Comparative study of home and community participation among children with and without
cerebral palsy

Milena Milićević^{a,*}, Goran Nedović^b

^a Institute of Criminological and Sociological Research, Gračanička 18, 11000 Belgrade, Serbia

^b Faculty of Special Education and Rehabilitation, University of Belgrade, Visokog Stevana 2,
11000 Belgrade, Serbia

* Corresponding author.

E-mail addresses:

milenaadresa@gmail.com (M. Milićević)

goran.ned@sbb.rs (G. Nedović)

Abstract

Background: Children with cerebral palsy (CP) are at increased risk of reduced participation.

Parental evaluation of child's participation is often the decision-making factor in the process of special education and/or rehabilitation.

Aims: Examine and compare home and community participation of children with CP and typical development (TD) and the associations between their parents' desire for change and participation dimensions in both settings.

Methods and procedures: This cross-sectional study included a convenience sample of 110 children with CP (55% males; mean age 12.7 years) and 134 children with TD (49% males; mean age 12.1 years). The Participation and Environment Measure for Children and Youth (PEM-CY) was used.

Outcomes and results: Home and community participation and environmental supportiveness of children with CP were lower compared to children with TD ($p < .001$, family income controlled).

The effect sizes indicated that there may be no clinically important difference in participation frequency. Parents of children with CP desired change if participation was less diverse at home, less frequent in the community, or if involvement was lower in both settings (environmental supportiveness and income controlled).

Conclusions and implications: At home, parents expressed a desire for change more intensely through the range of activities, while parents of children with TD emphasized participation frequency. In the community, parents of children with CP equally perceived participation diversity and focused more on frequency and involvement.

Keywords: children with cerebral palsy, participation, change, parental perspective

What this paper adds

This research expands the current knowledge on participation of children with cerebral palsy (CP) by exploring the association between dimensions of participation and additionally, confirming that their overall participation was lower in relation to the comparison group of children with typical development (TD). Effect sizes revealed the biggest differences in environmental supportiveness and involvement level both at home and in the community. Although statistically significantly lower in the group of children with CP, the frequency of home and community participation was comparable between two groups. However, the findings indicated that children with CP who did participate in some activities were involved in those activities at a similar frequency to children with TD, supporting the notion that the real difference was in diversity of participation, within the attendance construct. Parents of children with CP desired more change if participation was less diverse at home, less frequent in the community, or if involvement was lower in both settings. In summary, the results of this study documented that parents' satisfaction with the children's current participation varied across different settings in relation to three dimensions participation (range or diversity of activities, frequency, and involvement). The present study highlighted differences in parents' satisfaction with their children's participation and demonstrated that participation restrictions should not be related only to low frequency of attendance.

Highlights

- We examined the association between dimensions of participation at home and in the community.
- Limited participation of children with CP was confirmed in both settings.
- Although lower, the frequency was comparable between children with and without CP.
- Parents' satisfaction with the current participation varies across different settings.
- More change desired if participation was less diverse at home, less frequent in the community, or involvement was lower in both settings.

Comparative study of home and community participation among children with and without cerebral palsy

1. Introduction

Cerebral palsy (CP) is the most common group of permanent disorders of movement and posture, causing activity limitation attributed to non-progressive disturbances that occur in developing fetal or infant brain (Rosenbaum et al., 2007). CP affects 2 to 3 children per 1000 live births (Cans, 2000). The International Classification of Functioning, Disability and Health (ICF) defines participation as a person's "involvement in life situation" and participation restriction as "problems an individual may experience in involvement in life situations" (World Health Organization, 2001). The focus of participation is on everyday functioning and intersection between the individual and the environment. One of the ways to describe the essence of this complex and multidetermined concept is through two key elements: attendance and involvement. Attendance is expressed as frequency and/or the range or diversity of activities, whereas involvement is defined as subjective experience of participation while attending (Imms et al., 2016, 2017). Numerous studies have shown that children with CP are at increased risk of reduced participation in terms of diversity, frequency, and involvement, both at home and in the community which they live in (Bedell et al., 2013; Engel-Yeger, Jarus, Anaby, & Law, 2009; Imms, Reilly, Carlin, & Dodd, 2008; Law et al., 2013; Majnemer et al., 2008; Majnemer, Shikako-Thomas, Schmitz, Shevell, & Lach, 2015; Mc Manus, Corcoran, & Perry, 2008; Michelsen et al., 2009; Parkes, McCullough, & Madden, 2010).

According to the ICF, the presence of restriction in participation should be “determined by comparing an individual’s participation to that which is expected of an individual without disability in that culture or society” (World Health Organization, 2001). Research focusing on participation and participation restriction of children with developmental disabilities, including children with CP, has increased significantly over the past two decades. However, the differences in the parents’ evaluation of participation between various settings have not been addressed in the previous studies. Particularly, it is not understood whether overall parental satisfaction with their child’s current participation is associated with dimensions of participation, and if it is, in what way. This is important because families are increasingly encouraged to take an active role in health care, education, rehabilitation, professional training and employment of their child with physical disabilities (Darrah, Magil-Evans, & Adkins, 2002). Given that parents’ reports are often a guide to decision-making for children (Davis, Mackinnon, & Waters, 2012), more comprehensive understanding is essential and required with regard to differences in the parents’ subjective evaluation of participation between various settings, and in comparison to parents of children with typical development (hereinafter referred to as TD). In other words, if we seek to evaluate and explore the quality of participation by asking about the extent of the parents’ satisfaction, then one of the first steps would involve examining the relationship with key dimensions of participation. It is noteworthy that the legal provisions regulating inclusive education in Serbia have not been fully implemented yet (Jovanovic-Popadic, 2016). The conditions for adequate reception of children with disabilities into the regular school system, related to attitudes towards persons with disabilities and towards educational inclusion, preparation of regular schools, support system and financing have not been met (Dimoski &

Nikolić, 2015; Kovačević & Maćešić-Petrović, 2012; Mijatović, 2013). Therefore, it has been decided to focus on participation at home and in the community environment in this study.

This study is part of a larger research project focused on participation of children with CP living in Serbia. The research project that forms the empirical basis of this study is a cross-sectional and descriptive study of two groups of children. The purpose of this study is to explore the views of parents of children with CP and parents of children with TD about their child's home and community participation and overall supportiveness in each setting, as well as the relationships between dimensions of participation. In order to meet this objective, we have pursued the following aims: 1) examine home and community participation of children with CP, 2) examine the association between the number of activities done in each setting, frequency of participation and the child's involvement, and the parents' desire for change in their child's participation, and 3) draw comparisons with children with TD.

2. Method

2.1. Sample and procedure

Participants were recruited using the convenience sampling method. Sixty-five different health, educational and social welfare institutions, as well as national and local disability organizations and associations of persons with CP from 48 municipalities of Serbia were invited, and 35 (53.8%) of them gave permission for participation in our research. The participants were selected from their registers. Children with TD were recruited through regular schools, while children with CP were recruited mostly through special schools and special school services, hospitals and rehabilitation centers, as well as through several associations of persons with CP or

associations of persons with disabilities. The general inclusion criteria were as follows: children of both genders, aged 7–18 years, residing with their families on the territory of the Republic of Serbia. In addition, children with TD had no history of psychological, neurological, motor or speech and language issues that might affect their participation, according to their parents' report. The inclusion criterion of the group of children with CP was the cerebral palsy diagnosis, according to the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10; World Health Organization, 2004).

In the next step, 397 research invitations with the questionnaire package were distributed by regular mail. They included both a demographic and a participation questionnaire. The accompanying letter contained an introduction to and information about the study. A total of 235 questionnaires were returned, bringing the response rate to 59.2%. After the informed consent was obtained, the data about the level of intellectual disability of children with CP were collected from the available personal medical, educational or psychological records and categorized as normal, borderline, mild, moderate and severe intellectual disability according to the ICD-10. The data had been gathered from June 2014 to April 2015. The study was approved by the Professional Boards of The University of Belgrade (No. 61206-2385/2-14).

The final sample included approximately equal numbers of children with CP ($n = 110$) and children with TD ($n = 125$). The groups were similar in a number of demographic characteristics (Table 1). Most respondents were mothers, aged 35–44 years, with higher levels of education (most graduated from high school or college/university). Most families had two parents and resided in urban areas. There were between-groups differences for respondent age ($\chi^2(2) = 8.86, p < .05, V = .19$), respondent education ($\chi^2(2) = 21.43, p < .001, V = .31$), and average monthly household income categories ($\chi^2(3) = 66.37, p < .001, V = .53$). These three

demographic characteristics were subsequently included in the statistical analysis as potentially confounding variables. There were no statistically significant differences between groups in relation to gender ($\chi^2 (1) = .79, p > .05, \phi = .07$) and age of children ($\chi^2 (2) = 1.62, p > .05, \phi = -.09$).

Additional characteristics of the group of children with CP are summarized in Table 2.

The most common was a spastic type of CP diagnosed in 70% of children, accompanied by cognitive (67.3%) and visual impairments (33.6%), as well as epilepsy (25.4%). The majority (56.3%) attended special schools.

Table 1

Child, family and respondent characteristics

Variable	Children with CP (<i>n</i> = 110)	Children with TD (<i>n</i> = 125)	<i>p</i> (ϕ or <i>V</i>)
Child gender			
Male	61 (55.5)	61 (48.8)	.375 (.07)
Female	49 (44.5)	64 (51.2)	
Child age (years)	<i>M</i> = 12.67, <i>SD</i> = 3.41	<i>M</i> = 12.07, <i>SD</i> = 3.15	
7–12	48 (43.6)	66 (52.8)	.203 (-.09)
13–18	62 (56.4)	59 (47.2)	
Respondent relation to child			
Mother	87 (79.1)	104 (83.2)	.188 (.12)
Father	18 (16.4)	20 (16.0)	
Guardian	5 (4.5)	1 (0.8)	
Respondent age (years)	<i>M</i> = 41.28, <i>SD</i> = 7.16	<i>M</i> = 40.38, <i>SD</i> = 4.87	
25–34	17 (15.4)	9 (7.2)	.012 (.19)
35–44	64 (58.2)	95 (76.0)	
44+	29 (26.4)	21 (16.8)	
Respondent education			
Primary school	9 (8.6)	1 (0.8)	< .001 (.31)
High school	69 (65.7)	57 (46.7)	
College or university	27 (25.7)	64 (52.5)	
Family type			
Single-parent	22 (20.0)	21 (16.8)	.643 (-.04)
Two-parent	88 (80.0)	104 (83.2)	
Family income per month			

(EUR) ¹			
< 165	26 (23.6)	2 (1.6)	< .001 (.53)
165–410	52 (47.3)	23 (18.4)	
410–820	20 (18.2)	68 (54.4)	
> 820	12 (10.9)	32 (25.6)	
Type of community			
Urban	63 (57.3)	89 (71.2)	.052 (.16)
Suburban/Small town	21 (19.1)	20 (16.0)	
Rural	26 (23.6)	16 (12.8)	

Note: CP = cerebral palsy; TD = typical development. Values are *n* (%) or as otherwise indicated.

p is based on chi-square analysis.

¹Converted from RSD 2014-11-24.

Table 2

Characteristics of group of children with cerebral palsy (n = 110)

Variable	<i>n</i> (%)
GMFCS I / II / III / IV / V	15 (13.6) / 29 (26.4) / 22 (20.0) / 29 (26.4) / 15 (13.6)
MACS I / II / III / IV / V	12 (10.9) / 35 (31.8) / 19 (17.3) / 28 (25.5) / 16 (14.5)
Type of cerebral palsy	
Spastic quadriplegia / diplegia / hemiplegia	37 (33.6) / 25 (22.8) / 15 (13.6)
Dyskinetic / Athetoid	12 (10.9)
Ataxic	11 (10.0)
Mixed	10 (9.1)
Intellectual functioning	
Normal / borderline	26 (23.6) / 10 (9.1)
Mild / moderate / severe intellectual disability	31 (28.2) / 31 (28.2) / 12 (10.9)
Comorbidities and associated conditions	
Sensory impairments (visual / hearing / combined)	37 (33.6) / 4 (3.6) / 9 (8.2)
Epilepsy	28 (25.4)
Health problems	23 (20.9)
Type of classroom / schooling	
Mainstream	37 (33.6)
Special education	62 (56.3)
Not in school	11 (10.1)

Note: GMFCS = Gross Motor Function Classification System; MACS = Manual Ability Classification System.

2.2. Instrument

The Serbian version of the Participation and Environment Measure for Children and Youth (PEM-CY; Coster, Law, & Bedell, 2010) was used to gather the data. The PEM-CY is a reliable and valid parent/caregiver-report instrument that combines assessment of children's participation and the environment across three settings: home, school and community. Detailed information about the conceptual basis, development, and psychometric properties of the PEM-CY have been described elsewhere (Anaby et al., 2014; Bedell et al., 2013; Bedell, Khetani, Cousins, Coster, & Law, 2011; Coster et al., 2011, 2012; Khetani et al., 2014; Law et al., 2013).

With written consent and approval of the first author (Wendy Coster) and the PEM-CY Coordinator (Rachel Teplicky, personal communication, July 2, 2013), the instrument was completely translated from English into Serbian, using the back-translation method. The original PEM-CY was translated into Serbian and then back into English by two separate individuals. After some minor adjustments, these two versions were compared and approved by the authorized person from the CanChild research group. When a positive review was received, the PEM-CY in Serbian was finalized. The following cultural adaptations were made: 1) *washing the dishes* was added in 'Household chores', 2) *packing snacks* replaced *packing lunch* in 'School preparation', 3) *studying* replaced *school projects* in 'Homework', 4) *hockey* and *martial arts* were excluded, while *fencing* was included in the 'Organized physical activities', 5) *skateboarding* was excluded from the 'Unstructured physical activities', 6) *brownies/girl guides* was excluded from 'Organizations, groups, clubs, and volunteer or leadership activities', 7)

paper route was excluded from ‘Working for pay’, and 8) *camp* was changed to *trips* in ‘Overnight visits or trips’.

Home and community sections were used for the purpose of this study. The PEM-CY demonstrated acceptable to good reliability, comparable to the values reported by the authors (Coster et al., 2011). Internal consistency coefficients for ‘frequency’ were .80 and .78, and .84 and .70 for ‘involvement’ across home and community, respectively. Similarly, Cronbach’s alpha for the ‘change desired’ were .82 and .84, and for the ‘total environmental supportiveness’ .86 and .90.

First, the parent/caregiver was asked to identify how frequently the child participated in each of the ten activity types over the past four months on an 8-point scale, ranging from 0 (*never*) to 7 (*daily*). Secondly, how involved the child was while participating on a 5-point scale, ranging from 1 (*minimally involved*) to 5 (*very involved*). Next, the parent/caregiver was asked if he or she would like to see the child’s participation change (*no* or *yes*). If *yes*, the parent/caregiver was asked to clarify the type(s) of change desired among five options. Finally, for each setting, the parent/caregiver was also asked whether certain features of the environment helped or hindered their child’s participation in activities (*not an issue, usually helps, sometimes helps/sometimes makes harder, usually makes harder*) and about perceived adequacy/availability of resources (*not needed, usually yes, sometimes yes/sometimes no, usually no*). There are 12 and 16 items on the environment subscales of the PEM-CY home and community sections, respectively. Five summary scores related to participation calculated from the PEM-CY are described in Table 3.

Table 3

Descriptions of PEM-CY home and community summary scores

Variable	Full description and scoring
1. Percent ever participates	An indicator of the range or diversity of activities in which a child takes part. Number of items responded 1 (<i>once in last four months</i>) to 7 (<i>daily</i>) divided by the total number of items rated and then multiplied by 100. Higher scores indicate greater number of activities that child participates in (range = 0–100%).
2. Participation frequency	Mean of frequency ratings across all 10 activity types except those to which parent responded <i>never</i> for frequency. Higher scores indicate greater frequency across activities (range = 1–7).
3. Involvement	Mean of all involvement ratings except those to which parent responded <i>never</i> for frequency. Higher scores indicate greater involvement across activities (range = 1–5).
4. Percent that parents desired change	An indicator of overall parental satisfaction with child's current participation. Number of <i>yes</i> responses divided by the total number of items rated and then multiplied by 100. Higher scores indicate greater number of activities that parents desire change in their child's participation (range = 0–100%).
5. Percent total environmental supportiveness	Sum of ratings divided by the number of items rated multiplied by 100. Higher scores indicate greater environmental supportiveness in that setting.

2.3. Data analysis

Descriptive data and inferential statistics are presented. Internal consistency was examined using the Cronbach's alpha coefficients and interpreted as excellent ($\alpha > .9$), good ($.7 < \alpha < .9$), acceptable ($.6 < \alpha < .7$), poor ($.5 < \alpha < .6$) or unacceptable ($\alpha < .5$) (George & Mallery, 2003, p. 231). Chi-squared tests were conducted for categorical responses (i.e. gender, age, education). As a measure of association, ϕ coefficient and Cramer's V were reported and interpreted as small (.10), medium (.30) or large (.50) effect sizes (Cohen, 1988). Analysis of covariance (ANCOVA) was used to compare differences between the PEM-CY home and community participation and environment summary scores between the group of children with CP and the group of children with TD. The family income category was entered as covariate because of group differences in this variable in our sample (Table 1). Respondents' age and

education categories were not included in the analyses because the F -tests indicated no significant interaction effects between these variables and the group across all participation scores (Table A.1, A.2, A.3 and A.4, Supplementary material online). Partial Eta squares (η^2_p) were used to examine effect sizes, and interpreted according to the Cohen (1988) classification, where $\eta^2_p = .01-.05$ was considered small, $\eta^2_p = .06-.13$ moderate, and $\eta^2_p \geq .14$ large effect size. Due to multiple comparisons, Bonferroni corrections were made and the level of significance was set to 0.01 in order to reduce the chance for a Type I error. In order to test the relationships between the selected variables while controlling for the effects of total environmental supportiveness and family income, the partial correlations procedure was used (two-tailed). Coefficients (r) were interpreted as small (.10–.29), moderate (.30–.49) or strong (.50–1.00) correlation (Cohen, 1988). All analyses were performed in SPSS, version 23 (IBM, Armonk, NY, USA).

3. Results

3.1. Home and community participation

Statistically significant differences between the group of children with CP and the group of children with TD adjusted for family income category were observed for all of the PEM-CY home and community participation and environment summary scores ($p < .001$). Unadjusted means were very similar to the ANCOVA adjusted means in both groups, so unadjusted means are presented with their corresponding SDs (Table 4 and Table 5). Differences between adjusted and unadjusted means ranged from -1.68% to 1.48% for “percent ever participates”, -.03 to .03 for “frequency”, -.05 to .05 for “involvement”, -.98% to .09% for “percent that parents desired

change” and -1.59 to 1.40 for “percent total environmental supportiveness” at home and in the community, respectively (Table A.5 and A.6, Supplementary material online).

Specifically, children with CP participated in fewer activities at home and in the community, less frequently and had lower levels of involvement compared to children with TD. More parents of children with CP confirmed that they would like to see their child’s home and community participation change and reported lower overall environmental supportiveness ($p < .001$; Table 4 and 5). Effect sizes (η^2_p) comparing the magnitude of differences were large, except for participation frequency with moderate effect both at home and in the community (.08 and .09, respectively).

Table 4

PEM-CY home summary scores: descriptive statistics and differences between groups

PEM-CY home summary scores	Children with CP ^a		Children with TD ^b		ANCOVA	
	Min–Max	<i>M</i> (<i>SD</i>)	Min–Max	<i>M</i> (<i>SD</i>)	<i>F</i> (<i>df</i>)	η^2_p
Percent ever participates	10.00–100.00	77.36 (21.79)	80.00–100.00	98.56 (3.75)	72.597 (1, 232)*	.24
Participation frequency	3.13–7.00	6.14 (.65)	4.70–7.00	6.43 (.40)	19.839 (1, 232)*	.08
Involvement	1.00–5.00	3.42 (1.05)	3.10–5.00	4.56 (.43)	81.290 (1, 232)*	.26
Percent that parents desired change	.00–100.00	63.91 (24.35)	.00–90.00	40.56 (27.89)	36.600 (1, 232)*	.14
Percent total environmental supportiveness	47.22–100.00	78.64 (12.34)	75.00–100.00	94.62 (5.63)	96.343 (1, 232)*	.29

Note: CP = cerebral palsy; TD = typical development; η^2_p = Partial Eta squares (effect sizes) are rounded to two decimal points (small = .01–.05; moderate = .06–.13; large $\geq .14$) (Cohen, 1988).

^a $n = 110$. ^b $n = 125$.

* $p < .001$ for the total model based on ANCOVAs adjusting for family income category

(Bonferroni adjustment of the significance level was set at $p < .01$).

Table 5

PEM-CY community summary scores: descriptive statistics and differences between groups

PEM-CY community summary scores	Children with CP ^a		Children with TD ^b		ANCOVA	
	Min–Max	<i>M</i> (<i>SD</i>)	Min–Max	<i>M</i> (<i>SD</i>)	<i>F</i> (<i>df</i>)	η^2_p
Percent ever participates	.00–90.00	50.36 (20.36)	20.00– 100.00	74.56 (15.11)	65.927 (1, 232)*	.22
Participation frequency	1.00– 6.50	4.20 (1.07)	1.50– 6.40	4.83 (.76)	22.228 (1, 228)*	.09
Involvement	1.00–5.00	3.16 (1.07)	2.67–5.00	4.63 (.53)	134.399 (1, 228)*	.37
Percent that parents desired change	.00– 100.00	72.55 (23.12)	.00– 100.00	35.84 (27.57)	85.128 (1, 232)*	.27
Percent total environmental supportiveness	41.67– 100.00	71.57 (12.38)	60.42– 100.00	92.02 (7.69)	146.394 (1, 232)*	.39

Note: CP = cerebral palsy; TD = typical development; η^2_p = Partial Eta squares (effect sizes) are rounded to two decimal points (small = .01–.05; moderate = .06–.13; large $\geq$.14) (Cohen, 1988).

^a*n* = 110. ^b*n* = 125.

* $p < .001$ for the total model based on ANCOVAs adjusting for family income category

(Bonferroni adjustment of the significance level was set at $p < .01$).

3.2. Association between dimensions of participation

After controlling for the effects of total environmental supportiveness and family income, only the coefficient of correlation between the desire for change and involvement level reached statistical significance in both groups (Table 6). These two moderate and negative correlations indicated that parents of children with CP and parents of children with TD would like to see their child's participation change in more home-based activities if their child's involvement was lower ($r = -.49$ and $-.50$, respectively). On the other hand, while parents of children with TD expressed desire for change in a greater number of activities if home participation was less frequent ($r = -$

.23), parents of children with CP reported that they would like to see their child's participation change if their child participated in fewer activities ($r = -.37$).

When exploring the community participation, all three correlations reached statistical significance in the group of children with TD. This finding indicated that parents of children with TD expressed a desire for change in more activities if their child participated in fewer activities, less frequently, or when their child's involvement level was lower (Table 6). In the group of children with CP, the only correlation that was not significant was the one between the percentage of activities that parents desired change in and the percent of activities done. The values of statistically significant correlation coefficients in both groups indicated weak to moderate relationship ($r = -.22$ to $-.36$).

Table 6

Relationship between the percent of activities done, frequency and involvement and the parents' desire for change in their child's participation

Participation	Percent that parents desired change			
	Home		Community	
	CP	TD	CP	TD
Percent ever participates	-.37***	-.14	-.17	-.33***
Participation frequency	-.05	-.23*	-.22*	-.36***
Involvement	-.49***	-.50***	-.30**	-.29**

Note: CP = Children with cerebral palsy; TD = Children with typical development; Presented are the partial correlation coefficients controlled for total environmental supportiveness and family income.

* $p < .05$, two-tailed. ** $p < .01$, two-tailed. *** $p < .001$, two-tailed.

4. Discussion

4.1. Home and community participation

One aim of this research was to examine differences related to certain dimensions of home and community participation between the group of children with CP and the group of children with TD. The groups were not matched by family income, a factor known to influence participation (King et al., 2003, 2006; Law et al., 2006; Law, Petrenchik, King, & Hurley, 2007). After adjusting for family income, overall participation of children with CP was lower compared to participation of children with TD. This finding was consistent across all dimensions of home and community participation and environment measured by the PEM-CY and included in this study (range or diversity of activities, frequency, involvement level, parents' desire for change in their child's participation, and environmental supportiveness). Moreover, this finding was in accordance with the previous studies (Bedell et al., 2013; Coster et al., 2011; Engel-Yeger et al., 2009; King, Law, Hurley, Petrenchik, & Schwellnus, 2010; Law et al., 2013; Majnemer et al., 2008; Mc Manus et al., 2008; Michelsen et al., 2009).

On average, children with CP were absent from almost one-fifth of home-based and half of community-based activities. Their peers with TD participated in nearly all home-based and two-thirds of community-based activities. In conclusion, children with CP participated in a significantly smaller number of activities. Along with the large effect size, this finding reflects great disparities between the two groups of children in this participation dimension. However, when home and community activities occurred, they occurred with comparable frequency, but with a significantly lower level of involvement. Participation frequency ranged from few times a week to daily in the home setting, and from few times a month to once a week in the community

setting with the effect size that can be described as moderate. At the same time, children with CP were “*somewhat involved*”, while children with TD were mostly “*very involved*” in activities. Effect sizes revealed large differences in both settings (Table 4 and 5).

This finding should be carefully considered. First, both diversity of types of activities and level of involvement were lower in participants with CP as compared to other participants’ groups with various developmental disabilities (Bedell et al., 2013; Law et al., 2013). In contrast, our study noted higher average frequencies and participants with TD were involved to a greater extent in comparison to those with TD from the aforementioned studies. These differences may be a result of somewhat different age structures of samples. It has been suggested previously that age differences do not follow a consistent pattern (Coster et al., 2011). Participants involved in our research were on average older (12.7 and 12.1 years compared to 11.7 and 10.6 years). In addition, children with disabilities in other samples had a broad range of diagnoses and disabling conditions and the results were collectively given (Bedell et al., 2013; Law et al., 2013). Secondly, our findings demonstrated that discrepancies between groups were reflected on two participation dimensions in a different way. Although statistically different, data on how often children from our two groups participated were similar. This further confirmed that frequency of participation, as a more objective aspect of attendance (Imms et al., 2016), could not denote all on its own the participation problems and that diversity and involvement dimensions reflected the essential differences. It can be concluded that participation restriction should not be related only to the low frequency of attendance.

Parents were asked to consider and report whether various environmental features of home and community settings had had an impact on their child’s participation. Overall, environmental supportiveness was lower in the group of children with CP. In other words,

parents of children with CP evaluated both home and community environments as relatively unsupportive. Considering that previous studies had documented that numerous environmental factors affected participation of children across various settings, this finding was expected (Anaby et al., 2014; Bedell et al., 2013; King et al., 2006; Law et al., 2013, 2007; Mihaylov, Jarvis, Colver, & Beresford, 2007). Therefore, it was decided to include environmental supportiveness in the partial correlations procedure as a confounding variable.

4.2. Association between dimensions of participation

The obtained results showed that overall parental satisfaction with a child's current participation was associated with the involvement level in home, as well as in community. However, while parents of children with TD expressed a desire for a change in more home-based activities if their children less frequently participated, parents of children with CP emphasized the diversity or a number of these activities (Table 6). It is necessary to further analyze the trend of association in the group of children with CP between the parents' subjective evaluation of home participation and diversity instead of the frequency of home participation. Clinical manifestations of CP are numerous and include motor deficits, perceptive disturbances, cognitive impairment, and behavioral and emotional disorders (Rosenbaum et al., 2007). It is important to note that this revised definition of CP from 2007 emphasizes development basis of CP as a neurodevelopmental disability, as well as the potential impact of motor development disorders on other aspects of child development (Rosenbaum, 2009). Over time, many of the secondary problems are becoming functionally more important than primarily motor limitations (Rosenbaum, 2009). Secondly, caring for a child with developmental disabilities, including CP, often presents a burden and sets new and intense requirements from parents (McCann, Bull, &

Winzenberg, 2012). Frequent hospitalization, getting out of bed at night to take care of the child, physically and time-consuming feeding and dressing are just some of the activities that parents do every day (Bulić, Joković Oreb, & Nikolić, 2012; Hansen, Siame, & van der Veen, 2013; Tadema, Vlaskamp, & Fontaine, 2006). Previous studies reported various difficulties in everyday care for a child with profound intellectual and multiple disabilities, including CP, which parents had to take upon themselves (Bulić et al., 2012; Tadema et al., 2006). Most children need significant assistance in activities of daily living. As reported by parents of children and youth with CP, the most frequent priority was daily activities, while self-care was the most frequent priority sub-category (Chiarello et al., 2010). Overall, all of the above could emerge as a source of parents' reduced satisfaction with their children's current participation in home-based activities. Consequently, they expressed desire for home participation to change more intensely through its diversity or the range of activities in which their child with CP actually took part.

When it comes to community participation, the extent to which the parents were satisfied was associated with involvement level and frequency in both groups. Additionally, parents of children with TD expressed a desire for community participation change in a number of activities when participation of their children was less diverse; this trend was not mirrored by parents of children with CP (Table 6). Generally speaking, the consequences of CP as a primary motor disorder are visible in participation through the reduced number of activities (Imms et al., 2008; Imms, Reilly, Carlin, & Dodd, 2009; Longo, Badia, & Orgaz, 2013; Majnemer et al., 2008; Shikako-Thomas et al., 2013). Our finding may result from generally uniform and low diversity of community participation in the group of children with CP. As a result, the correlation between diversity and desire for change did not reach statistical significance. In other words, parents equally perceived this dimension of participation and focused more on the other two, namely

frequency and level of involvement of their children with CP in the community. Lower diversity was reported earlier, especially in more structured activities, mostly organized and conducted in the community, possibly reflecting their availability (Bedell et al., 2013; King et al., 2013). This outcome may also reflect children's personal preferences or family preferences for participation in certain types of activities. The literature on leisure and recreation participation recognized importance of a child's activity preferences and family activity orientation as direct predictors of the participation intensity (Imms et al., 2009; King et al., 2006; Law et al., 2006). Individual preferences or affinities for specific types of activities are closely related to participation diversity as well (Shimmell, Gorter, Jackson, Wright, & Galuppi, 2013), and children with CP tend to engage more in the activities they prefer the most (Majnemer et al., 2010). On the other hand, continuity of involvement seems to depend on a child's enjoyment (Heah, Case, McGuire, & Law, 2007). Unlike enjoyment, preferences may remain stable from school age to adolescence in children with CP (Majnemer et al., 2015). They are presented as predecessors and consequences of participation at the same time (Imms et al., 2017). A number of activities may also indicate the choice of a child's to participate in some activity rather than others, or reflect the enjoyment and satisfaction he or she experiences while participating, which could partly explain our findings (Engel-Yeger et al., 2009; Kang et al., 2010).

Another possible explanation is related to parental expectations regarding the outcomes of participation, their awareness of available opportunities and inclusiveness of local communities (Colver et al., 2010; Michelsen et al., 2009). In order to promote home and community participation, parents use different strategies. These strategies vary according to their expectations, the activity setting and/or its purpose, and their perceptions about resource availability and supports (Khetani, Cohn, Orsmond, Law, & Coster, 2013). Our finding could be

interpreted as a reflection of acceptance of their child's condition and its consequence as permanent one, as well. Other studies found that expectations of parents of children with CP regarding their children's future independence, acceptance by society, access to education, and success in different life areas were low, most likely representing their realistic expectations and awareness of the challenges ahead (Hansen et al., 2013; Magill-Evans, Darrah, Pain, Adkins, & Kratochvil, 2001). Accordingly, it is necessary to supplement this finding qualitatively and clarify the reasons of parents' satisfaction with the children's current diversity in community participation.

4.3. Limitations and recommendations for future research

A series of shortcomings should be considered when interpreting the results. First, the convenience sampling approach was used, mostly because no population-based register of persons with CP is available in Serbia. The lack of representation of population, possibility of a sampling error, and inadequacy in generalizing the findings of the study have been the most frequent disadvantages of the convenience sampling method (Bornstein, Jager, & Putnick, 2013). Secondly, as part of a larger project, this study was initiated to preliminarily explore a research topic that was insufficiently addressed in Serbia. Next, no data were collected from both institutions and parents/caregivers contacted about the reasons for refusing to participate in this research project. Still, regarding possible selection bias, there were no statistically significant differences related to gender ($p = .263$, $\phi = -.06$) and age ($p = .100$, $\phi = .09$) of children whose parents/caregivers responded or did not respond to our invitation to participate. However, data on the additional characteristics of children with CP (i.e. type of CP, associated impairments and conditions, health problems) were collected only about those children whose parents/caregivers

responded positively to our invitation. Accordingly, it remained unknown whether there were statistically significant differences in comparison to those children with CP whose parents/caregivers refused to participate. Given the lack of accurate statistics on the number of children with CP in Serbia and their functional characteristics, in addition to several methodological issues, the data concerning participation should be taken with caution. It is advisable to extend the scope and structure of the assessed group in terms of gender, age, motor impairment variability and presence of associated disorders.

The desire for change was examined only as a dichotomous variable (whether change was wanted or not), therefore excluding additional data on the type(s) of change: frequency, involvement, and/or variety of activities. Future studies could examine what changes parents referred to as needed and/or desired and relate these differences to specific dimensions of participation. No data on preferences, enjoyment, or additional characteristics of families or children were collected or analyzed as potential variables that could have influenced participation (Engel-Yeger et al., 2009; Longo et al., 2013; Majnemer et al., 2010; Shikako-Thomas et al., 2015). Furthermore, considering the wide age range of our sample, the increased risk of reduced participation in terms of intensity, enjoyment or preferences that comes with increasing age was not taken into consideration (King et al., 2007; Law et al., 2006; Shikako-Thomas et al., 2013). As stated previously, the results were based on the data collected from parents only. Finally, participation is multidetermined; for that reason, replication of this study with larger samples and application of criteria of representativeness could provide more assurance for the findings.

5. Conclusion

Participation of children with CP in Serbia was less diverse and frequent, with less involvement, as measured on the PEM-CY, compared to children with TD. Parents expressed lower overall satisfaction with their child's current participation, and reported lower environmental supportiveness both at home and in the community. This study adds to the previous theoretical and empirical understanding of participation. First, differences in dimensions of home and community participation between children with CP and children with TD are confirmed. As presented, direction of differences between the groups and the effect size are consistent across the settings. Interestingly, frequency of participation of children with CP is statistically significantly lower in comparison to their peers with TD, yet the effect size of differences and descriptive values indicate that this difference may not be clinically meaningful. This may indicate that children with CP who did participate in some activities were engaging in those activities at a similar frequency as children with TD and that the real difference was in diversity of participation, within the attendance construct. In order to capture different aspects of participation, it is important to include all dimensions when assessing children's participation. Secondly, this study provided an indication of the extent to which the examined dimensions of participation were related in both settings. Parents' satisfaction with the children's current participation varied differently across different settings. Considering the "percent that parents desired change" variable not just as an expression of parents' satisfaction, but also as an expression of their expectations, it could be concluded that somewhat different parental expectations were manifested through their evaluation of home and community participation.

Further research is underway to examine data on the type of change desired and its possible connection to environmental factors specifically for the children with CP in this sample.

Acknowledgments

The authors would like to thank the families who participated in this project and shared their unique experiences with us. This work resulted from the project “Crime in Serbia: Phenomenology, risks, and possibilities of social intervention” (registration number 47011) funded by the Ministry of Education, Science and Technological Development of the Republic of Serbia. All authors declare no conflicts of interest.

References

- Anaby, D., Law, M., Coster, W., Bedell, G., Khetani, M., Avery, L., & Teplicky, R. (2014). The Mediating Role of the Environment in Explaining Participation of Children and Youth With and Without Disabilities Across Home, School, and Community. *Archives of Physical Medicine and Rehabilitation*, 95(5), 908–917. doi: 10.1016/j.apmr.2014.01.005
- Bedell, G., Coster, W., Law, M., Liljenquist, K., Kao, Y., Teplicky, R., ... Khetani, A. (2013). Community participation, supports, and barriers of school-age children with and without disabilities. *Archives of Physical Medicine and Rehabilitation*, 94(2), 315–323. doi: 10.1016/j.apmr.2012.09.024
- Bedell, G., Khetani, M. A., Cousins, M. A., Coster, W. J., & Law, M. C. (2011). Parent Perspectives to Inform Development of Measures of Children's Participation and Environment. *Archives of Physical Medicine and Rehabilitation*, 92(5), 765–773. doi: 10.1016/j.apmr.2010.12.029
- Bornstein, M. H., Jager, J., & Putnick, D. L. (2013). Sampling in developmental science: Situations, shortcomings, solutions, and standards. *Developmental Review*, 33(4), 357–370. doi: 10.1016/j.dr.2013.08.003
- Bulić, D., Joković Oreb, I., & Nikolić, B. (2012). Angažman majki djece s teškoćama u razvoju u aktivnostima svakodnevnog života. *Hrvatska Revija Za Rehabilitacijska Istraživanja*, 48(2), 1–12.
- Cans, C. (2000). Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. *Developmental Medicine & Child Neurology*, 42(12), 816–824. doi: 10.1111/j.1469-8749.2000.tb00695.x

- Chiarello, L. A., Palisano, R. J., Maggs, J. M., Orlin, M. N., Almasri, N., Kang, L.-J., & Chang, H.-J. (2010). Family Priorities for Activity and Participation of Children and Youth With Cerebral Palsy. *Physical Therapy, 90*(9), 1254–1264. doi: 10.2522/ptj.20090388
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences*. Hillsdale, NJ, USA: Lawrence Earlbaum Associates.
- Colver, A. F., Dickinson, H. O., Parkinson, K., Arnaud, C., Beckung, E., Fauconnier, J., ... Thyen, U. (2010). Access of children with cerebral palsy to the physical, social and attitudinal environment they need: A cross-sectional European study. *Disability and Rehabilitation, 33*(1), 28–35. doi: 10.3109/09638288.2010.485669
- Coster, W., Bedell, G., Law, M., Khetani, M. A., Teplicky, R., Liljenquist, K., ... Kao, Y.-C. (2011). Psychometric evaluation of the Participation and Environment Measure for Children and Youth. *Developmental Medicine & Child Neurology, 53*(11), 1030–1037. doi: 10.1111/j.1469-8749.2011.04094.x
- Coster, W., Law, M., & Bedell, G. (2010). *Participation and Environment Measure for Children and Youth*. Boston, MA: Boston University.
- Coster, W., Law, M., Bedell, G., Khetani, M., Cousins, M., & Teplicky, R. (2012). Development of the participation and environment measure for children and youth: conceptual basis. *Disability and Rehabilitation, 34*(3), 238–246. doi: 10.3109/09638288.2011.603017
- Darrah, J., Magil-Evans, J., & Adkins, R. (2002). How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery. *Disability and Rehabilitation, 24*(10), 542–549. doi: 10.1080/09638280210121359

- Davis, E., Mackinnon, A., & Waters, E. (2012). Parent proxy-reported quality of life for children with cerebral palsy: Is it related to parental psychosocial distress?. *Child: Care, Health and Development*, 38(4), 553–560. doi: 10.1111/j.1365-2214.2011.01267.x
- Dimoski, S., & Nikolić, G. (2015). Značaj odnosa društva prema osobama sa smetnjama u razvoju za realizaciju obrazovne inkluzije u Srbiji [Importance of social attitudes towards people with disabilities in the realization of educational inclusion in Serbia]. *Sociološki Pregled*, XLIX(4), 419–443.
- Engel-Yeger, B., Jarus, T., Anaby, D., & Law, M. (2009). Differences in patterns of participation between youths with cerebral palsy and typically developing peers. *American Journal of Occupational Therapy*, 63(1), 96–104. doi: 10.5014/ajot.63.1.96
- Hansen, A. M., Siame, M., & van der Veen, J. (2013). A qualitative study : Barriers and support for participation for children with disabilities. *African Journal of Disability*, 3(1), 1–9. doi: 10.4102/ajod.v3i1.112
- Heah, T., Case, T., McGuire, B., & Law, M. (2007). Successful participation: The lived experience among children with disabilities. *Canadian Journal of Occupational Therapy*, 74(1), 38–47. doi: 10.2182/cjot.06.10
- George, D., & Mallery, P. (2003). *SPSS for Windows step by step: A simple guide and reference, 11.0 update* (4th ed.). Boston: Allyn & Bacon.
- Imms, C., Adair, B., Keen, D., Ullenhag, A., Rosenbaum, P., & Granlund, M. (2016). “Participation”: a systematic review of language, definitions, and constructs used in intervention research with children with disabilities. *Developmental Medicine & Child Neurology*, 58(1), 29–38. doi: 10.1111/dmcn.12932

- Imms, C., Granlund, M., Wilson, P. H., Steenbergen, B., Rosenbaum, P. L., & Gordon, A. M. (2017). Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. *Developmental Medicine & Child Neurology*, 59(1), 16–25. doi: 10.1111/dmcn.13237
- Imms, C., Reilly, S., Carlin, J., & Dodd, K. (2008). Diversity of participation in children with cerebral palsy. *Developmental Medicine & Child Neurology*, 50(5), 363–369. doi: 10.1111/j.1469-8749.2008.02051.x
- Imms, C., Reilly, S., Carlin, J., & Dodd, K. J. (2009). Characteristics influencing participation of Australian children with cerebral palsy. *Disability and Rehabilitation*, 31(26), 2204–2215. doi: 10.3109/09638280902971406
- Jovanovic-Popadic, A. (2016). Inclusive education: Ideas vs reality. *Sinteze*, 5(10), 35–46. doi: 10.5937/sinteze0-12363
- Kang, L. J., Palisano, R. J., Orlin, M. N., Chiarello, L. A., King, G. A., & Polansky, M. (2010). Determinants of Social Participation--With Friends and Others Who Are Not Family Members--for Youths With Cerebral Palsy. *Physical Therapy*, 90(12), 1743–1757. doi: 10.2522/ptj.20100048
- Khetani, M. A., Cohn, E. S., Orsmond, G. I., Law, M. C., & Coster, W. J. (2013). Parent Perspectives of Participation in Home and Community Activities When Receiving Part C Early Intervention Services. *Topics in Early Childhood Special Education*, 32(4), 234–245. doi: 10.1177/0271121411418004
- Khetani, M., Marley, J., Baker, M., Albrecht, E., Bedell, G., Coster, W., ... Law, M. (2014). Validity of the Participation and Environment Measure for Children and Youth (PEM-

- CY) for Health Impact Assessment (HIA) in sustainable development projects. *Disability and Health Journal*, 7(2), 226–235. doi: 10.1016/j.dhjo.2013.11.003
- King, G., Imms, C., Palisano, R., Majnemer, A., Chiarello, L., Orlin, M., ... Avery, L. (2013). Geographical patterns in the recreation and leisure participation of children and youth with cerebral palsy: A CAPE international collaborative network study. *Developmental Neurorehabilitation*, 16(3), 196–206. doi: 10.3109/17518423.2013.773102
- King, G., Law, M., Hanna, S., King, S., Hurley, P., Rosenbaum, P., ... Petrenchik, T. (2006). Predictors of the Leisure and Recreation Participation of Children With Physical Disabilities: A Structural Equation Modeling Analysis. *Children's Health Care*, 35(3), 209–234. doi: 10.1207/s15326888chc3503_2
- King, G., Law, M., Hurley, P., Petrenchik, T., & Schwellnus, H. (2010). A Developmental Comparison of the Out-of-school Recreation and Leisure Activity Participation of Boys and Girls With and Without Physical Disabilities. *International Journal of Disability, Development and Education*, 57(1), 77–107. doi: 10.1080/10349120903537988
- King, G. A., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., & Rosenbaum, P. (2007). Measuring children's participation in recreation and leisure activities: Construct validation of the CAPE and PAC. *Child: Care, Health and Development*, 33(1), 28–39. doi: 10.1111/j.1365-2214.2006.00613.x
- King, G., Law, M., King, S., Rosenbaum, P., Kertoy, M. K., & Young, N. L. (2003). A Conceptual Model of the Factors Affecting the Recreation and Leisure Participation of Children with Disabilities. *Physical & Occupational Therapy in Pediatrics*, 23(1), 63–90. doi: 10.1300/J006v23n01_05

- Kovačević, J., & Maćešić-Petrović, D. (2012). Inclusive education - Empirical experience from Serbia. *International Journal of Educational Development*, 32(3), 463–470. doi: 10.1016/j.ijedudev.2011.11.008
- Law, M., Anaby, D., Teplicky, R., Khetani, M. A., Coster, W., & Bedell, G. (2013). Participation in the home environment among children and youth with and without disabilities. *British Journal of Occupational Therapy*, 76(2), 58–66. doi: 10.4276/030802213X13603244419112
- Law, M., King, G., King, S., Kertoy, M., Hurley, P., Rosenbaum, P., ... Hanna, S. (2006). Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental Medicine & Child Neurology*, 48(5), 337–342. doi: 10.1017/S0012162206000740
- Law, M., Petrenchik, T., King, G., & Hurley, P. (2007). Perceived Environmental Barriers to Recreational, Community, and School Participation for Children and Youth With Physical Disabilities. *Archives of Physical Medicine and Rehabilitation*, 88(12), 1636–1642. doi: 10.1016/j.apmr.2007.07.035
- Longo, E., Badia, M., & Orgaz, B. M. (2013). Patterns and predictors of participation in leisure activities outside of school in children and adolescents with Cerebral Palsy. *Research in Developmental Disabilities*, 34(1), 266–275. doi: 10.1016/j.ridd.2012.08.017
- Magill-Evans, J., Darrah, J., Pain, K., Adkins, R., & Kratochvil, M. (2001). Are families with adolescents and young adults with cerebral palsy the same as other families? *Developmental Medicine & Child Neurology*, 43(7), 466. doi: 10.1017/S0012162201000858

Majnemer, A., Shevell, M., Law, M., Birnbaum, R., Chilingaryan, G., Rosenbaum, P., & Poulin, C. (2008). Participation and enjoyment of leisure activities in school-aged children with cerebral palsy. *Developmental Medicine & Child Neurology*, 50(10), 751–758. doi: 10.1111/j.1469-8749.2008.03068.x

Majnemer, A., Shikako-Thomas, K., Chokron, N., Law, M., Shevell, M., Chilingaryan, G., ... Rosenbaum, P. (2010). Leisure activity preferences for 6- to 12-year-old children with cerebral palsy. *Developmental Medicine and Child Neurology*, 52(2), 167–173. doi: 10.1111/j.1469-8749.2009.03393.x

Majnemer, A., Shikako-Thomas, K., Schmitz, N., Shevell, M., & Lach, L. (2015). Stability of leisure participation from school-age to adolescence in individuals with cerebral palsy. *Research in Developmental Disabilities*, 47, 73–79. doi: 10.1016/j.ridd.2015.08.009

McCann, D., Bull, R., & Winzenberg, T. (2012). The daily patterns of time use for parents of children with complex needs: A systematic review. *Journal of Child Health Care*, 16(1), 26–52. doi: 10.1177/1367493511420186

Mc Manus, V., Corcoran, P., & Perry, I. J. (2008). Participation in everyday activities and quality of life in pre-teenage children living with cerebral palsy in South West Ireland. *BMC Pediatrics*, 8, 50. doi: 10.1186/1471-2431-8-50

Michelsen, S. I., Flachs, E. M., Uldall, P., Eriksen, E. L., McManus, V., Parkes, J., ... Colver, A. (2009). Frequency of participation of 8–12-year-old children with cerebral palsy: A multi-centre cross-sectional European study. *European Journal of Paediatric Neurology*, 13(2), 165–177. doi: 10.1016/j.ejpn.2008.03.005

Mihaylov, S. I., Jarvis, S. N., Colver, A. F., & Beresford, B. (2007). Identification and description of environmental factors that influence participation of children with cerebral palsy.

Developmental Medicine & Child Neurology, 46(5), 299–304. doi: 10.1111/j.1469-8749.2004.tb00489.x

Mijatović, S. (2013). The most frequent obstacles to inclusion in the educational system of Serbia. *Inovacije u nastavi – časopis za savremenu nastavu*, 26(3), 69-82.
<http://scindeks.ceon.rs/article.aspx?artid=0352-23341303069M>

Parkes, J., McCullough, N., & Madden, A. (2010). To what extent do children with cerebral palsy participate in everyday life situations? *Health and Social Care in the Community*, 18(3), 304–315. doi: 10.1111/j.1365-2524.2009.00908.x

Rosenbaum, P. (2009). Cerebral Palsy in the 21st Century: What's New? In C. Morris & D. Condie (Eds.), *Recent Developments in Healthcare for Cerebral Palsy: Implications and Opportunities for Orthotics (Report of a meeting held at Wolfson College, Oxford, 8–11 September 2008)* (pp. 25–39). Copenhagen: International Society for Prosthetics and Orthotics.

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., ... Jacobsson, B. (2007). A report: The definition and classification of cerebral palsy April 2006. *Developmental Medicine and Child Neurology*, 49(Suppl.109), 8–14. doi: 10.1111/j.1469-8749.2007.tb12610.x

Shikako-Thomas, K., Shevell, M., Lach, L., Law, M., Schmitz, N., Poulin, C., ... Group, Q. (2013). Picture me playing — A portrait of participation and enjoyment of leisure activities in adolescents with cerebral palsy. *Research in Developmental Disabilities*, 34(3), 1001–1010. doi: 10.1016/j.ridd.2012.11.026

Shikako-Thomas, K., Shevell, M., Lach, L., Law, M., Schmitz, N., Poulin, C., & Majnemer, A. (2015). Are you doing what you want to do? Leisure preferences of adolescents with

cerebral palsy. *Developmental Neurorehabilitation*, 18(4), 234–240. doi:
10.3109/17518423.2013.794166

Shimmell, L. J., Gorter, J. W., Jackson, D., Wright, M., & Galuppi, B. (2013). “It’s the participation that motivates him”: Physical activity experiences of youth with cerebral palsy and their parents. *Physical and Occupational Therapy in Pediatrics*, 33(4), 405–420. doi: 10.3109/01942638.2013.791916

Tadema, A. C., Vlaskamp, C., & Fontaine, H. (2006). The time and effort in taking care for children with PMD: a study on care load [Abstract]. *Profound and Multiple Disabilities. Journal of Applied Research in Intellectual Disabilities*, 19(3), 261–266. doi:
10.1111/j.1468-3148.2006.00322_13.x

World Health Organization. (2001). *International Classification of Functioning Disability and Health (ICF)*. Geneva: World Health Organization. Retrieved from
<http://www.who.int/classifications/en/>

World Health Organization. (2004). *International statistical classification of diseases and related health problems (ICD10)*. Geneva: World Health Organization. Retrieved from
http://apps.who.int/iris/bitstream/10665/42980/1/9241546530_eng.pdf

Appendix A. Supplementary data

Table A.1.

PEM-CY home summary scores: interaction effects between respondent age and group

PEM-CY home summary scores	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>df</i>	<i>p</i>	η^2_p
Percent ever participates	2.918	1.459	.006	2	.994	.000
Participation frequency	.238	.119	.424	2	.655	.004
Involvement	.411	.206	.332	2	.718	.003
Percent that parents desired change	2636.753	1318.377	1.934	2	.147	.017
Percent total environmental supportiveness	13.331	6.665	.075	2	.928	.001

Note: Respondent age (years) = Categorized as 25–34, 35–44 and 44+; *SS* = Sum of Squares; *MS* = Mean Square; η^2_p = Partial Eta squares (effect sizes) are rounded to two decimal points and interpreted as small = .01–.05, moderate = .06–.13 or large $\geq$.14 (Cohen, 1988).

Table A.2.

PEM-CY community summary scores: interaction effects between respondent age and group

PEM-CY community summary scores	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>df</i>	<i>p</i>	η^2_p
Percent ever participates	801.342	400.671	1.269	2	.283	.011
Participation frequency	1.761	.880	1.041	2	.355	.009
Involvement	.081	.041	.059	2	.942	.001
Percent that parents desired change	876.500	438.250	.663	2	.516	.006
Percent total environmental supportiveness	204.653	102.327	.985	2	.375	.009

Note: Respondent age (years) = Categorized as 25–34, 35–44 and 44+; *SS* = Sum of Squares; *MS* = Mean Square; η^2_p = Partial Eta squares (effect sizes) are rounded to two decimal points and interpreted as small = .01–.05, moderate = .06–.13 or large $\geq$.14 (Cohen, 1988).

Table A.3.

PEM-CY home summary scores: interaction effects between respondent education and group

PEM-CY home summary scores	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>df</i>	<i>p</i>	η^2_p
Percent ever participates	34.230	17.115	.078	2	.925	.001
Participation frequency	.438	.219	.796	2	.452	.007
Involvement	.607	.303	.515	2	.598	.005
Percent that parents desired change	1212.248	606.124	.900	2	.408	.008
Percent total environmental supportiveness	68.180	34.090	.418	2	.659	.004

Note: Respondent education = Categorized as primary school, high school and graduated college/university; *SS* = Sum of Squares; *MS* = Mean Square; η^2_p = Partial Eta squares (effect sizes) are rounded to two decimal points and interpreted as small = .01–.05, moderate = .06–.13 or large $\geq$.14 (Cohen, 1988).

Table A.4.

PEM-CY community summary scores: interaction effects between respondent education and group

PEM-CY community summary scores	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>df</i>	<i>p</i>	η^2_p
Percent ever participates	161.561	80.780	.283	2	.754	.003
Participation frequency	5.808	2.904	3.477	2	.829	.002
Involvement	.652	.326	.470	2	.626	.004
Percent that parents desired change	1638.836	819.418	1.229	2	.295	.011
Percent total environmental supportiveness	87.758	43.879	.448	2	.640	.004

Note: Respondent education = Categorized as primary school, high school and graduated college/university; *SS* = Sum of Squares; *MS* = Mean Square; η^2_p = Partial Eta squares (effect sizes) are rounded to two decimal points and interpreted as small = .01–.05, moderate = .06–.13 or large $\geq$.14 (Cohen, 1988).

Table A.5.

PEM-CY home summary scores: unadjusted means and adjusted means for family income

category

PEM-CY home summary scores	Group	Unadjusted	Adjusted for family income		
		<i>M</i> (<i>SD</i>)	<i>M</i>	<i>SE</i>	95% CI
Percent ever home	CP	77.36 (21.79)	78.58	1.53	[75.56, 81.60]
	TD	98.56 (3.75)	97.49	1.43	[94.68, 100.30]
Participation frequency	CP	6.14 (0.65)	6.11	.05	[6.00, 6.21]
	TD	6.43 (.40)	6.46	.05	[6.36, 6.55]
Involvement	CP	3.42 (1.05)	3.47	.08	[3.32, 3.63]
	TD	4.56 (.43)	4.51	.07	[4.36, 4.66]
Percent that parents desired change	CP	63.91 (24.35)	64.01	2.69	[58.71, 69.32]
	TD	40.56 (27.89)	40.47	2.50	[35.53, 45.40]
Percent total environmental supportiveness	CP	78.64 (12.34)	80.23	.91	[78.43, 82.03]
	TD	94.62 (5.63)	93.22	.85	[91.54, 94.90]

Note: CP = Children with cerebral palsy ($n = 110$); TD = Children with typical development ($n = 125$); *SE* = standard error; CI = confidence interval in format [lower bound, upper bound].

Table A.6.

PEM-CY community summary scores: unadjusted means and adjusted means for family income category

PEM-CY community summary scores	Group	Unadjusted	Adjusted for family income		
		<i>M</i> (<i>SD</i>)	<i>M</i>	<i>SE</i>	95% CI
Percent ever home	CP	50.36 (20.36)	52.04	1.79	[48.51, 55.57]
	TD	74.56 (15.11)	73.08	1.67	[69.80, 76.37]
Participation frequency	CP	4.20 (1.07)	4.20	.10	[4.01, 4.38]
	TD	4.83 (.76)	4.84	.09	[4.66, 5.01]
Involvement	CP	3.16 (1.07)	3.20	.08	[3.03, 3.36]
	TD	4.63 (.53)	4.60	.08	[4.45, 4.75]
Percent that parents desired change	CP	72.55 (23.12)	71.57	2.61	[66.42, 76.71]
	TD	35.84 (27.57)	36.70	2.43	[31.91, 41.49]
Percent total environmental supportiveness	CP	71.57 (12.38)	73.15	1.00	[71.18, 75.11]
	TD	92.02 (7.69)	90.63	.93	[88.80, 92.46]

Note: CP = Children with cerebral palsy ($n = 110$); TD = Children with typical development ($n = 125$); *SE* = standard error; CI = confidence interval in format [lower bound, upper bound].