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Transcultural adaptation, content validity and reliability of the instrument 'Picture My Participation' for children and youth with and without intellectual disabilities in mainland China

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ABSTRACT

Background: '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.

Aim: To describe the cross-cultural adaptation of the simplified Chinese version of 'Picture My Participation' (PMP-C; Simplified) and explore its validity and reliability.

Methods: A cross-sectional study using convenience sampling was conducted using PMP-C (Simplified) with structured interviews supported by pictures for children and youth with and without intellectual disabilities (ID) in mainland China. The validity of the PMP-C (Simplified) was demonstrated by face validity and content validity while the reliability was evaluated for internal consistency and test-retest reliability.

Results: Five items were slightly modified and eight pictures were revised to improve their fit with the culture of mainland China. All the items in PMP-C (Simplified) had excellent content validity, and face validity. The internal consistency, reliability coefficient and test-retest reliability of the subscale attendance for children and youth with and without ID were excellent.

Conclusion: Preliminary evidence of the content validity of PMP-C (Simplified) items and reliability of the subscale attendance for use with children and youth in mainland China has been gathered. However, psychometric properties in terms of construct validity for the whole instrument and reliability for the engagement subscale need further exploration.

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Introduction

According to China's Second National Sampling Survey on Disability in 2006 (NO.2), intellectual disabilities (ID) accounts for 70% of all disabilities among children in China [1,2]. The outline for the Development of Children in China (2011–2020) emphasizes the need to 'guarantee the right of participation and expression of children' [3]. In addition, the Convention on the Rights of Persons with Disabilities [4] states that children with disabilities have the same rights as children with typical development (TD) to function fully in all life situations. Functioning fully can be expressed as participation. Participation is always contextualized and describes the child or youth's involvement in daily activities that are

affected by the surrounding environment. In the International Classification of Functioning, Disability, and Health (ICF) and its Children and Youth version (ICF-CY), participation is considered an important indicator of health and well-being and the ultimate goal of services for children with disabilities in everyday activities [5–8].

The United Nations Convention on the Rights of the Child (UNCRC) asserts the right of every child to express opinions, regardless of their age, background, or disability [9–11]. In a recent study [11,12], the results highlight the importance of promoting children's rights to express themselves when their more complex needs are surveyed, especially in poverty settings. Research with 'Picture My Participation' (PMP) on children's everyday living

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contexts primarily concern outcomes that include children's perceptions and feelings, so children's own voices can probably express the needs of participation better than proxy ratings [10,11]. However, the use self-reports with children may vary on the continuum from taking more or less the child's perspective depending on the child's capacity to participate and to communicate.

Most instruments used to assess participation are developed and validated in Western high income countries [13], such as the Child and Adolescent Scale of Participation (CASP) and the School Function Assessment (SFA), the Children's Assessment of Participation and Enjoyment (CAPE) and the Child Occupation Self-Assessment (COSA) [14,15]. These measures do not assess environmental factors and may not be valid in a low- and middle-income countries (LMIC). A comparison of data collected in South Africa (LMIC) and Sweden (High income country) provided indications that the pattern of frequency of attending activities may vary with income level of country [2]. Participation cannot be separated from the overall environment prerequisites, in measurement and in practice [16–18]. Instruments in which both participation and environment are assessed simultaneously have all been developed in high income countries, such as the Participation and Environment Measure for Children and Youth (PEM-CY) [19] and the Young Children's Participation and Environment (YC-PEM) [20], but they are parent-/caregiver-report questionnaires and thus do not give a voice to children themselves. One existing measure based on interviews with children is CAPE [14]. However, the CAPE measure is only focussing on participation in leisure activities and is developed in a western high income country with activity types and examples provided based on a western culture. A systematic review of properties of participation measures by Rainey et al. [21] shows that only two of the 21 measures were developed in LMIC countries and both focussed on participation in a clinical setting – not in everyday contexts. There is a shortage of suitable instruments for measuring participation in non-western cultures such as mainland China. In addition, mainland China have a large variation in socioeconomic circumstances when rural and urban areas are compared. Rural areas are less developed concerning income, access to school and intervention services and parental educational level [1,22]. Psychometrically sound self-report instruments to measure participation that are validated for use with children and youth with ID in both urban and rural areas in mainland China are needed [23].

The 'Picture My Participation' (PMP) is unique as it is a self-report measure of participation and environment

that focuses on children and youth 5–21 years of age from marginalized communities and low socio-economic backgrounds [2]. It was founded in ICF-CY and an adaptation of the PEM-CY [24] and the Paediatric Activity Card Sort [25]. It contains 20 items focussing on the home, community and school and aims to use clear, plain culturally and contextually appropriate language and pictures to provide an interactive and structured way to enable children and youth with ID express participation experiences and goals [6]. The administration procedure is 'Talking Mats' method which uses a mat with pictures symbols attached as a means of communication [26,27]. In the PMP, pictures are used to present each of the activities, environmental factors, and visual scales participation frequency and level of involvement. The content validity of PMP in Sweden, like in South Africa, has been reported as satisfactory [2] when trialed on children with ID, and the cross-cultural adaptation for school-age children in Taiwan has been finished for the traditional Chinese version of 'Picture My Participation' (PMP-C; traditional) [28,29], but it is not yet available in simplified Chinese. Children and youth with ID in mainland China, like all children and youth, have the right to fully engage in everyday activities. There is an urgent need for a simplified Chinese version of 'Picture My Participation' (PMP-C; Simplified), which would have a positive effect on the screening of participation, support, education and medical prevention services for children and youth with ID in both rural and urban areas in mainland China [30].

This study is the first step in a larger research project aiming to develop and explore the utility of the instrument PMP in mainland China. It is also contributing to providing a basis for measuring differences in children and youth's participation between countries. The objectives of the present study are to: (a) describe the process of translation and cross-cultural adaptation of PMP-C (Simplified) and (b) to investigate the psychometric properties of PMP-C (Simplified) by exploring face validity, and content validity of the items. A final objective is to investigate test-retest reliability and internal consistency of the subscale attendance of PMP-C (Simplified) in children and youth with and without ID in mainland China.

Materials and methods

Adaptation and validation based on experts' agreement

Cross-cultural adaptation procedures

Adaptations were made to the items and pictures based on the original edition. Translation of the

English PMP into PMP-C (Simplified) was performed using the guidelines for the process of cross-cultural adaptation of self-report measures [31] as a reference. This process consists of six phases: initial translation, synthesis, back translation, expert committee, pretesting and submission of documentation to the coordinating committee for appraisal of the adaptation process. Two Chinese bilingual experts partook in the process, one was a medical assistant professor and the other a native translator with Test for English Majors-Band 8 (TEM-8) Certification for teaching English majors. Each one translated the English PMP into PMP-C (Simplified). The translators were given the following guidelines: to consider the characteristics of typical respondents (children and youth with and without ID, different contexts) and to use simple, clear and concise language. Differences between the translations were discussed by the translators and a third expert (with a background in the PMP project) who acted as a mediator to synthesize the results of the translations and reach a final translation. Back translation was conducted by two other bilingual translators with English as their mother tongue without medical backgrounds who had not seen the original English PMP. The back-translated version was then compared with the original. Small modifications were made by an expert committee (forward and back translators, a researcher on the PMP project, a doctor of child psychology and a teacher in special needs education) to correct for cultural differences and preserve the translation's equivalence to the English version of PMP. For the pretesting, children and youth with ID and TD ($n = 20$) were interviewed to find out what they thought when seeing a picture and if it was clear and relevant to their daily lives, if not they were asked to propose a better idea to revise it. In this step, the twenty children and youths provide key information for modifying the pictures. Finally, all the records were submitted to the developers of the PMP to evaluate the cultural adaptation process, with a final version being accepted for evaluation of its face validity, content validity, and reliability and validity by a large sample population.

Face validity

As participation is influenced by environmental factors and the PMP-C (Simplified) is a self-rating scale, cognitive interviews were necessary to assess children and youth's understanding of the items and pictures [2]. Having a fresh pair of eyes examine PMP-C (Simplified) can point out flaws and issues which may not be apparent to the creator. After the final version

of PMP-C (Simplified) was agreed, purposive sampling was used to ensure heterogeneity. As the children and youth with ID graduate at the age of 21 years old in special school in mainland China, another sixteen children and youths from different age groups (5–8, 9–12, 13–16 and 17–21 years old) and with different health conditions (some with ID and some with TD) were interviewed to test and verify the face validity.

Content validity

The content validity was evaluated by five experts, including one nurse, two doctors at a children's hospital and two directors of special needs schools. All these experts had experience of rehabilitation or psychotherapy for children and at least ten years of work experience in senior clinical roles. A four-point ordinal rating scale was used by the five experts in which 4 = very relevant, 3 = strong relevance, 2 = weak relevance and 1 = not relevant. Both the scale-level content validity index (S-CVI) /universal agreement (S-CVI/UA) and the scale-level CVI/average agreement (S-CVI/Ave) were calculated as quantitative data for scale-level content validity. S-CVI/UA is defined as the proportion of ratings with a three or four on the scale, and S-CVI/Ave is calculated by taking the average of the item-level CVIs (I-CVIs). If experts rate an item less than 3 an explanation is added in the feedback as qualitative data. A final version of the instruments was established based on the experts' comments.

Psychometric testing based on the survey data

Design

A cross-sectional comparative survey design was used for the validation of the responses of children and youth with ID to the attendance scale by comparing their responses with those of their peers with TD. By including a comparison group with children with TD, it was possible to test if the method is sensitive enough to discriminate between groups. It was hypothesized that children with TD should report higher attendance than children with ID.

Setting

Settings included outpatient care at children's hospitals, mainstream education and special needs education in Tianjin and Hebei provinces in mainland China. In 2017, the total population of Tianjin was 15.57 million, and the registered population of Hebei Province was 75.2 million.

Participants

Children and youth aged 5–21 years with and without ID were recruited using a convenience sampling method of outpatients of children's hospitals and students at special needs schools and mainstream schools in Tianjin and Hebei provinces in mainland China. Data collection took place from May 2017 to January 2019. A sample of 111 children and youth with ID and 651 children and youth with TD ($n = 762$) were recruited; for details see Table 1. Children and youth with ID were eligible for inclusion if they attended a special school or were histologically diagnosed at a hospital with 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) and the impairment is considered mild or moderate. Children and youth with either ID or TD needed to meet the following criteria to be included: (i) aged between 5 and 21 years; (ii) able to understand Mandarin, pass three trial items and express their thoughts verbally; (iii) Participants and their caregivers must give informed consent and participate voluntarily. Children and youth with uncorrected visual or hearing impairments, and who with unstable health conditions such as cancer who have had surgery within the last 3 months, have infections or other active medical conditions that affect their daily lives, or have a progressive disease (e.g. neuromuscular disease) or a degenerative disorder (e.g. degenerative seizures), were not included.

Instrument

The PMP-C (Simplified) contains 20 items and is available in a paper-based questionnaire format. This instrument uses culturally sensitive pictures and a structured approach to help children and youth identify participation from four aspects [2]: (1) frequency of attendance for each item, rated on a four-point Likert scale (Never; Seldom; Sometimes; Always), (2)

level of involvement when performing each item, rated on a three-point Likert scale (Not involved; Somewhat involved; Very involved), (3) choice of three important activities determined independently, and (4) evaluation of perceived barriers to and facilitators of participation (2–4 were not the focus of this study). The interview takes about 10–20 min for each child or youth and varies depending on the communication ability. For the purpose of the study, it concerns using the instrument as a tool for gathering knowledge about the attendance aspect of participation in mainland China, only data from the first part (frequency of attendance) were used.

Data collection

All the participants and their caregivers were informed of the purpose and procedures of the study. The 'Talking Mats' format, namely a specific picture supported interview method was used [26,27]. The method involves placing a mat in front of the child or youth. For the ratings of attendance, one mat was divided into four equal columns using the visual representation of the four-point Likert scale depicted with pictures of baskets of apples: 'Never' (empty basket), 'Seldom' (basket filled with two apples), 'Sometimes' (basket filled with five apples) and 'Always' (basket filled with apples), it help the children or youth to indicate their responses concerning frequency of attending. The children and youth were asked 'How often do you participate in daily routine activities' while being shown the picture of the specific activity then the child or youth could place it on the mat in the column to indicate the item that they felt the best represented the frequency of their participation [2]. Three trial items were used to facilitate children and youth's understanding of the process and content of PMP-C (Simplified). Items were presented one by one, with response options presented using pictures selected from Picture Communication Symbols (PCS) revised to fit the Chinese culture [2] for the purposes of enhancing the participants' understanding of the items. The researcher recorded the responses to each item on separate score sheets until all 20 items were completed. The administration procedure was the same for children and youth with TD. To evaluate test-retest reliability, participants were asked to complete the PMP-C (Simplified) face to face a second time, two weeks after the first, using the same procedure. Three researchers conducted the interviews. All had experience working with children with ID or on the PMP project and were trained in interviewing children and youth using PMP-C

Table 1. Demographic characteristics of children and youth of mainland China.68 (61.3%)

	Children and youth with ID ($n = 111$)	Children and youth with TD ($n = 651$)	All participants ($n = 762$)
Gender: n (%)	43 (38.7%)	296 (45.5%)	339 (44.5%)
Girls	355 (54.5%)	423 (55.5%)	
Boys	0	0	0
Missing			
Age			
Min-Max	6–21	5–19	5–21
Mean (Sd)	13.5 (3.8)	12.9 (2.3)	13.0 (2.6)
Median	13.0	13.0	13.0
Missing	0	0	0

(Simplified). The same protocol for training was used as for the original validation and included an interview schedule and training video [2]. Data relating to participants' characteristics, including date of birth, gender and level of perceived disability, were collected using a primary caregiver report survey.

Ethics

The study adhered to the principles of the Declaration of Helsinki and was approved by the Tianjin Medical University Ethics Committee (TMUhMEC2016017) as well as by the principals of the schools and hospitals from which the data were collected. The participants and their caregivers received oral and written information and were informed that their participation was voluntary and that data confidentiality was guaranteed. In addition, participants were informed that they were free to withdraw from the study without the need to give a reason. Information was provided regarding the aim and procedures of the study and how the data would be collected.

Data analysis

Data were exported to SPSS Statistics 21.0 and analysed. For nominal data, codes were assigned on an arbitrary basis (e.g. Male '1', Female '2'). The responses on the attendance scale in PMP-C (Simplified) were coded from 1 to 4, where 1 = Never, 2 = Seldom, 3 = Sometimes and 4 = Always. Descriptive statistics were used to describe the population characteristics and instrument results. The content validity of assessment instruments is defined as the degree to which the content of an instrument adequately reflects the construct assumed to be measured [32,33]. To initially determine the content validity ratings with the content validity index (CVI) was used, the scale-level CVI/universal agreement (S-CVI/UA), scale-level CVI/average agreement (S-CVI/Ave) and K^* (kappa designating agreement on relevance) were calculated. $S-CVI/UA > 0.8$, $S-CVI/Ave > 0.9$, $K^* > 0.74$ means the content validity is excellent [34,35]. As questions in PMP-C (Simplified) were more or less age related, internal consistency was assessed by Cronbach's alpha coefficient of the total score and four age groups of the PMP-C (Simplified) for children and youth with ID by comparing their responses to those of their peers with TD. Cronbach's alpha coefficients greater than 0.7 indicate that a scale has acceptable internal consistency, greater than 0.8 is good and greater than 0.9 is excellent [36]. Test-retest reliability with the two-week interval for participants with ID ($n = 50$) and those with TD ($n = 50$) was

measured by calculating two-way random effects of average measures of the intra-class correlation coefficient (ICC) and their 95% confidence intervals respectively. Based on the 95% confident interval of the ICC estimate, values between 0.75 and 0.9 and greater than 0.9 are indicative of good and excellent reliability respectively [37]. The examination of psychometric properties, including reliability and validity, was guided by the international COSMIN (Consensus-Based Standards for the Selection of Health Measurement Instruments) guidelines on taxonomy, definition and methodological quality [32]. By having a control group with TD children, it was possible to investigate if hypothesized group differences between children with ID and children with TD could be found, i.e. known group validity.

Results

Validation based on expert agreement

Translation

No items were deleted from or added to the instruments. Across the home, school and community settings [29], five participation items and eight pictures were revised to improve their fit with the culture of mainland China. For example, the term 'garden work' was translated as 'sweep the floor or yard'. In addition, the term 'community' was translated into Chinese as 'residential area'; to term 4, 'picking vegetables', we added 'wash vegetables or fruits' to the explanation; for term 6, 'cleaning up at home', we added 'sweep the floor' to the explanation; and 'paid and unpaid employment' was translated into Chinese as 'volunteer activities'. The corresponding pictures for items 2,3,6,7,8,10,14 and 20 were also revised to improve their fit with Chinese culture and make them easier to understand for children and youth with ID.

Face validity

The face validity was good and no major remarks were made by any of the participants (from either the ID or the TD group). They all expressed that the items and pictures reflected what they wanted to measure.

Content validity

Table 2 shows the content validity of the instrument and its evaluation. None of the items received an I-CVI score lower than 0.78. All the items also showed excellent K^* (kappa designating agreement on relevance), indicating very good content validity. The S-CVI/Ave scores were 0.98 indicating acceptable content validity (Table 2).

Psychometric testing of the frequency of attendance Sub scale of PMP based on survey data

Sample characteristics

In total, 111 children and youths with ID and 651 children and youths with TD participated in this study. Among children and youth with ID, age-group were 5–8 years ($n=12$), 9–12 years ($n=20$), 13–16 years ($n=39$), 17–21 years ($n=25$). Among children and youth with TD, age-groups were 5–8 years ($n=21$), 9–12 years ($n=227$), 13–16 years ($n=375$), 17–21 years ($n=28$). The demographic characteristics of children and youth are shown in Table 1.

Analysis of the PMP-C content validity

For the item to be considered useful, all the points on the response scale should be used by at least some participants [2]. Here, the usefulness of the items used for rating attendance was analysed item by item by calculating frequencies of ratings for each point of the four-point Likert scale (Never, Seldom, Sometimes, Always) for attendance. Within the group of children and youth with ID ($n=111$), all four points of the scale were used for 18 activity items, and for the remaining 2 items three scale points were used. For the children and youth with TD ($n=651$), all points on the scale were used for all 20 items. The

extent to which the children and youth used all the scales for rating attendance is shown in Table 3.

Internal consistency

All the participation subscales showed acceptable to excellent internal consistency across the four age groups with two exceptions, as shown in Table 4. The group of 5–8-year-old children with ID and the group of 17–21-year-old youth with TD were slightly below the 0.7 threshold. The total Cronbach's alpha of ID report questionnaires is 0.80 and the Cronbach's alpha of TD report questionnaires is 0.82, as shown in Table 4.

Test-retest reliability

The temporal stability of the PMP-C (Simplified) was supported by the intra-class correlation coefficient (ICC) over two weeks. The reliability coefficients for questionnaires of Children and youth with ID and TD were all good [36]. The ICC and 95% confidence intervals (CI) are shown in Table 5.

Discussion

This first validation study of PMP in mainland China provides initial evidence for the cross-cultural face and content validity of the items and internal consistency and test-retest reliability of PMP-C (Simplified) attendance scale in measuring participation of children and youth with and without ID in mainland China.

Table 2. Evaluation of content validity PMP-C (Simplified).

	Number of experts	Number inagreement	I-CVI ^a	Pc ^b	K* ^{c,d}	Evaluation
PMP-C (Simplified) items ^a						
1. Daily personal care routines at home	5	5	1.00	0.00	1.00	Excellent
2. Family mealtimes	5	5	1.00	0.00	1.00	Excellent
3. Looking after own health	5	5	1.00	0.00	1.00	Excellent
4. Gathering daily necessities for the family	5	5	1.00	0.00	1.00	Excellent
5. Meal preparation with or for the family	5	5	1.00	0.00	1.00	Excellent
6. Cleaning up at home	5	5	1.00	0.00	1.00	Excellent
7. Taking care of other family members	5	5	1.00	0.00	1.00	Excellent
8. Taking care of animals	5	5	1.00	0.00	1.00	Excellent
9. Interacting with the family	5	5	1.00	0.00	1.00	Excellent
10. Family/community celebrations	5	5	1.00	0.00	1.00	Excellent
11. Getting together with other children in the community	5	5	1.00	0.00	1.00	Excellent
12. Organized leisure activities	5	5	1.00	0.00	1.00	Excellent
13. Quiet leisure	5	5	1.00	0.00	1.00	Excellent
14. Religious and spiritual gatherings and activities	5	4	0.80	0.16	0.76	Excellent
15. Shopping and errands	5	5	1.00	0.00	1.00	Excellent
16. Taking part in social activities in the community	5	5	1.00	0.00	1.00	Excellent
17. Visits to health centre	5	5	1.00	0.00	1.00	Excellent
18. Formal learning at school	5	5	1.00	0.00	1.00	Excellent
19. Overnight visits and trips	5	5	1.00	0.00	1.00	Excellent
20. Volunteer activities	5	4	0.80	0.00	1.00	Excellent
S-CVI/Ave ^e			0.98			

^aI-CVI (item content validity index) = number giving a rating of 3 or 4/number of experts.

^bPc (probability of a chance occurrence) = $[N!/A!(N-A)!] / 9 \cdot 0.5^N$ where N = number of experts and A = number agreeing on good relevance.

^cK* = kappa designating agreement on relevance: $K^* = (I-CVI-Pc)/(1-Pc)$.

^dEvaluation criteria for kappa: fair = j^* of 0.40–0.59, good = K^* of 0.60–0.74 and excellent = $K^* > 0.74$.

^eS-CVI/Ave (average scale content validity index) = mean of I-CVI.

Table 3. Proportion of ratings item by item allocated to each grade of the attendance scale for children and youth with ID and children and youth with TD.

Items	Children and youth of mainland China (n = 762)									
	With ID (n = 111)					With TD (n = 651)				
	Never (%)	Seldom (%)	Some-times (%)	Always (%)	Miss-ing (%)	Never (%)	Not really (%)	Some-times (%)	Always (%)	Miss-ing (%)
Personal care	4.5	1.8	10.8	82.9	0	0.2	3.7	16.6	79.6	0
Family mealtime	0.9	0	9.9	89.2	0	0.3	6.8	19.2	73.7	0
My own health	14.4	52.3	17.1	16.2	0	3.8	18.7	35.5	41.9	0
Gathering suppl.	26.1	36.9	24.3	12.6	0	4.3	27.0	48.1	20.6	0
Meal preparation	44.1	32.4	18.9	4.5	0	12.1	34.9	37.6	15.4	0
Cleaning at home	18.0	36.0	25.2	20.7	0	1.7	19.0	42.4	36.9	0
Caring for family	30.6	28.8	30.6	9.9	0	5.8	22.9	37.5	33.8	0
Caring for animals	63.1	21.6	8.1	7.2	0	23.8	27.5	22.1	26.6	0
Family time	23.4	29.7	29.7	17.1	0	2.9	17.8	35.2	44.1	0
Celebrations	25.2	46.8	22.5	5.4	0	4.3	28.1	43.2	24.4	0
Playing with others	33.3	21.6	36.0	9.0	0	5.7	21.5	29.3	43.5	0
Organized leisure	25.2	28.8	32.4	13.5	0	16.3	34.4	28.0	21.4	0
Quiet leisure	14.4	34.2	27.0	24.3	0	3.8	13.2	32.1	50.8	0
Spiritual activities	61.3	28.8	8.1	1.8	0	53.3	31.2	10.3	5.3	0
Shopping	13.5	36.9	36.0	13.5	0	4.5	22.1	39.5	33.9	0
Social activities	53.2	36.0	9.9	0.9	0	18.0	32.1	34.7	15.2	0
Health centre	23.4	55.0	17.1	4.5	0	14.3	40.4	30.6	14.7	0
School	7.2	2.7	11.7	78.4	0	1.4	4.0	13.4	81.3	0
Overnight visits	38.7	42.3	17.1	1.8	0	23.8	39.6	28.9	7.7	0
Volunteer activities	86.5	11.7	1.8	0	0	60.1	29.3	8.1	2.5	0
SUMMARY	23.9	24.6	25.4	26.1	0	24.6	24.9	25.1	25.4	0

Table 4. Homogeneity, internal consistency reliability of PMP-C (simplified).

	n	Total Cronbach's alpha	Age group (years)	n	Cronbach's alpha
Children and youth with ID	111	0.80	5–8	12	0.61
			9–12	20	0.82
			13–16	39	0.76
			17–21	25	0.76
Children and youth with TD	651	0.82	5–8	21	0.72
			9–12	227	0.74
			13–16	375	0.78
			17–21	28	0.50

Table 5. Test-retest reliability of PMP-C (Simplified).

	n	ICC	95% CI	
			Lower bound	Upper bound
Children and youth with ID	50	0.89	0.808	0.949
Children and youth with TD	50	0.81	0.657	0.890

Cultural adaptation is important to ensure sensitivity and responsiveness of an instrument in a foreign cultural and language setting [38]. A substantial literature has been published on China's inequality, the income gap between urban and rural Residents in China is large [22]. This gap not only makes a difference on the availability and accessibility of services but indicates that other underlying causes of participation constraints of children with disability may be associated with personal, social, environmental and policy factors. The translation procedure of the PMP-C (Simplified) was performed using a guideline [31], and the various views of the experts, and children and youth with and without ID in both urban and

rural areas were taken into account. The cultural adaptation of the PMP-C (Simplified) was considered based on four aspects of equivalence to maintain the function and content of an instrument in a different context [31,39]: The first aspect was semantic equivalence, language translation and consideration of the items' content, which is necessary to ensure the instrument's relevance to the culture of mainland China [40–43]. This led to some minor changes in wording, for example, the term 'community' was changed to 'residential area', which is more familiar to children and youth in mainland China. As all items of the PMP-C (Simplified) represent simple activities in daily life in mainland China and according to cognitive interviews and expert panel, the second aspect of idiomatic equivalence was satisfied. The third, concerning the experiential point of view, was necessary to give socially acceptable activities or explicit and relevant examples to help the children and youth understand them, for example item 20 (paid and

unpaid employment), paid employment is a legally prohibited activity for children and youth in mainland China [44,45], so it was changed to 'volunteer activities', which is promoted to strengthen the ideological and moral education of children and youth in mainland China [44]. The term 'picking vegetables' is not common in urban areas of mainland China, so we added 'wash vegetables or fruits' as one explanation of this item. Lastly, conceptual equivalence is associated with relevance and acceptability of the underlying concept [46]. The core concept of the PMP-C (Simplified) is 'participation', which is a fairly new notion for children and youth in mainland China, according to previous research [39]. For this reason, 'participation' was explained using easy comprehension sentences before the interview. A key example is the phrase 'participation includes frequency and degree of interest in partaking in an activity' [2] and a judgement on 'how much do you enjoy it'. In addition, eight pictures were revised to improve their relevance to Chinese culture and make them easier for children and youth with ID to understand, for example picture 2, people in Western culinary traditions tend to have their own portion of food while in Chinese culture all dishes are served at the table and everyone at the table can reach whichever dish they like [47], so the picture of 'Family mealtime', was revised (see Appendix 1).

Face and content validity are necessary and related concepts in self-report outcome measures [37,48]. Face validity ensures that the construct studied is actually being monitored, while content validity assesses the extent to which the key concepts are relevant and comprehensible for the target population [33,49]. The modified items and pictures were clear and easy to understand by the children and youth participating in this study, thus demonstrating good face validity. Related research shows that children are able to understand the meanings of items with supporting pictures measured in PMP-C (traditional) [28]. The content validity of PMP has been established by children with ID and children with TD in South Africa and Sweden [2]. In this study, CVI-I, S-CVI/Ave and the modified Cohen's kappa index produced concordant figures [50] and experts agreed that all the items in PMP-C (Simplified) had excellent content validity. Regarding cultural adaptation and content validity it concerns all items in PMP-C (Simplified).

When exploring the psychometric aspects of validation, probing into the usefulness of the instrument can be a strength [2]. This study shows that children and youth used all four points on the scale of the attendance subscale, except in the case of two items for which only

three points were used when interviewing children and youth with ID. This result implies that all levels of the scale were relevant to the children and youth with ID and TD. However, the children and youth with ID did not use all the scale points to rate two activities. None of the group selected 'not really' for the 'family mealtime' item, and none of them selected 'always' for the 'volunteer activities' item. This result could be explained by difficulty using the rating scales rather than difficulties understanding the items themselves. Alternately, it could indicate that children and youth with ID do not have assured attendance at this activity. The fact that children and youth with TD used all the points on all the items of PMP-C (Simplified) provides some evidence of a potential gap in participation opportunities between the group of children and youth with ID and those with TD. For example, the results for the item 'playing with others' show significant proportional differences between the number of children and youth that selected 'always' in the ID and TD groups (Table 3). Prior studies have indicated that children with ID experience loneliness and have fewer friends and poor quality friendships [51–54]. The results for the item 'family time' show the greatest difference in the proportion of children and youth who selected 'always' between the two groups which appeared to be an evidence that PMP-C (Simplified) can pick up expected differences between children and youth with ID and TD [55]. Some research shows similar conclusions: that the pressure on women with children, especially those with ID, to play the dual role of mother and breadwinner is great, and labour force participation of mothers in both urban and rural areas of China correlate with declining parental time with children [51,56]. Another important context is the increasing popularity of authoritative parenting in mainland China; high expectations are focussed on children in the hope that they will be top of the class academically or perform better than their peers in arts, sciences or sports. Based on these changes in Chinese parenting, we would anticipate greater time investment by parents of the TD group than the ID group [57]. The results suggest that the PMP-C (Simplified) instrument is sensitive to detect disability-related group differences [58]. Another important finding from this section was the quantity and distribution of missing data. There were no missing data for the two groups, suggesting that the concepts in the study can be well understood through pictorial support, including by the children and youth with ID. The potential participation gap between the ID and TD groups demonstrated by the study leaves room for continued research.

In this study, Cronbach's alpha was used to evaluate the appropriateness of the domains (subscales) for measuring the attendance dimension of participation. Compared with the original PMP, which has a Cronbach's alpha of 0.85 [59], the PMP-C (Simplified) showed a good internal consistency reliability coefficient for children and youth with ID and with TD who scored 0.80 and 0.82 respectively. According to previous research [60] and the guidelines and documentation form of PMP, testing the internal consistency for a different age group can illustrate usefulness of the PMP-C (Simplified) over different age groups much better. When comparing four age groups, Cronbach's alpha showed acceptable to excellent internal consistency with two exceptions. The group of 5–8-year-old children with ID and the group of 17–21-year-old youth with TD were slightly below the 0.7 threshold [36]. The instrument appeared to work for all the groups but with somewhat lower reliability for the youngest age group with ID and the oldest group with TD. The former may be due to the small sample size of the 5–8 age group and the latter to the oldest group of TD having changed life roles from being a child to being a young adult and therefore participated in a greater variety of activities and fewer childish ones. This result was expected, as the original intention of the instrument was for it to be used for children with ID aged 7–17 [61]. The intra-class correlation coefficient (ICC) when testing test-retest reliability is generally indicative of the reliability of a self-report survey instrument [37]. The test-retest reliability was good [37] and was further supported by the ICC value for children and youth with TD and ID, a result that confirms the reported findings when investigating the original PMP [56]. It therefore shows a high level of the stability of the PMP-C (Simplified). The findings suggest that the PMP has the potential to be developed across different settings, countries and health conditions. The PMP-C (Simplified) will allow researchers to elaborate on the knowledge of different cultural and language aspects of participation as well as assessment of participation. The PMP-C (Simplified) is an ICF-CY-based questionnaire to screen and assess children and youth's participation in mainland China and can guide the next step of increasing the uptake of the instrument for use in intervention planning.

Limitations

This study focused on adapting the PMP-C (Simplified) to the cultural context of children and youth in mainland

China. However, data were collected primarily in Tianjin and Hebei provinces, which are both in northern China. These results may not be representative of other parts of China. The convenience sampling method also limits the generalisation of our findings. Further validation is needed in other provinces in southern China to examine participation under different geographical and economic conditions. In addition, psychometric testing of the engagement scale and recruitment of larger samples for test-retest reliability of the PMP-C (Simplified) over different age groups should be done in future research. Construct validity of the PMP-C (Simplified) need to be tested by implementing exploratory factor analysis and confirmatory factor analysis.

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Appendix 1

