the extraction method to explore the construct validity of
the PMP-C (simplified) attendance scale. The Kaiser–Meyer–Olkin (KMO) and Bartlett’s tests of sphericity coefficients were used to assess the suitability of the factor solution (Finch, 2020)—the KMO should exceed 0.6 and Bartlett’s test should be significant. The number of factors obtained from the parallel analysis was compared with that of the factors obtained from the eigenvalues (Çokluk & Koçak, 2016). An eigenvalue greater than 1 was the criterion for factor extraction. According to the guidelines of the *International Consensus-based Standards for the Selection of Health Measurement Instruments* (COSMIN) on taxonomy, definition, and methodological quality, factor loadings greater than 0.50 were considered significant (Mokkink et al. 2010a). In addition, naming a factor based on its conceptual underpinnings remains subjective. A factor must be labelled to capture the whole conceptual meaning of each variable explicating a particular latent dimension (Reio & Shuck, 2015).

### 6.5.2. Study III: Preliminary application of the instrument

The demographic characteristics were summarised using descriptive statistics. For nominal data, codes were assigned on an arbitrary basis (e.g., Male ‘1’, Female ‘2’). For the PMP-C (simplified), the responses on the attendance scale were coded from 1 to 4, where 1 = never, 2 = seldom, 3 = sometimes, and 4 = always; responses on the involvement scale were coded on a 3-point rating scale from 1 to 3, where 1 = not involved, 2 = somewhat involved, and 3 = very involved). Descriptive statistics were used to describe the population characteristics and instrument results. Since the data were normally distributed, the independent samples t-test was used to analyse the differences between groups of children with IDs and TD and the rural–urban comparison in participation in terms of attendance and involvement for the total scores and five subcomponent scores of the PMP-C (simplified).

### 6.5.3. Study IV: Inductive qualitative content analysis

In Study IV, the transcripts were explored using a qualitative inductive content analysis (Elo & Kyngäs, 2008). The transcripts focused on content, especially the participants’ experiences, and included verbal utterances as well as non-
verbal aspects of the interview interaction (e.g., gestures, pauses, overlapping speech, or sign language usage). The analysis included three main procedures: preparation, organising, and reporting. Meaning units, condensed meaning units, emerging codes, subcategories, and categories were identified to analyse the data. The researchers carefully read the transcripts several times to get a wholistic sense of the text. Next, the text was then divided into meaning units, condensed, labelled with a code by two researchers independently, and compared until agreement was reached. Similar codes were then collected on a separate sheet for analysis and subcategories were identified. Through abstraction, similar factors in the subcategories were grouped on a separate sheet, and categories were generated. Data analysis was critically discussed and compared by all authors until a unanimous conclusion was reached. The transcripts were then re-read and keyword searches were performed to ensure that no relevant aspects of the categories were overlooked.
7. Ethical considerations

Ethics approval was obtained from the local ethics committee of Tianjin Medical University in the People’s Republic of China (TMUEC201400201), and the study was conducted in accordance with the Declaration of Helsinki (Shi et al. 2021). Five ethical principles were considered in selecting participants, defining informed consent, and conducting a risk/benefit assessment: human rights, validity, distributive justice, beneficence/non-maleficence, and autonomy (Yan & Munir, 2004).

7.1. Human rights

Child with IDs is a uniquely vulnerable population. Collectively, they experience a greater burden from emotional and mental disorders and obtain less and poorer quality care than their general peers (Samuels et al. 2020). All participants were respected throughout the study to ensure that their human rights were vigorously protected. The researchers in this study were aware that special safeguards may be necessary to protect the rights and welfare of children with IDs. When selecting participants, the researchers considered cultural, individual, and role differences, including those related to age, sex, ethnicity, culture, disability, and socioeconomic status. Along these lines, children with and without IDs were selected from rural and urban areas of mainland China.

7.2. Validity

This study used clear objectives and a scientific design. Furthermore, all investigators underwent prerequisite scientific training. Considering the possible risks and benefits, this study justified the use of these resources and was conducted in a methodologically rigorous manner.
7.3. Distributive justice

Confidentiality was implemented by coding the participants’ interviews with numbers at the transcription stage and ensuring that no individual was identifiable in the results. All data were stored on a password-protected hard drive and were used only in this study.

7.4. Autonomy

The children and their primary caregivers participated voluntarily and were informed of their right to participate or not to participate, including the right to withdraw from the interviews without a reason.

7.5. Beneficence and non-maleficence

In all four studies, all participants were informed of the purpose and procedures of the study. Written informed consent was obtained prior to data collection. According to the Pediatric Guidelines for Informed Consent described in the National Research Act (1974) (Jacobs & Zonnenberg, 2004), children with IDs require special protection; accordingly, informed consent in paediatric research refers to permission from parents, other legal representatives, or guardians. As a general rule, in research involving minimal risk, obtaining consent from one primary caregiver may be sufficient (Yan & Munir, 2004). However, it is necessary to weigh the benefits against the risks that participation may entail. The benefit to the participants was the possibility of giving voice to children with IDs and their primary caregivers, making their individual insights visible and meaningful. This work is necessary to better tailor healthcare to improve the participation of children with IDs. Detailed information was given in advance to the primary caregivers who were interviewed about how the data collection would be executed to prevent potential harm, and we considered that the primary caregivers participating in the study may experience perceived psychological distress from the interviews and sound recordings.
8. Summary of findings

The perspective of the child and the primary caregiver about children's participation complement each other and reinforce one another by quantitative and qualitative studies. The following sections present the main findings of the four sub-studies. Descriptive statistics, qualitative analyses, and complete interpretations of inferential statistics can only be found in the four original papers. The summary findings provide answers to the two overarching research questions posed in this thesis.

Research question: Is the PMP a valid measure for children with and without IDs aged 5–21 years in urban and rural areas in mainland China? (Studies I and II)

8.1. Main findings of Studies I and II

Study I expounded information about the transcultural translation and adaptation (TTA) of PMP and provided preliminary evidence for the validity of the items of the PMP-C (simplified) and the reliability of the attendance subscale for use with children and youth in mainland China. Five items and eight pictures in PMP were revised to improve their fit with mainland China’s culture. For example, the item ‘paid and unpaid employment’ was changed to ‘volunteer activities’ because paid employment is legally prohibited for children and youth in mainland China while volunteering is promoted to strengthen their ideological and moral education. Meanwhile, for item 4, ‘picking vegetables’ was extended by adding ‘washing vegetables or fruits’ to reflect the more probable activity among children in urban areas. For item 6, ‘cleaning up at home’, ‘sweep the floor’ was added to the explanation and ‘garden work’ was translated to ‘sweep the floor or yard’. In addition, the term ‘community’ was translated into Chinese as ‘residential area’. Further, the corresponding pictures for items 2, 3, 6, 7, 8, 10, 14, and 20 were revised to improve their fit with Chinese culture and to make them easier to understand for children and youth with IDs. For example, the picture of ‘Family mealtime’ was revised to reflect the Chinese cultural trend of eating ‘family style’ (where
all dishes are served at the table so that everyone can reach whichever dish they like) rather than the Western trend of serving pre-portioned food. The pictures for ‘Taking care of animals’ and ‘Looking after your own health (medication)’ were also changed to improve the participants’ abilities to respond—when we showed the original picture for ‘Taking care of animals’ to the children with IDs, they intuitively focused on the names of the animals and did not indirectly understand the meaning of the picture; meanwhile, when we showed them the original picture of ‘Looking after your own health (medication)’, they mistook the medication for a drink. The revised pictures (Original picture) for ‘Family mealtime’, ‘Taking care of animals’ and ‘Looking after your own health (medication)’ are presented on the right side of Figures 5–7, respectively.

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**Figure 5.** Picture of ‘Family mealtime’

**Figure 6.** Picture of ‘Taking care of animals’

**Figure 7.** Picture of ‘Looking after your own health (medication)’
After the transcultural translation and adaptation, psychometric testing of the PMP-C (simplified) was conducted. In Study I, 111 children and youths with IDs and 651 children and youths with TD participated. The Cronbach’s alphas of the ID and TD report questionnaires were 0.80 and 0.82, respectively (Table 3). In addition, the temporal stability of the PMP-C (simplified) was supported by the ICC over two weeks. The reliability coefficients for the questionnaires of the children and youths with IDs and TD were good.

Table 3. *Internal consistency reliability and test-retest reliability*

<table>
<thead>
<tr>
<th>Children and youth</th>
<th>n</th>
<th>Cronbach’s alpha</th>
<th>n</th>
<th>ICC</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID</td>
<td>111</td>
<td>0.80</td>
<td>50</td>
<td>0.89</td>
</tr>
<tr>
<td>TD</td>
<td>651</td>
<td>0.82</td>
<td>50</td>
<td>0.81</td>
</tr>
</tbody>
</table>

The final version of the PMP-C (simplified) was used to evaluate the face, content, and construct validities. Face validity concerns whether the test is valid from the surface and whether the test questions are consistent with the purpose of the test. It only considers the direct relationship between the test item and test purpose. Importantly, this face validity is determined from the perspective of service users (Connell et al. 2018). To establish the face validity of each item and picture, children and youths from different age groups and with different health conditions (IDs and TD) were asked whether the items and pictures were clear, understandable, easy to use, meaningful, and reflective of something they experienced regularly. All participants expressed that the items and pictures reflected what they wanted to measure, and the pictures were considered easy to understand. Therefore, the face validity was good, and no major remarks were made. Meanwhile, five experts evaluated the content validity; all items had I-CVI scores above 0.78 and showed excellent K* (kappa designating agreement on relevance) and the S-CVI/Ave score was 0.98, indicating acceptable content validity. Similarly, the classification of dimensions for the PMP-C (simplified) attendance scale had good construct validity.
In Study II, EFA extracted five factors with eigenvalues greater than one and the cumulative contribution rate of these factors was 51.62%. All items had factor loadings greater than 0.50. The five subcomponents were as follows: organised activities, including six activity items: ‘overnight visits and trips’, ‘organised leisure’, ‘cleaning at home’, ‘going to the health centre’, ‘gathering supplies’, and ‘shopping’; social activities, including four activity items: ‘playing with others’, ‘spiritual activities’, ‘celebrations’, and ‘social activities’; (3) taking care of others, including three activity items: ‘caring for family’, ‘caring for animals or pets’, and ‘volunteer activities’; (4) family life activities, including four activity items: ‘family time’, ‘family mealtime’, ‘meal preparation’, and ‘quiet leisure’; and (5) personal care and development activities, including three activity items: ‘school’, ‘personal care’, and ‘my own health’. In summary, the psychometric properties of the PMP-C (simplified) for use with children and youth in mainland China were proven.

**Research question:** How do children and youth with IDs and their primary caregivers describe their level of participation in everyday activities and related barriers and facilitators? (Studies III and IV)

### 8.2. Main findings of Study III

Study III was a descriptive, comparative, and cross-sectional quantitative study focused on children’s voices. It evaluated the self-rated attendance and involvement in everyday activities of children with IDs and TD in rural and urban areas of mainland China. Children with IDs in both rural and urban areas reported lower participation than children with TD in terms of the total scores of attendance and involvement; however, they rated their involvement for the subcomponents of ‘taking care of others’ and ‘family life activities’ the same as children with TD in urban areas. Differences were also observed between urban and rural contexts: both children with TD and children with IDs in rural areas rated their total attendance lower than their urban counterparts; this trend held for all subcomponents except ‘social activities’. For the total involvement score, there was no significant difference between rural and urban contexts for children with IDs; meanwhile, children with TD in urban areas reported higher involvement than their rural counterparts.
8.3. Main findings of Study IV

The fourth study explored the viewpoints of 20 primary caregivers regarding the barriers to and facilitators of participation in everyday activities faced by the children with IDs for whom they cared. Four categories of barriers to and facilitators of participation in everyday activities for children with IDs were identified (Table 4).

Table 4. *Barriers to and facilitators of participation in everyday activities for children with IDs*

<table>
<thead>
<tr>
<th>Categories of barriers</th>
<th>Categories of facilitators</th>
</tr>
</thead>
<tbody>
<tr>
<td>The primary caregiver has insufficient</td>
<td>The primary caregiver has an optimistic attitude</td>
</tr>
<tr>
<td>knowledge, attitudes, and skills</td>
<td></td>
</tr>
<tr>
<td>The primary caregiver has insufficient</td>
<td>The primary caregiver has an optimistic attitude</td>
</tr>
<tr>
<td>knowledge, attitudes, and skills</td>
<td></td>
</tr>
<tr>
<td>ID-related characteristics of children</td>
<td>Adequate family support</td>
</tr>
<tr>
<td>Stigma and Chinese culture</td>
<td>Enjoyable characteristics of children with IDs</td>
</tr>
<tr>
<td>Lack of societal support</td>
<td>Active environment in school and policies</td>
</tr>
</tbody>
</table>
9. Discussion

This chapter addresses how the integrated findings from Studies I, II, III, and IV contribute to the understanding of items and pictures of the PMP-C (simplified), the estimation of the level of participation in everyday activities (attendance and involvement), and the identification of related barriers and facilitators for children with IDs in rural and urban areas of mainland China. These findings were guided by the overarching research questions of this thesis and are taken up in this section in relation to its conceptual framework. The chapter concludes with an outline of the methodological considerations and limitations of the study and a discussion of possible directions for future research.

9.1. An ecological systems theory understanding of participation

9.1.1. Issues related to the PMP-C (simplified)

Bronfenbrenner's theory of EST defines complex "layers" of environment and looks at children's development within the context of the system of relationships that form their environment. The interaction between factors in the children's maturing biology, his immediate family/community environment, and the societal environment and steers their participation and development. To study children's participation then, we must look not only at the child, but also at the interaction with their environment as well. According to EST, participation can be seen both as an indirect producer of and a product of development (Hayes et al. 2022), a function of force issues from multiple settings, and a product of the relations within these settings (Suwannawong, Auemaneekul, Powwattana, & Chongsuwat, 2023). As established earlier in this thesis, measuring participation in everyday activities requires assessment instruments that are locally suitable and applicable to culturally relevant activities (Arvidsson et al. 2020). Recent guidance advocates the clear and transparent reporting of the development of measures and the assessment of
their properties, and a key stage in the development of any measure is the
testing of its reliability and validity (Connell et al. 2018). In the cross-cultural
adaptation of PMP in Study I into the PMP-C (simplified), the items and
pictures were revised to improve their relevance to Chinese culture and to
make them easier for children and youth with IDs to understand. Psychometric
evidence showed that this adapted instrument is a sound measure to assess the
participation of children and youth with in rural and urban areas of mainland
China. Notably, the PMP-C (simplified) can be used to measure the children’s
participation based on their attendance (i.e., frequency of attendance) and
involvement (i.e., level of involvement) in everyday contexts based their own
expressions of their experiences with attendance and involvement (Li et al.
2023; Shi et al. 2021).

As outlined above, in EST, ‘exposure’ refers to the extent of time that the
developing person spends engaging in the activity in which the proximal
processes occur. One dimension of exposure is frequency (How often do
sessions occur over time—hourly, daily, etc.?); the other is intensity (the
strength of exposure) (Hayes et al. 2022). The PMP-C (simplified) maintains
these features of participation (Shi et al. 2021). A child’s attendance in and
involvement in a specific activity at a specific time may be viewed as a
snapshot of a proximal process (Merçon-Vargas et al., 2020). Children with
IDs may experience recurrent difficulties in controlling and integrating their
behaviours across situations and different domains of development (Carulla et
al., 2011). Therefore, their exposure partly depends on whether they receive
relevant and adequate support (McGarty & Melville, 2018).

Because participation is a complex and contextualized phenomenon (Imms et
al. 2017a), it is important to assess not only participation itself but also the
factors affecting participation it when working to uncover insights useful for
planning interventions to improve everyday functioning. Accordingly, from
theory to study design, the transcultural adaptation of PMP was rooted in an
understanding of how the micro-, meso-, exo-, macrosystems and
chronosystem within the culture of mainland China study influence
participation (Suwannawong et al., 2023). Along these lines, participation
(both the measurement of participation and participatory practices) cannot be
separated from the overall environmental prerequisites for participation (Liao
et al. 2019b). Therefore, the PMP-C (simplified) was translated in light of the participants’ personal factors and the differences between urban and rural environments, and the measure was pretested by children and youth with and without IDs in both urban and rural areas (Shi et al. 2021).

Notably, one item, ‘volunteer activities’, was added to the PMP-C (simplified) and was not originally in the PMP-C (traditional). Meanwhile, the dimensions of the PMP-C (simplified) attendance scale were reflected in five subcomponents: organised activities, social activities, taking care of others, family life activities, and personal care and development activities. This result overlaps, to a large extent, with the item-factor distribution defined in the original PMP scale, indicating that the PMP-C (simplified) is a product of context and intrinsic factors. Therefore, the PMP-C (simplified) indicates that the environment plays a significant role in whether or to what extent a child is able to participate (Shi et al. 2021).

9.1.2. Issues related to participation across different system levels

According to EST (Eriksson et al. 2018), the environment is structured across the different system levels listed above. The environmental level closest to the individual is the microsystem, but the environment extends outwards to the macrosystem (Hayes et al. 2022). For children with IDs, the primary point of departure is the micro-system, which includes their families and schools. Meanwhile, the exo- and macro-systems involve interactions with primary caregivers and workplaces or healthcare services (Merçon-Vargas et al., 2020). The macrosystem extends to narratives related to socioeconomic status, culture, laws, and policies related to ID. Therefore, measuring the full range of participation dimensions is paramount.

In this study, the microsystem comprised the nearest settings in which children with IDs directly interacted with others, including their family and school environments. Home is the starting point for children’s proximal processes and primary caregivers are the most important factors in their participation (Imms et al. 2017a; Shi et al. 2022). The findings of Study IV including the optimistic attitude of the primary caregiver and adequate family support as
facilitators of participation in everyday activities for children with IDs, which support prior research suggesting that family circumstances are crucial determinants of children’s participation. For example, scholars have shown that primary caregivers are a key component of a child’s context and can accordingly regulate their child’s participation opportunities—notably, the child’s experience of participation is formed in these everyday situations (Raval & Walker 2019; Kinnunen et al. 2021). The rating for participation in everyday activities in the PMP-C (simplified) is also a rating of children attending different settings in their microsystems, some of which involve solo activities; interactions with primary caregivers; and group activities with classmates, teachers, or peers. This thesis also suggested that barriers to and facilitators of participation in everyday activities for children with IDs may be found at the individual level (i.e., at the level of the child with an ID and their primary caregiver) within family and school environments (Shi et al. 2022).

At the individual level, ID is characterised by reduced intellectual functioning and deficits in adaptive functioning in areas of daily life, such as self-care, communication, and social and school activities (Schalock et al. 2021). Such impairment can limit a child’s opportunities for participation in everyday activities if the environment is not adapted to their needs (Arvidsson et al. 2014). Simultaneously, lower levels of participation in everyday activities among children with IDs may result in their social isolation (Shi et al. 2022). United Nations Convention on the Rights of the Child (CRC) highlights the importance of including children’s own views, every child has the right to voice their opinions and the opportunity to participate in everyday activities (Huus et al. 2015). Thus, based on children’s self-ratings, Study III found that children with IDs in both rural and urban areas more rarely attended everyday activities than children with TD in terms of their total scores for attendance and involvement—this tendency may cause children with IDs to experience fewer effective proximal processes. This finding corresponds with those of previous studies showing that children with disabilities participate in less diverse activities and engage in activities more rarely than their typical peers (King et al. 2013; Abells, Burbidge, & Minnes, 2008). In Study IV, this result was extended by one of the categories for barriers to participation in everyday activities for children with IDs from the primary caregiver’s viewpoint,
namely: ‘ID-related characteristics of children’ (Shi et al. 2022); that is, Study IV suggested that the particular characteristics of a child’s ID can limit their participation.

Participation is an amalgamation of two perspectives—the perspective of the child and that of the primary caregiver; this is because primary caregivers play a significant role in accessing and facilitating participation opportunities for the children for whom they care (Dada, Bastable, et al. 2020). In other words, they cocreate the context for participation in interaction with the child. Often, the parents of children with IDs are typically their primary caregivers and the people with whom they interact ‘on a fairly regular basis over extended periods of time’ (Dada, Bastable, et al. 2020). However, this role may also be filled by others, such as relatives, siblings, and peers, especially as children with IDs get older. Moreover, in school settings, teachers take on the role of the primary caregivers. As the child’s everyday environment and the activities of people around them are a key part of their development and well-being, the child’s primary caregiver and other adults close to the child should possess a great amount of knowledge of about how to act with the children with IDs (Kinnunen et al. 2023). Study IV found that primary caregivers’ knowledge, attitudes, and skills can serve as both barriers to and facilitators of participation in everyday activities for children with IDs. More specifically, inadequate primary caregiver knowledge, attitudes, and skills were key barriers to participation, while an optimistic attitude from the primary caregiver promoted participation (Shi et al. 2022). This finding is supported by existing empirical evidence indicating that primary caregivers act as role models for living habits and play a key role in providing children with opportunities to participate in everyday activities (Kaiser et al. 2015).

In step with previous research (Hopwood et al. 2020), Study IV establishes that the primary caregivers of children with IDs face dilemmas related to financial support, family support and social support. A child’s ID can influence both their own well-being and the well-being of their family members. Primary caregivers may be burdened by demands on their time, their work, and financial stress (Liao & Li 2020; Luijkx et al. 2017)—caring for and raising a child with an ID often involves many obligations and special requirements. The burden on primary caregivers also negatively impacts
Children’s participation and well-being. In the case of children with IDs, it is important to consider and support primary caregivers’ abilities to provide the best possible care and prioritise the participation and well-being of the entire family (De Gaetano et al. 2022). Healthcare and special education institutions should offer rehabilitation training curricula and a series of lectures on the care and education of children with IDs for primary caregivers (Kinnunen et al. 2023). Simultaneously, appropriate and effective family-centred service plans should be implemented to relieve the care burden of primary caregivers for children with IDs (Imms et al. 2017a).

Children with IDs often spend approximately eight hours per day in school settings. Therefore, schools are important microsystems for improving participation in classroom lessons and other types of activities. Specifically, participation can be supported by suitable facilities and flexible spatial solutions and schedules (which can notably promote the fluent implementation of rehabilitation). However, these supports require a good school system and regular planning and scheduling (Kinnunen et al. 2023). More specifically, Study IV revealed that the participation of children with IDs can be facilitated by integrating policies, curricula, and activities into the school environment in the urban areas of mainland China (Shi et al. 2022). However, the study also suggested that poor facilities and unsuitable schedules and spaces for rehabilitation in schools are barriers to participation for children with IDs. These barriers are particularly prevalent in rural areas. Although these barriers may pose significant challenges, overcoming these barriers represent opportunities to use an understanding of context to unfreeze the status quo and promote change to enhance participation of children with IDs.

The mesosystem refers to the connections or mutual relationships between the microsystems in which family members participate. For example, a mesosystem can comprise interactions between schools and families and their effects on the proximal processes within microsystems. Mesosystems can be optimised by forming strong positive connections.

The interviews with the primary caregivers in Study IV revealed that the caregivers felt that it was important to have a smooth flow of mutual
information exchanges about children's performance between teacher and primary caregiver. Limited caregiver–teacher relationships resulted in disconnects between the child’s experiences at school and everyday life at home, which in turn limited the degree to which the child’s participation was supported. This finding is supported by previous studies stating that strong linkages between schools and families enhance children’s participation (Fonseca et al. 2016) and that collaborative relationships between families, therapists, and educators support the successful rehabilitation of children with IDs (Kinnunen et al. 2023). Therefore, primary caregivers should collaborate with schools to develop ideas to improve children’s participation together (Eriksson et al. 2018). It is important to note that primary caregivers are not the only ones responsible for inciting such collaborations; teachers must also proactively and actively communicate with their students’ families.

The exosystem describes settings in which children are not influenced by direct interactions but indirect forces, which do not themselves contain the child but indirectly influence them as these social structures may affect one of the microsystems (Zhang et al. 2020). Examples of exosystems include the neighbourhood, primary caregivers’ workplaces and friends, and the mass media. Along these lines, an existing study revealed that external environments impact parent–child interactions and parenting style (Zhang et al. 2020). An instance of exosystems affecting the child’s development in Study IV is the primary caregiver had a stress at work and then come home and have a short temper with the child thus no time to attend any activity, which may result in a negative effect on development of children with IDs.

The macrosystem is an overarching pattern involving laws, government agencies, social policies, healthcare resources, economic systems, educational resources and many values and symbolic forms of influence that create social, political, and financial contexts for children’s development (Eriksson et al. 2018). This thesis assumes that potential cultural and social differences between rural and urban environments contribute to macrosystems. For example, cultural understandings may affect participation, as evidenced by the differences found in Study III: regarding total frequency and attendance, both children with TD and children with IDs in rural areas reported lower levels of participation in everyday activities than their urban counterparts. These results
may be due to the features of rural areas in mainland China. For example, limited healthcare in rural regions may impact participation. A previous study indicated that the relatively low supply of specialty health providers in rural areas, particularly for children, may lead to rural–urban differences in the utilisation of certain types of health services (Chen et al. 2009). As noted above, previous studies have shown that the rates of IDs in children are associated with several factors, such as dwelling area, gender, age, number of children in the family, preschool education, child-raising status, average annual household and personal income, and parental occupation and education, which are possibly related to economic development, healthcare (especially perinatal care), and birth control policies in China (Xie et al. 2008). Rural children with IDs are often diagnosed at later ages, and issues related to the access and use of health services are further exacerbated in children with IDs who need to access particular services (e.g., behavioural health, speech therapy, occupational therapy) (Zheng et al. 2012) which has indicated that children with IDs living in rural areas experience inadequate access to services and supports. Given the reduced access to services, and the unique influences regional and cultural can have on participation, it is possible that the participation profiles of children with IDs are impacted.

The current study found that rural environments are less favourable than urban environments for promoting children’s attendance at everyday activities. Therefore, health professionals should focus on collaboratively designing and implementing different strategies to help children with ID participate in different activities in rural areas. Regarding involvement, no significant differences were observed between the rural and urban contexts for children with IDs; however, children with TD in urban areas reported higher levels of involvement than their rural counterparts). Therefore, proximal processes had the greatest impact in the most disadvantaged environment, but only among healthier children (Imms et al. 2017a).

The individual and the context have a mutually reinforcing, multiplicative, and indirect effect on the power of proximal processes as the ‘engines of development’. Within this framework, the limited development of primary healthcare and medical insurance systems is a barrier to the participation of children with IDs in mainland China (Chiu et al. 2013). The lack of formal
services and supports places a heavy burden on the families of children with IDs (Chiu et al. 2013). Thus, healthcare services and special schools should work to share the responsibilities of family caregivers to promote the participation of children with IDs.

Study IV found that children with IDs in mainland China face barriers to participating in everyday activities, including ‘stigma and Chinese culture’ and a ‘lack of societal support’ (Shi et al. 2022). Macrosystem processes may play especially important roles in these barriers; how children with IDs are accepted by others, receive social support, and adjust to their schools and communities may depend to a great extent on the general social attitudes towards children with IDs in their context (Chen, Wang, & Wang, 2009). Further, environmental changes that occur over the lifetime is often influence participation, namely, chronosystem was perceived as an important factor supporting participation. While not within the scope of the current study, these life transitions that occurs over time may have critical implications for participation among children with ID. It should be noted that the processes by which social and cultural contexts shape the level of participation are likely to occur at multiple levels—from institutional to personal. These processes with time may include social policies, community value orientations, educational goals and activities in schools, and the socialization beliefs and practices of family members and peers. In addition, contextual influences on the functional meanings of social behaviour may involve prolonged processes (Chen et al. 2009). Therefore, it may be necessary to use multiple (e.g., quantitative and qualitative) multilevel (e.g., individuals nested within groups or schools in multiple communities) methods more deeply understand these issues related to participation.

The above findings suggest the government and society should pay more attention to children with IDs and call for them to be treated equally and respectfully. More specifically, to enhance the participation of children with IDs, administrations should prioritize appropriate supports adapted to Chinese culture, such as family-centred services, inclusion policies, respite care, paid leaves and child-sitting services for primary caregivers, and volunteer services for the families of children with IDs. Broadly, to create sustainable opportunities for children with IDs to participate in everyday activities over
the long run, it is necessary to implement a network of initiatives focused on children’s unique abilities, child and primary caregiver mental health, social interactions within families, and legal and disability assistance policies.

9.2. Understanding participation in relation to the fPRC

The PMP-C (simplified) captures participation-related constructs and includes intrinsic person-related concepts and extrinsic factors. Intrinsic person-related concepts include activity competence, a sense of self, and preferences. Extrinsic factors include the context and the environment, which are related constructs in the fPRC model (Imms et al. 2017a).

9.2.1. Intrinsic factors associated with activity competence, sense of self, and preferences

Imms et al. (Imms et al. 2017a) defined activity competence as cognitive, physical, and affective skills and abilities; sense of self as the individual’s perception of their own confidence, satisfaction, self-esteem, and self-determination; and preferences as meaningful or valued interests or activities. As established above, participation can be studied based on attendance (a child’s desire to engage in an activity relatively often) and involvement (the extent to which the child enjoys or focuses on an activity). In this thesis, the attendance and involvement of children with IDs emerge from interactions between the above intrinsic factors and environmental opportunities. Therefore, the subcomponents of the participation of children with IDs that this study identified can offer insights into activity competence, sense of self, and preferences (Imms et al. 2017a).

The PMP-C (simplified) was designed to capture children’s attendance (through frequency) at and involvement in 20 daily activities. Subjective experiences of involvement require a certain frequency of attendance, as the child needs to have significant experience with the activity to rate it. However, the frequency of attendance also reflects the quality of subjective experience. A certain degree of exposure is probably need for a factor to have an impact.
Perceived involvement when the children attend the activity can be seen as an indicator of children’s preferences, and it affects their frequency of attendance. Typically, preferred activities lead to increased attendance, especially for the children with IDs who like to do things that they are familiar with and can understand. Participation can be an entry point (a process) and an outcome (endpoint) of health and education services (Imms et al. 2017a)—both are important for learning, development, and health and well-being.

In Study III, children with IDs rated their involvement as high as children with TD in urban areas for the subcomponents of taking care of others and family life activities; however, they rated their involved lower than their TD peers for the subcomponents of organised activities, social activities, and personal care and development activities. To some extent, taking care of others and family life activities require a strong activity competence, a stable sense of self, and clear preferences. These factors play a crucial role in a child’s independence and may be related to whether their primary caregiver has sufficient knowledge and skills and an optimistic attitude to exercise and strengthen their children’s basic ability. Similarly, a child can be motivated by their sense of their own competence (Missiuna & Pollock, 2000); accordingly, previous findings have revealed that a child’s sense of self-competence predicts their actual level of functioning and academic performance (Mantzicopoulos, 2006). Thus, measuring each participation dimension can provide insights into the nature of child participation. Future studies comparing the participation of children with IDs using the PMP-C (simplified) may do well to use different subcomponents to explore the impacts of the intrinsic factors of preferred activity settings and/or the components of particular settings.

This study established that it is critical to explore participation first from the child’s perspective and evidenced that proxy reports (e.g., primary caregiver reports) can provide specific and in-depth interpretative information useful for scientific research and clinical practice. Children’s subjective feelings about their own participation, which are notably related to intrinsic factors (motivation, engagement, perseverance, social connections and affections), therefore, self-reporting is an effective way to assess children’s involvement in activities (Kooijmans et al. 2022). Study III measured participation across children with IDs and TD based on their own experiences and found that
children with TD in urban areas reported higher total involvement than their rural counterparts; however, there were no significant differences between the rural and urban contexts for children with IDs. The involvement of children with IDs in activities seems to depend on the interactions between biological and environmental factors. When exploring participation through attendance and involvement, it is important to identify and consider how best to intervene in environmental barriers to and facilitators of participation. However, such environmental adaptations can only be made based on good knowledge of the cognitive functioning of an individual child. In Study IV, based on the perceptions of primary caregivers, four categories of barriers to and facilitators of participation in everyday activities for children with IDs were identified across micro-, meso-, exo-, and macrosystems. The findings emphasized the importance of the microsystem, including the children’s characteristics; the primary caregivers’ knowledges, attitudes, and skills; family support; and the school environment. However, positive changes within microsystems require good support systems at the exo- and macro-levels.

9.2.2. Factors associated with context and environment

The context is personal, considered from the perspective of the person participating, and relates to the people, place, activity, objects, and time at which participation is set (Pynes, 2015). The environment is external and refers to the broader, objective, social, and physical structures in which we live (Pynes, 2015). Previous studies showed that contextual and environmental factors (e.g., home environment, family habits, routines, and educational curriculum) may determine the frequency of participation (Rosenberg et al. 2011). In this thesis, children with IDs and TD in rural areas had a lower frequency of total attendance in everyday activities and in four subcomponents—organised activities, taking care of others, family life activities, personal care and development activities—than their counterparts in urban areas. This discrepancy highlights that differences in participation among children can be attributed to different cultural and economic settings. Importantly, the results suggest that interventions need to focus on rural areas and, by extension other similarly less-advantaged environments.
Ultimately, connecting the present findings to the fPRC adds to existing understandings of the intrinsic and extrinsic factors of participation in everyday activities for children with IDs. Healthcare professionals should consider these new insights when planning follow-ups and interventions to support the participation of children with IDs.
10. Methodological considerations

10.1. Research approach

A cross-sectional design was used in Studies I and II, as it was suitable for questionnaire validation. A cross-sectional, comparative survey design was used in Study III to compare the frequency of attendance and involvement of participation in everyday activities of children with IDs and TD in rural and urban areas of mainland China. Participants—namely, children and youths with IDs and their sex- and age-matched TD peers—were recruited using a convenience sampling method in rural and urban areas of mainland China to guarantee equality between the two groups at baseline. ID and TD groups were created in the same contexts to compare the effect of personal factors (e.g., ID), to avoid bias, and to make the results comparable and reliable. Meanwhile, Study IV was designed to uncover barriers and facilitators related to participation in everyday activities among children with IDs in mainland China based on a qualitative content analysis of interviews with their primary caregivers; this approach was considered a suitable open-ended method for collecting insights into the processes affecting participation.

10.2. Trustworthiness of the quantitative method

According to Lincoln and Guba (1985), trustworthiness in a quantitative analysis is important for evaluating its worth. The trustworthiness of the quantitative method in this study was evaluated based on the validity and reliability of its concepts (Lincoln & Guba, 1985).

10.2.1. Validity

External validity refers to the extent of generalisability by which the results of a study can be applied to a broader population and other settings (Creswell, 2008). In Studies I–III, the data were collected from only four provinces in China, which affected the external validity and reproducibility of the results beyond this specific site. Additionally, the use of convenience rather than
random sampling also affected the generalisability of the results. TD counterparts in the same context were used to attempt to control for confounding variables (III), which strengthened external validity. Meanwhile, this study involved one-on-one interviews and had a low percentage of missing data, which minimised the threat of external validity (Neuman, 2014).

Internal validity is a measure of how well a study is conducted (its structure) and how accurately its results support inferences about covariation and causality (Christensen et al. 2011). The internal validity of the data was ensured by addressing the details of instrumentation, data collection, and data analysis (Creswell, 2008; Neuman, 2014). The internal validity of this cross-sectional study was based on its accuracy and strong research methods. To ensure the validity of the study, the data utilised in Study III were collected using a validated instrument with good psychometric properties, the PMP-C (simplified). This questionnaire asks respondents to use a Likert scale to respond to its items. The researcher facilitated the respondents’ use of the scale through a specific picture-supported interview method and by providing help when needed. This approach can help researchers clarify misunderstandings and minimize missing data. Notably, the use of a control group could decrease the risk of internal validity by preventing misinterpretations of the meaning of pre- and post-measures (Marsden & Torgerson, 2012). Meanwhile, the validity of the research can be assured by using a pre-test to evaluate the time needed to complete the measurement and to ensure that children, especially children with IDs, have no problem understanding the items of the instrument (Zimmerman, 2003). These study designs ensured that the results were rigorous and valid.

10.2.2. Reliability

Reliability is the dependability or consistency of a measure, including whether the instrument provides the same results under identical or similar conditions (Kimberlin & Winterstein, 2008). Study II showed that the Chinese version of PMP has good psychometric properties, with excellent internal consistency and test-retest reliability. A pre-test study was conducted to obtain feedback on the practicability of the questionnaires. To ensure data correction and enhance the reliability of the study, the data from Studies I–III were entered.
into SPSS by one researcher and separately checked by another experienced researcher.

10.3. Trustworthiness of the qualitative method

The most important indicators of the trustworthiness of a qualitative study are credibility, dependability, confirmability, and transferability (Morse et al. 1995).

10.3.1. Credibility

Credibility refers to whether the research findings are plausible and trustworthy (Graneheim & Lundman, 2004). First, credibility can be improved by choosing participants with various experiences (Patton, 1987). In the present study, credibility was strengthened by strategically selecting primary caregivers with different ages, sexes, educational levels, employment statuses, marital statuses, and relationships with the children for whom they cared—this varied sample may provide more comprehensive results and thus increase the possibility of adequately answering the research questions. Second, appropriate data collection methods and amounts of data are important for establishing credibility (Graneheim & Lundman, 2004). Third, credibility can also be supported by thoroughly informing the interviewees about the interview processes and the topic of the study. Face-to-face semi-structured interviews were conducted with the participants until the data were saturated. The rich descriptions obtained from the interviews with representative quotations strengthened their credibility (Creswell, 2008). Fourth, credibility was also ensured in this study by using tables to present the primary caregivers’ characteristics (educational level, employment status) and their children’s age, diagnose and impairment. Finally, credibility was also established by ensuring that the co-researchers reached a consensus on the labels for and type of data.

10.3.2. Dependability

Dependability refers to the extent to which a study can be replicated under similar conditions (Graneheim & Lundman, 2004). Researchers must provide
sufficient information about the procedural steps. In this study, two pilot interviews were conducted with the first author and reviewed by all the authors before the remaining interviews were conducted. The first author’s previous understandings of the primary caregivers’ context and non-verbal forms of communication during the interview, such as facial expressions and movements, may have influenced the interpretation of the data. In response, potential bias was reduced by reaching consensuses on the sampling, data collection, and analysis methods through frequent and extensive discussions among the authors. These processes are clearly described in this study to increase the dependability of the qualitative research.

10.3.3. Confirmability

Confirmability refers to a clear link or relationship between the data and findings. Researchers can validate the criticality and thoroughness of their data by describing their in-depth data analysis method (Cope, 2014); put differently, they can demonstrate confirmability by describing how they derived their findings from their data (Cope, 2014). In Study IV, all the interviews were audiotaped and transcribed verbatim. The researchers rigorously compared and discussed meaning units, codes, subcategories, and categories until an agreement was reached. Likewise, thick and rich quotations from participants were presented in the findings to strengthen confirmability (Cope, 2014).

10.3.4. Transferability

Transferability refers to findings that may be transferred to another setting, context, or group (Graneheim & Lundman, 2004). In this study, transferability was supported by providing a rich and detailed description of the context and setting in which the research was performed and how this shaped the findings.
11. Conclusion

This study tested the reliability and validity of a rigorous measurement for participation in everyday activities using a large heterogeneous sample of children with IDs in mainland China. Children with IDs’ own opinions were included which makes an important positive contribution to research aiming to improve the rights of children with IDs. Additionally, this study explored the importance of participation in everyday activities and the influential role of environmental factors in supporting and restricting the participation of children with IDs in mainland China. The results of this study can guide further research on interventions aimed at increasing the participation of children with IDs.
12. Implications for practice

The validation of the PMP-C (simplified) in this thesis, confirmed that it can be used to assess participation reliably and validly in everyday activities among children with IDs in mainland China. When applied PMP-C (simplified) seems to uncover insights into the participation of children with IDs in mainland China as well as to map indicators of barriers to and facilitators of participation. Notably, the measure allowed for children to self-report their experiences of participation and may offer insights into what opportunities children with IDs in mainland have to attend activities as well as their involvement in everyday activities. Besides, it highlights the influential role of environmental factors in supporting and restricting participation for children with IDs. The results of this study may inform the development of further research and interventions aimed at increasing the participation and well-being of children with IDs. To be implemented these interventions require cooperation with the children with IDs, their primary caregivers, teachers and related healthcare professionals. In particular, such interventions should be geared towards assessing the children’s cognition to inform adaptations to the environment. On exo- and macro system levels, this thesis underscores the need for society to encourage and promote the participation of children with IDs in everyday activities—this requires financial support for related social organisations and relevant policies to ensure consistent access to various activities to enrich the daily lives of children with IDs.
13. Limitations and directions for future research

This study had some limitations related to the characteristics of its sample, data collection, and analytical methods. First, most participants with and without IDs were selected from four centres with representative populations of different ethnic groups in rural and urban areas. However, data were collected primarily from schools in Hebei Province, located in northern China. Accordingly, these results may not be representative of other areas of China. Convenience sampling also limited the generalisability of our findings. Second, criterion validity was not examined as there were no standard measures for the assessment of the PMP-C (simplified). Third, while the study sought to give voice to primary caregivers to develop a more comprehensive description of the barriers to and facilitators of participation in everyday activities among children with IDs in China, the participants only included primary caregivers of children with mild-to-moderate IDs from special schools in urban areas; therefore, the results may not be representative of primary caregivers of children with severe IDs or from other settings. Additionally, the study’s findings were limited by the lack of data collected on other important family demographic variables, such as average monthly household income, household registration type, and the marital status of the primary caregiver. These variables should be further studied and developed.

Various strategies are required to implement the changes this thesis suggests are necessary to improve the participation of children with IDs in mainland China. For example, primary caregivers, therapists, and teachers should be trained or supervised to develop participatory practices. Additionally, children and families should be included in service planning to develop higher-quality child- and family-oriented services. Last, moving forward, scholars should conduct longitudinal studies on this topic to improve existing understandings of the most effective strategies for increasing the participation of vulnerable populations in everyday activities.
14. Chinese summary

研究背景

智力障碍（intellectual disabilities, IDs）指个体的智力功能方面和适应性行为两个方面均存在显著性限制，且发生在 18 周岁之前。2006 年我国第二次残疾人抽样调查数据显示，智力残疾患者(含多重残疾中的智障者)大约为 988 万人，约占总人口的 0.75%，占残疾人口的 11.9%。与健康儿童相比，智障儿童在日常生活中经历更多的健康与社会融入问题，这对智障儿童的身心健康和生活质量产生了严重的负面影响。

《国际功能、残疾和健康分类》(International Classification of Functioning, Disability and Health, ICF)从 4 个维度评估被试者的健康状况，包括身体结构和功能、活动和参与、环境因素和个人因素。现代的智力残疾研究也采用 ICF 的理论与方法，强调个体的智力功能、活动和参与障碍以及环境因素的影响。其中，参与日常活动被视为儿童干预和康复的主要目标与结果。此外，《儿童权利公约》和《残疾人权利公约》规定，残疾儿童享有机会均等、平等对待、不歧视及回归主流的权利。这个“参与”概念是指儿童在其家庭、学校及社区生活中被视为主动的参与者，同时充分反映了个体应有完全被社会接纳的权利。因此，持续关注智障儿童在日常生活中的参与度是重要的社会关切。

“参与”与环境相辅相成，对于生活在中低收入国家的智障儿童的“参与”的研究非常有限，这和在这些情情境下测量参与的工具缺乏有很大的关系。“图示我的参与”（Picture My Participation，PMP）是一个儿童的自我评估工具，借助图片探讨儿童在不同环境中的参与，具体包括两个方面：日常环境中的参与频率和参与强度（参与的投入程度）。有关“参与”频率包括儿童活动种类的广度及多样性、活动的频率、与谁一起从事哪些活动等；参与强度所测量的内容包括参与活动的愉悦、投入、偏好及动机强烈程度、照顾者或儿童对于活动儿童活动参与的满意度等。理论上，参与的两个方面与个人技能和偏好等内在因素以
及情境和环境因素有关。PMP 包含 20 个问卷条目和图片，适用于 5-21 岁的智障儿童，旨在使用清楚、简单的语言和图片，有效的与儿童进行引导性对话，更好地评估他们日常生活中的参与频率和参与强度以及阻碍和促进因素。PMP 已经在瑞典、南非、东非等国家进行了预试，证实其可以在多种文化环境和国家评估智障儿童的日常生活的参与度，但目前中国大陆还缺少经过验证的简体中文版 PMP，用于评估中国大陆智障儿童的日常生活的参与度情况。

研究目的

本文的总目标是汉化、验证及应用简体中文版本的“图示我的参与”作为中国大陆儿童日常生活参与度的评估工具。具体包括：
● 描述“图示我的参与”的汉化，并探讨其表面效度、内容效度和信度。
● 探索简体中文版“图示我的参与”中参与频率量表的结构效度。
● 应用简体中文版“图示我的参与”，比较中国大陆农村和城市地区智障儿童和正常儿童日常活动的参与频率和参与强度。
● 描述智障儿童主要照顾者对智障儿童参与日常活动的阻碍因素和促进因素的观点。

研究方法

第一部分 汉化、验证简体中文版“图示我的参与”

1. 研究对象

研究一，便利选取中国河北省和天津市的儿童医院门诊的智障儿童、特殊教育学校的智障儿童和普通学校的正常儿童作为研究对象，共招募 111 名智障儿童以及 651 名正常的小学或初中青少年（n=762）。纳入标准：(1) 年龄在 5 岁至 21 岁之间患有轻度或中度智障的儿童或青少年；(2) 能够听懂普通话；(3) 能够通过问卷的三个测试项目；(4) 能够口头表达自己的想法；(5) 知情同意并自愿参与。排除标准：(1) 未矫正的视力或听力障碍；(2) 近 3 个月内因癌症等状况不稳定的患者；(3) 影响日常生活的感染或疾病；(4) 进性疾病（如神经肌肉疾病）
或退行性疾病（如退行性癫痫发作）。研究二，在中国大陆河北省、天津市、广西壮族自治区和新疆维吾尔自治区的特殊教育学校和普通学校进行横断面研究。招募 96 名 5-21 岁的智障儿童和 194 名正常儿童为研究对象，其中来自天津市城市地区的智障儿童（n=64）和正常儿童（n=49），河北农村地区的智障儿童（n=26）和正常儿童（n=55），新疆维吾尔自治区农村地区的智障儿童（n=3）和正常儿童（n=47），广西壮族自治区农村地区的智障儿童（n=3）和正常儿童（n=43）。研究对象共计 290 名，纳入和排除标准与研究一相同。

2. 研究方法

研究一和研究二均为横断面研究，采用工具验证设计的定量方法，对原量表进行翻译、回译，经过文化调适及预测试后，确定中文版问卷的条目和图片并测量量表的信效度。研究工具主要包括一般资料调查表和简体中文版“图示我的参与”。

2.1 一般资料调查表 包括儿童年龄，性别，居住地，就读学校及年级，残疾的水平、儿童及家人的健康状况，家庭人口数，平时主要照顾者等基本信息。

2.2 简体中文版“图示我的参与” 包含 20 个条目，借助图片来评估儿童的参与：(1)每个条目的参与频率，以李克特四分量表评分（从不；很少；有时；总是）；(2)参加每个活动时的投入程度，用李克特三分量表评分（不投入；有些投入；非常投入）；(3)选择三个认为最重要的活动；(4)评估参与的阻碍和促进因素。参与频率分为四个等级（总是=4 分，有时=3 分，很少=2 分，从来没有=1 分，各条目分数相加，得分越高，说明儿童的参与频率越高；参与强度，同参与频率条目，分为三个等级（积极投入=3 分，一般投入=2 分），极少投入=1 分），各条目分数相加，得分越高，说明儿童参与投入程度越高。每个儿童访谈时间为 10-20 mins。

2.3 统计学方法 采用 SPSS 26.0 软件对资料进行统计分析。计数资料用例、百分比进行描述。量表的效度采用内容效度和结构效度进行评价；信度通过计算 Cronbach's α 系数和重测信度进行评价。
第二部分 简体中文版本 “图示我的参与”的应用

1. 研究对象

研究三，便利选取河北省农村地区和天津市城市地区的特殊教育学校和普通学校的学生共计 312 名，包括 153 名智障儿童（农村：62 例；城市：91 例）和 159 名正常儿童（农村：65 例；城市：94 例）。纳入和排除标准与研究一相同。

2. 研究方法

对河北省农村地区和天津市城市地区的智障儿童及性别和年龄匹配的正常同龄儿童分别进行比较。研究工具主要包括一般资料调查表和简体中文版“图示我的参与”。

2.1 一般资料调查表 包括儿童年龄，性别，居住地，就读学校及年级，残疾的水平、儿童及家人的健康状况，家庭人口数，平日主要照顾者等基本信息。

2.2 简体中文版“图示我的参与” 共有 20 个条目，根据研究二的结果分为五个维度。第一维度为“有组织的活动”，主要包括参加学校组织的活动，购物，在保健中心就诊等 6 个条目；第二维度为“社会生活”，包括“与他人玩耍”、“精神活动”、“庆祝活动”和“社交活动”4 个条目；第三维度为关爱他人，包括“关爱家人”、“关爱动物或宠物”、“志愿者活动”3 个条目；第四维度为“家庭活动”，包括“家庭时间”、“家庭进餐时间”、“备餐”、“安静休闲”4 个条目；第五维度为“个人照顾和发展”，包括“学校”、“个人关怀”、“照顾自己的健康”3 个条目。计分方法同第一部分。

2.3 统计学方法 采用 SPSS 26.0 软件对资料进行统计分析。使用描述性统计学方法总结人口统计学特征和问卷测量结果。由于数据是正态分布的，因此采用独立样本 t 检验分别比较中国大陆农村和城市地区的智障儿童和正常儿童日常活动的参加频率和参与强度的总分和五个维度方面的差异。
第三部分 中国智障儿童参与日常活动的阻碍因素和促进因素的
   质性研究

1. 研究对象

采用目的性抽样方法，在参与研究三的调查的智障儿童的主要照
顾者中抽取 20 名作为研究对象，主要是来自天津市区四所特殊学校的
智障儿童的主要照顾者。纳入标准：(1)平日为患有轻度至中度智力障
碍的儿童提供护理者；(2)与儿童一起生活至少一年；(3)完成简体中文
版“图示我的参与”问卷的填写，对其条目内容已了解；(4)能够说和听
懂普通话。

2. 研究方法

采用半结构化访谈，了解智障儿童主要照顾者对其孩子在参与日
常活动的阻碍因素和促进因素的相关观点。分析方法应用内容分析法
中的归纳法，整个分析过程包括编码、分类和提取三个阶段。

研究结果

简体中文版“图示我的参与”共 20 个条目，经过汉化和跨文化调适
后，5 个项目略有修改，8 个图片被修改，提高了其与中国大陆文化的
契合度，所有项目均具有良好的信效度。智障儿童总量表的 Cronbach's
α 系数为 0.80，重测信度为 0.89。正常儿童总量表的 Cronbach's α 系数
为 0.82，重测信度为 0.81。经探索性因子分析后共提取 5 个公因子，累
计方差贡献率为 51.62%。

验证简体中文版本的“图示我的参与”之后，进一步应用此工具进行
调查和比较中国大陆农村和城市地区的智障儿童和正常儿童参加日常
活动的频率和参与强度的总分和五个维度方面的差异。参与频率和参
与强度的总分结果，农村和城市地区的智障儿童的参与度均低于正常
儿童，但在参与强度方面，两个维度方面（照顾他人、家庭生活），
智障儿童的参与强度与城市地区的正常儿童差异无统计学意义。关于
城市和农村环境之间的差异，农村地区的正常儿童和智障儿童在参与频率的总分和其中的四个维度方面均低于城市儿童，只有‘社会活动’这一维度差异无统计学意义。在参与强度方面，智障儿童在农村和城市环境中参与强度差异无统计学意义，但城市地区正常儿童的参与强度高于农村儿童。

为了更加深入地了解儿童日常参与度的阻碍和促进因素，采用质性研究进行半结构式访谈，共计 20 名主要照顾者表达了对其所照顾的智障儿童参与日常活动所面临的阻碍和促进因素的观点。最终归纳出智障儿童参与日常活动的四类阻碍和促进因素，其中阻碍因素包括：主要照顾者的知识、态度和技能不足；儿童的智力障碍表现的特征；污名化与中国文化；以及缺乏社会支持。促进因素包括：主要照顾者的乐观态度；充足的家庭支持；积极的学校环境和政策；以及智障儿童的性格特征。

结论与意义

简体中文版“图示我的参与”适用于中国大陆儿童和青少年的心理测量特性已得到证实。本研究采用智障儿童自评的方法，对提升智障儿童权利的相关研究做出了积极贡献。与此同时，环境因素在促进和阻碍中国大陆智障儿童日常生活参与度的影响的探讨，为进一步开展增加智障儿童的参与和福祉的干预性研究奠定了一定的基础。

参与是干预的方法，也是干预的目标。以参与为基础的干预应强调以家庭为中心，专业人员与家庭合作式的团队模式，引导家长主动参与并与专业人员共同讨论制定符合这一群体生活情境需求的目标，提供更多智障儿童与其家长参与日常生活活动的机会与策略。同时，在强调社会关注并给予更多的财政支持和政策支持，综合多因素、多层面共同促进智障儿童的日常生活参与度水平。
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Participation in everyday activities among children with intellectual disabilities in mainland China

– The development, verification, and application of the Picture My Participation instrument

This thesis reports four studies conducted to carry out the overall aims of validating a simplified Chinese version of Picture My Participation as a participation assessment tool, the PMP-C (simplified). The aim was also to describe the attendance and involvement in everyday activities of children with IDs and their TD peers in rural and urban areas of mainland China as well as barriers and facilitators of participation from the perspectives of children and their primary caregivers.

Studies I and II used a quantitative method with a cross-sectional instrument validation design to cross-culturally adapt the PMP-C (simplified) and explored its validity and reliability. Findings revealed that the content validity, face validity, the internal consistency, reliability coefficient and test-retest reliability of the subscale attendance of the PMP-C (Simplified) were excellent as well as the construct validity extracted five subcomponents. Based on this, Study III used a cross-sectional design to compare the frequency and involvement of children with IDs and TD in everyday activities in rural and urban areas of mainland China. Findings revealed that ID–TD and urban–rural disparities. Meanwhile, Study IV used a descriptive and explorative design with an inductive qualitative content analysis approach to describe primary caregivers' perceptions of barriers and facilitators related to participation in everyday activities among children with IDs in mainland China. Four categories describing barriers and facilitators were identified.

This thesis provides psychometric evidence that the PMP-C (simplified) is a valid and reliable measure of participation in mainland China and enable children with ID to have “a voice” and to report their own perspectives. The findings regarding ID–TD and urban–rural disparities in participation and the barriers and facilitators of participation among children with IDs offer important insights concerning important environmental aspects when planning future intervention studies focused on promoting participation in mainland China.

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