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Participation and Environmental Factors of Children with Physical Disabilities in Taiwan

Lin-Ju Kang, Ai-Wen Hwang and Chia-Ling Chen

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Abstract

Participation is a critical health and education outcome of children and can be optimized by environmental supports. Children with physical disabilities often experience participation restriction and environmental barriers. Research is limited in describing participation in everyday activities of children with physical disabilities and identifying environmental barriers faced by those children in Taiwan. This chapter presents data of 94 children with physical disabilities aged 2-6 years and their families in Taiwan. Children with physical disabilities were primarily children with cerebral palsy (36%) and developmental (motor) delay (34%). Parents completed the Chinese version of Assessment of Preschool Children's Participation (APCP-C) and the Chinese version of the Child and Adolescent Scale of Environment (CASE-C) by structured interview to assess pattern of participation and impact of environment factors to their children's daily life. Participation of children with physical disabilities differed on the basis of level of severity, but not age and sex. Parents reported increased impacts of problems with the quality and availability of family and community resources than problems with assistance/attitude supports and physical design and access. The findings provide a profile of children's pattern of participation and environmental barriers that impact participation in Taiwan.

Keywords: participation, environment, preschool, children, physical disabilities

1. Introduction

The importance of participation and interaction between environment and participation has been emphasized in the International Classification of Functioning, Health, and Disability (ICF) [1]. The ICF provides a conceptual framework for understanding health and well-being



of children with physical disabilities [2]. The ICF describes participation as a child's involvement or engagement in life situations and environmental factors such as physical, social, and attitudinal environments that surround an individual. A working definition of participation is "the extent of engagement in the full range of activities that accomplish the larger goal" proposed by Coster and Khetani [3]. In Taiwan, the People with Disabilities Rights Protection Act (2007) states that people with disabilities are viewed as active participants in their lives and participation is the right of all individuals regardless of ability. As supported by the contemporary framework and legislation, participation has been viewed as a critical health and education outcome of children that can be optimized by environmental supports.

Physical disability refers to "any disabilities which limit the physical function of one or more limbs, or movement impairments which limit other facets of daily living." Common congenital and childhood-onset physical disabilities include diagnosis or conditions associated with insults in the central nervous system (CNS), neuromuscular disabilities, or musculoskeletal conditions. These conditions have been used as inclusion criteria for investigation of participation by children with physical disabilities [4–6]. Healthcare services for young children with physical disabilities have traditionally focused on treating impairments (e.g. stretching and strengthening exercises) and training functional skills (e.g. constraint-induced movement training) [7]. Enhancing participation in daily activities through context or environment-based therapies has only recently been considered as a new approach of intervention [8–10].

Emerging research has highlighted participation restrictions and environmental barriers experienced by preschool children with disabilities. Bult et al. indicated that preschool children with physical disabilities participated in fewer play, physical, social, and learning activities and did so less frequently than those without disability [6]. In contrast, Ehrmann et al. reported that preschool children with and without disabilities showed similar patterns of type and frequency of participation in community activities. Children with disabilities, however, participated in fewer family orientated leisure and recreational activities that usually require financial resources compared with peers without disabilities [11]. Khetani et al. reported that children with disabilities demonstrated lower levels of participation frequency, involvement in activities, and parent-perceived environmental supports than those without disabilities, particularly in daycare/preschool settings [12]. Research is limited regarding participation in daily activities and environmental barriers of children less than 6 years of age with physical disabilities in Taiwan.

A multidimensional model of participation of children with physical disabilities would be helpful to understand the complex relationship between participation and environment [13, 14]. Conceptualization of this model was based on contemporary frameworks, empirical evidence, and the ICF model. Based on this model, we proposed that participation encompasses three dimensions: *capability* (i.e. what a child can do in real life), *performance* (i.e. what a child does do), and *subjective experience* (i.e. how a child feels), and the three dimensions of participation are influenced by the determinants of *child*, *family*, and *environment* (**Figure 1**). This model provides a framework for consideration of dimensions and determinants of participation that are relevant to a child's goals and wishes for full participation. A comprehensive review of current literature was performed in order to understand factors that may influence participation of preschool and school-aged children with physical disabilities. Key determinants of child, family, and environment-related attributes are summarized in **Table 1**.

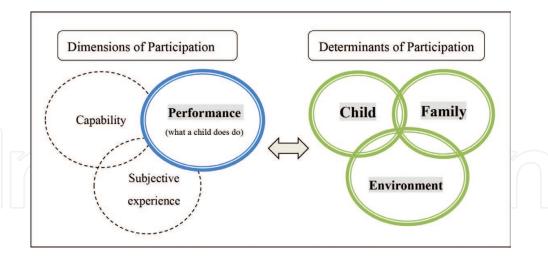


Figure 1. The conceptual framework of this study (adapted from Palisano et al. [13] and Kang et al. [14]).

Dimensions	Attributes for preschool children	Attributes for school-aged children
Child	Age and gender [6, 16, 19]	Age and gender [4, 23–25]
	Severity of impairment [19, 26] Gross motor function [17, 19]	Physical, cognitive, and communicative functioning [4, 23, 25, 27–29].
	Adaptive behaviors [17]	Emotional and behavioral functioning [30]
		Preferences and enjoyment of certain activities, personality, or social orientation [4, 25]
Family	Family income [31]	Family income [24]
	Parental supports and perception of neighborhood safety [31]	Family functioning [4, 25, 32, 33] Family activity preference [25, 32, 33] Parental education [24, 27] Parental stress [24, 27]
Environment	District of residence [34]	Physical environment [35–38]
	Services, support, and attitudes [26]	Social supports [4] Social attitudes [39]
		Services and professional supports [40–42]

Table 1. Summary of determinants of participation identified in literature.

Although current evidence suggests that preschool children with physical disabilities often experience participation restriction and environmental barriers, related research is quite limited in Taiwan. In this chapter, we would like to present findings that are part of a larger longitudinal study investigating determinants of participation of preschool children with physical disabilities. The study is still ongoing and we plan to recruit about 150 preschool children with physical disabilities and 150 age-matched peers with typical development. We will present data from a subsample of children with physical disabilities. First, we will describe patterns of participation in daily activities based on child's age, sex, and level of severity. Second, we will present environmental barriers that impact participation identified by parents of those children with physical disabilities.

2. Patterns of participation of children

2.1. Research methods and materials for measuring participation

Data on 94 children with physical disabilities aged 2–6 years and their families were collected from various regions in Taiwan. This sample was also used for establishing the reliability and validity of the key participation measure (described below) used in this study [15]. Children had a mean age of 4.2 years (SD = 1.4), 67% were boys, and 73% attended preschool or developmental centers. Children with physical disabilities were primarily children with cerebral palsy (36%) and developmental (motor) delay (34%), followed by chromosomal disorder (15%), acquired brain injury (13%), and congenital anomalies (2%). Medical diagnoses and level of severity (mild, moderate, severe, profound) were determined by children's physicians in the certified hospitals and reported by parents. Parent respondents were primarily mothers (84%), followed by fathers (14%) and grandparents (2%). Parents completed the Chinese version of Assessment of Preschool Children's Participation (APCP-C) by structured interview.

The APCP-C is a measure of participation in play, skill development, active physical recreation, and social activities of preschool children with and without disabilities. The English version of the APCP was developed and validated for children with cerebral palsy in Canada [16]. The APCP was also used in several studies involving young children with CP in the United States, Canada, and Taiwan [8, 17–19] and young children with physical disabilities in the Netherlands [6]. The APCP-C includes 45 activities, and for each activity, a parent indicates whether the child has performed the activity over the past 4 months ("yes" or "no"). If yes, the parent then reports how often the child performed the activity on a seven-point Likert scale (1 = "once over the past 4 months" to 7 = "once daily or more"). Diversity and intensity scores were calculated for total scores (all items) and for each activity type. A diversity score was the sum of the total number of activities performed, and an intensity score is the sum of frequencies for all items divided by the number of possible items for all items as well as items in each activity type. Evidence of internal consistency (Cronbach's α = 0.54–0.86) and test-retest reliability (ICCs = 0.56–0.79), cultural validity, and convergent validity has been reported for the APCP-C diversity and intensity scores [15].

2.2. Describing participation by age, sex, and severity

Participation of children with physical disabilities differed on the basis of level of severity in impairments, but not age and sex (**Tables 2–4**). Children younger and older than 4 years, and boys and girls did not differ in participation diversity and intensity across all types of activities (p > 0.05) (**Tables 2** and **3**). Significant differences in participation diversity and intensity in the total and three activity types other than play activities were found between children with different levels of severity (**Table 4**). Children with a higher level of severity had a lower level of participation diversity and intensity. *Post hoc* comparisons revealed a similar pattern across all types of activities. Children who were classified as mild level had significantly higher total participation diversity and intensity than children at moderate, severe, or profound levels. Children who were classified as mild level had significantly higher participation

Age group	<4 years n = 43	≥4 years <i>n</i> = 51	t^{a}	p ^a (two-tailed)
Total				
Diversity	23.1 (7.3)	26.5 (7.8)	-2.20	0.03
Intensity	2.6 (0.8)	2.8 (0.9)	-1.17	0.24
Play				
Diversity	5.7 (1.6)	6.1 (1.7)	-1.11	0.27
Intensity	3.7 (1.1)	3.7 (1.1)	0.23	0.81
Skill developmen				
Diversity	7.4 (3.2)	9.3 (3.5)	-2.61	0.01
Intensity	2.5 (1.2)	3.1 (1.2)	-2.32	0.02
Active physical re	creation			
Diversity	5.1 (1.8)	5.4 (2.0)	-0.83	0.41
Intensity	2.7 (0.9)	2.6 (1.0)	0.38	0.70
Social				
Diversity	4.7 (1.9)	5.67 (2.1)	-2.04	0.04
Intensity	1.8 (0.8)	2.08 (0.8)	-1.57	0.11

^aIndependent t tests (significance level was set as p < 0.01 due to number of comparisons performed). Scores are presented as means (SD).

Table 2. Participation diversity and intensity based on child's age.

intensity than children at profound level in skill development, active physical recreation, and social activities. Participation diversity between children classified as mild severity and children classified as severe level differed only in skill development activities.

Children with physical disabilities aged under or above 4 years of age did not differ in the levels of participation in everyday activities. Our findings were supported by the study of Chiarello et al. in which they found no differences in amount of participation among 3-, 4-, and 5-year-old children with CP in the United States. In contrast, both the Canadian and Dutch studies found that the APCP distinguished participation of children with CP and physical disabilities under and above 4 years of age [6, 16]. Collectively, the inconsistent results from these studies suggest that age effects on patterns of participation at preschool years are culturally sensitive and in need for further study.

Boys and girls did not differ in the levels of participation across all types of activities. The results indicate that in a Taiwanese culture, boys and girls have not yet developed divergent interests and activities at this early developmental age. Boys and girls were probably given similar activity opportunities by their adult caregivers at home, preschool, or community. The social impact of sex may not play an important role in affecting participation of preschool children. Previous studies also showed inconsistent results regarding the sex effect on

Sex	Boys n = 63	Girls n = 31	t ^a	p ^a (two-tailed)
Total				
Diversity	25.5 (6.8)	23.8 (9.2)	1.04	0.30
Intensity	2.8 (0.8)	2.6 (1.0)	1.07	0.28
Play				
Diversity	6.1 (1.6)	5.5 (1.8)	1.41	0.16
Intensity	3.8 (0.9)	3.6 (1.3)	0.68	0.49
Skill development				
Diversity	8.5 (3.1)	8.2 (4.2)	0.38	0.70
Intensity	2.8 (1.2)	2.8 (1.3)	0.25	0.80
Active physical recreat	ion			
Diversity	5.5 (1.7)	4.7 (2.3)	1.84	0.06
Intensity	2.8 (0.9)	2.4 (1.0)	1.71	0.09
Social				
Diversity	5.3 (2.0)	5.1 (2.2)	0.34	0.73
Intensity	1.9 (0.8)	1.9 (0.8)	0.29	0.77

^aIndependent t tests (significance level was set as p < 0.01 due to number of comparisons performed). Scores are presented as means (SD).

Table 3. Participation diversity and intensity based on child's sex.

Severity	Mild n = 23	Moderate n = 14	Severe $n = 21$	Profound n = 14	Fª	p ^a (two-tailed)	Post hoc comparisons ^b
Total							
Diversity	30.1 (6.2)	24.0 (9.0)	24.5 (7.0)	20.7 (5.4)	5.97	0.001	Mild > severe ($p = 0.047$) Mild > profound ($p = 0.001$)
Intensity	3.4 (0.7)	2.5 (0.9)	2.6 (0.8)	2.2 (0.6)	8.09	<0.001	Mild > moderate ($p = 0.012$), mild > severe ($p = 0.007$), mild > profound ($p < 0.001$)
Play							
Diversity	6.7 (1.5)	5.5 (1.9)	5.9 (1.6)	5.0 (1.8)	3.34	0.02	-
Intensity	4.1 (1.0)	3.3 (1.2)	3.7 (1.0)	3.2 (1.0)	2.80	0.04	-
Skill develo	opment						
Diversity	10.8 (3.2)	8.5 (3.6)	7.5 (3.2)	6.7 (2.3)	6.31	0.001	Mild > severe ($p = 0.005$) Mild > profound ($p = 0.001$)

Severity	Mild n = 23	Moderate n = 14	Severe n = 21	Profound n = 14	Fª	p ^a (two-tailed)	Post hoc comparisons ^b
Intensity	3.7 (0.9)	2.8(1.3)	2.3 (1.2)	2.1 (0.9)	8.47	<0.001	Mild > severe ($p = 0.001$) Mild > profound ($p < 0.001$)
Active phys	sical recreati	on					
Diversity	6.3 (1.3)	5.0 (2.8)	5.3 (1.7)	4.5 (1.9)	2.93	0.04	-
Intensity	3.3 (0.7)	2.4 (1.1)	2.5 (0.9)	2.2 (0.8)	5.09	0.003	Mild > profound $(p = 0.004)$
Social							
Diversity	6.2 (2.0)	4.9 (2.4)	5.7 (1.9)	4.4 (1.4)	2.82	0.04	-
Intensity	2.3 (0.8)	1.7 (0.9)	2.0 (0.7)	1.4 (0.5)	4.42	0.007	Mild > profound $(p = 0.005)$

^aANOVA tests (significance level was set as p < 0.01 due to number of comparisons performed).

Scores are presented as means (SD).

Table 4. Participation diversity and intensity based on child's level of severity.

preschool participation. The US study of the APCP reported no sex differences [17], whereas the Canadian and Dutch studies found that girls had higher intensity of participation in play [16] and skill development activities. It is worth of further studying of whether sex plays an important role in differentiating participation in this early period of life.

Children with mild severity as classified by their physicians were found to have higher participation intensity in skill development, active physical recreation, and social activities than children with profound severity. Skill development, active physical recreation, and social activities involve physical, cognitive, and social demands of the child and may require preparation and assistance from adults. Children with profound level of severity may experience particular difficulties even with activity adaptation or modification. Participation in play activities did not differ among children across the levels of severity. The result made practical sense, given that play activities are more easily adapted than other type of activities and use materials that are easily accessible at home (e.g. toys, TV, or other household items).

3. Environmental barriers

3.1. Research methods and materials for measuring environment

As described in the above section, the same set of data of 94 children with physical disabilities is reported. Parents completed the Chinese version of the Child and Adolescent Scale of Environment (CASE-C) by structured interview to assess impact of environment factors to their children's daily life.

 $^{^{}b}$ Tukey HSD tests (significance level was set as *p* < 0.05).

The CASE-C is a measure of the impact of environmental features to the child's home, school, and community, which contains three subscales: family/community resources, assistance/attitude supports, and physical design access problems [20]. The English version of the CASE was developed and validated for children with acquired brain injury and various chronic conditions in the United States [21, 22]. The first 18 items of the CASE-C were close-ended questions, and each item is rated on a three-point scale: no problem (1), little problem (2), and big problem (3). The CASE-C scores were calculated for total scores (all items) and for each subscale then adjusted to a 0 to 100-point scale. Higher scores indicate a greater impact of environmental problems. The 19th item is an open-ended question asking parents to specify special environmental conditions that are considered as important barriers. Parents' qualitative answers of the 19th item were classified by content analysis based on the five ICF domains of environmental factors: products and technology (e1), natural and human-made changes (e2), support and relationship (e3), attitude (e4), and services, systems, and policies (e5) [1].

3.2. Impacts of environmental barriers

Parents of children with physical disabilities perceived a low level of environmental problems to their children's participation in home, school, and community, as the CASE-C scores ranged from 40.8 to 44.3 of 100 (**Table 5**). Parents reported increased impacts of problems with the quality and availability of family and community resources, including lack of community programs and services, inadequate or lack of information about child's diagnosis or intervention, and problems with services and policies provided by government agencies.

CASE-C scale/subscale	Scores
Total scale	42.6 (8.9)
Family/community resources	44.3 (11.6)
Assistance/attitude supports	41.8 (12.2)
Physical design access problems	40.8 (8.9)
Scores are presented as means (SD).	П

Table 5. Scores for impacts of environmental barriers.

Twenty parents specified a total of 36 environmental conditions that were important barriers (**Table 6**), over half of the conditions pertained to the domain of services, systems, and policies (e5) (56%). The results again support the relatively higher perceived barriers of family and community resources.

In particular, we had the impression from interviews with families that parents often felt nervous and helpless during their children's transition to elementary school due to rapid decrease of therapy services. In Taiwan, early intervention services are provided for children less than 6 years of age. Many rehabilitation services are child-focused, and parents are not actively involved in the intervention process. When children reach school age and the early intervention services are no longer available, their parents are anxious about not getting help

ICF domains	Count (%)	Summary of conditions specified by parents	
e1 Products and technology e2	8 (22%)	• Insufficiency of accessible facilities in the public areas, for instance, restrooms for parents with young children are unavailable in the park, toilets are too high, and buses are inaccessible for a child with physical disability.	
Natural environment and human- made changes to environment		 Some mother resigned from work to look after their children, resulting in huge financial burden. They even could not afford products for daily living (such as diapers) and medical expenses. 	
e3 Support and	3 (8%)	• Parents expressed the difficulties to understand their therapists because of the professional terminologies.	
relationships		• Peers sometimes refuse to play with the child because they do not understand the child's condition and limitations.	
e4 Attitudes	5 (14%)	 Parents felt uncomfortable by the ways people looking at them while going out with their child. 	
		• Unfriendly service providers such as clinicians in the hospitals or taxi drivers.	
e5 Services, systems	20 (56%)	• Information was either unavailable or lack of integration. Parents usually did not know how and where to find information they need.	
and policies		• It was difficult for parents to apply for subsidy, because of restrictions set by the government.	
		• Some families need to find a place where children can play safely very far away from their home.	
			Lack of therapy services in the nearby area.
		 Parents were not allowed to enter therapy rooms during their child's therapy sessions; parents did not know their child's performance. 	
		• During transition to elementary school, the therapy services and resources were no longer available for some families.	
		• School professionals did not have sufficient competence in assisting children in engaging in classes.	
		• Lack of opportunity for children with disabilities to receive inclusion education in mainstream schools.	

Table 6. Parent-reported environmental conditions (total count = 36) classified by the ICF domains of environmental

from school professionals. We suggest that parents are encouraged to be actively involved in early intervention services and be empowered so they have the competence to advocate for their children.

4. Conclusions

The findings provide a snapshot of children's participation and environment in Taiwan. Participation of children with physical disabilities did not vary by child's age and sex. Children with severe or profound levels of severity tend to have lower diversity and intensity of participation than children with mild level of severity. Inadequate or lack of family and community resources had greater impacts than problems with support, assistance, and attitudes and physical design and access. Environmental barriers identified in our study will provide suggestions to the clinical practice and government policies to improve environmental accessibility, information availability, and integration and to support children's integration in society.

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