

Social and Community Participation of Children and Youth With Cerebral Palsy Is Associated With Age and Gross Motor Function Classification

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Background. Through social and community participation, children and youth with cerebral palsy (CP) form friendships, gain knowledge, learn skills, express creativity, and determine meaning and purpose in life.

Objective. The purposes of this study were: (1) to determine whether social and community participation of children and youth with CP differ based on age, sex, and gross motor function, and (2) to identify the types of activities in which social and community participation are highest.

Design and Methods. A prospective cross-sectional analytic design was used. The participants were a sample of convenience of 291 children (6-12 years of age) and 209 youth (13-21 years of age) with CP (55.4% males, 44.6% females) receiving services from 7 children's hospitals. Participants completed the Children's Assessment of Participation and Enjoyment (CAPE) by structured interview. Gross Motor Function Classification System (GMFCS) level was determined by the researchers.

Results. Youth did a higher percentage of activities with friends and others and outside the home than children. Children and youth in level I did a higher percentage of activities with friends and others compared with children and youth in levels II and III and in levels IV and V. Children and youth in level I and in levels IV and V did a higher percentage of activities outside the home than children and youth in levels II and III. Differences were not found between females and males. The percentage of activities done with friends and others and outside the home was highest for physical and skill-based activities.

Limitations. Findings cannot be attributed only to GMFCS level.

Conclusions. The ability to walk without restrictions is desirable for social and community participation. For children and youth with CP who have limitations in mobility, physical therapists have roles as consultants for accessibility, activity accommodations, and assistive technology and as advocates for inclusive environments.



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Cerebral palsy (CP) describes a group of disorders of posture and movement that occur as a result of a nonprogressive disturbance in the developing fetal or infant brain.¹ United Cerebral Palsy² estimates that in the United States 9,000 infants and children younger than school age are diagnosed with CP each year and the number of children and adults with CP is 764,000. Children with CP frequently receive physical therapy.³ Physical therapy interventions for individuals with CP focus on impairments in motor control, muscle performance, and musculoskeletal alignment that are thought to contribute to activity limitations in sitting, standing, transfers, and mobility.^{4,5}

Contemporary models for understanding health and disability, such as the *International Classification of Functioning, Disability and Health* (ICF)⁶ and the Social Model of Disability,⁷ suggest that an important outcome of rehabilitation services is to optimize children's participation in home, school, and community life. The ICF is a biopsychosocial model based on the premise that disability involves an interaction between features of the person and features of the environment. Components of functioning and disability (body functions and structures, activity, participation) are viewed as outcomes of interactions among health conditions and contextual factors (environmental and personal). The Social Model of Disability states that disability results when features of the physical, social, or attitudinal environment restrict participation in activities that an individual needs or wants to do.^{8,9}

Chen and Cohn¹⁰ proposed that, for children, social participation involves interactions with others within the contexts of home, school, and community and is influenced by the extent that environments are ac-

cessible and interactions are positive. Through social participation, children form friendships, gain knowledge, learn skills, express creativity, and determine meaning and purpose in life.^{11,12} People with childhood onset disabilities have reported that opportunities to form social networks and develop social competencies have positive benefits for mental and physical health.^{13,14} Belonging to social networks outside the family is a particular desire for adolescents with physical disabilities.¹⁵ Social self-efficacy (a person's belief in his or her ability to succeed in a particular situation) is associated with independence and persistence in adolescents with physical disabilities.¹⁶ Adolescents with CP identified being believed in, believing in yourself, and being accepted by others as important for success in life.¹⁷

Differences in participation have been reported between children and youth with and without physical disabilities and between females and males. Children and youth with physical disabilities participate in fewer social activities, are less socially active, and are less skilled when interacting with others compared with children and youth without disabilities.¹⁸⁻²⁰ Brown and Gordon²⁰ reported that children with physical disabilities spent more time in dependent activities, quiet recreation, and self-care and less time in social engagements, active recreation, household tasks, and community activities compared with children without physical disabilities. Children with disabilities who desire more social participation but have limited opportunities for participation may feel socially isolated and demonstrate more passive activity compared with children without disabilities.^{9,18-21} Differences in participation between females and males have been reported for children with and without disabilities. In general, females participate more in arts

and social activities, whereas males participate more in group activities involving physical activity and sports.²²⁻²⁵

Among individuals with disabilities, adolescents and youth have been reported to have less social participation than children.^{18-20,26} In a sample of 60 individuals with CP, aged 12 to 22 years, more than 50% indicated that their best friends had disabilities and their participation with friends was mostly passive (eg, watching television) or sedentary recreation (eg, playing chess).²¹ Adolescents with CP were reported to be less physically active²⁷ and to walk less than adolescents without CP.²⁸ Lack of information, limited disability awareness, program costs, and transportation were identified as barriers to participation in recreation for youth with disabilities.²⁹ Inadequate activity accommodations and difficulties in planning and coordinating services are other potential barriers to participation.³⁰

The aims of this study were: (1) to determine whether social and community participation of children and youth with CP differ based on age, sex, and gross motor function level; and (2) to identify the types of activities in which social and community participation are highest. *Social participation* was operationally defined as doing an activity with friends or other non-family members (instructors, coaches, and other individuals). *Community participation* was operationally defined as doing an activity



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Social and Community Participation of Children and Youth With Cerebral Palsy

Table 1.

Characteristics of the Children and Youth With Cerebral Palsy and Family Income^a

Characteristics	Children (6-12 y) (n=291)		Youth (13-21 y) (n=209)	
Age (y), mean, SD	9.7	2.0	16.2	2.3
Gross motor function level				
I-Walks without restrictions	74	25.4%	54	25.8%
II-Walks with limitations	69	23.7%	57	27.3%
III-Walks with assistive device	61	21.0%	33	15.8%
IV-Limited self-mobility	45	15.5%	26	12.4%
V-Severe limitations in posture and self-mobility	42	14.4%	39	18.7%
Sex				
Male	169	58.1%	108	51.7%
Female	122	41.9%	101	48.3%
Ethnicity				
Caucasian	231	79.4%	142	67.9%
African American	19	6.5%	21	10.0%
Hispanic/Latino	21	7.2%	21	10.0%
Other	20	6.9%	25	12.0%
Associated diagnosis ^b				
Intellectual disability	45	16.0%	32	16.4%
Learning disability	98	34.8%	80	41.0%
Attention deficit disorder	27	9.6%	27	13.8%
Associated conditions ^b				
Visual impairments	134	47.5%	118	60.5%
Hearing impairments	15	5.3%	13	6.7%
Communication impairments	83	29.4%	50	25.6%
Speech impairments	105	37.2%	69	35.4%
Behavioral/emotional problems	86	30.5%	48	24.6%
Seizure disorder	61	21.6%	46	23.6%
Heart conditions	12	4.3%	5	2.6%
Respiratory conditions	56	19.9%	27	13.8%
Orthopedic conditions	98	34.8%	99	50.8%
Family income ^c				
Less than \$15,000	29	11.3%	21	11.9%
\$15,000-\$29,999	33	12.8%	29	16.5%
\$30,000-\$44,999	59	23.0%	34	19.3%
\$45,000-\$59,999	38	14.8%	18	10.2%
\$60,000-\$74,999	36	14.0%	29	16.5%
\$75,000-\$99,999	35	13.6%	17	9.7%
\$100,000 and over	27	10.5%	28	15.9%

^a Reported values are numbers and percentages of participants, unless otherwise indicated.

^b Number of participants: children=282, youth=195.

^c Number of participants: children=257, youth=176.

outside the home or a relative's home. "Outside the home" includes in the neighborhood, at school (but not during classes), in the community, and outside the community. The results will increase knowledge of social and community participation of children and youth with CP and have implications for physical therapy interventions to optimize social and community participation.

Method

Participants

The participants were 500 children and youth with CP, (mean age=12.4 years, SD=3.8, range=6-21) who were receiving services from 6 Shriners Hospitals for Children (Chicago, Illinois; Erie, Pennsylvania; Lexington, Kentucky; Sacramento, California; Philadelphia, Pennsylvania; and Springfield, Massachusetts) and Kluge Children's Rehabilitation Center, Charlottesville, Virginia. Children and youth with CP were excluded only if they had a second diagnosis such as autism or a mental health disorder that might influence social participation. The study was approved by the institutional review board of each hospital. Informed consent was provided by parents or guardians and youth under the age of 18 years. Informed assent was provided by children and adolescents 7 to 17 years of age.

Participant characteristics are presented in Table 1. The sample comprised 291 children (6-12 years of age) and 209 youth (13-21 years of age) with CP; 277 (55.4%) of the participants were males and 223 (44.6%) were females. The number of participants in each of the 5 levels of the Gross Motor Function Classification System (GMFCS)³¹ varied from 71 to 128. Parents reported that 16% of the participants had a secondary diagnosis of intellectual disability, 37% had a diagnosed learning disability, and 11% had a diagnosis of attention deficit disorder. The per-

Table 2.

Examples of Items for Each Activity Type of the Children's Assessment of Participation and Enjoyment (CAPE)³²

Recreational	Physical	Social	Skill-Based	Self-Improvement
Playing computer or video games	Bicycling, in-line skating, or skateboarding	Talking on the telephone	Swimming	Getting extra help for schoolwork from a tutor
Watching television or a rented movie	Doing team sports	Hanging out	Horseback riding	Reading
Playing on equipment	Doing individual physical activities	Going to a party	Participating in community organizations	Doing homework

centage of children with health conditions and impairments in body functions and structures associated with CP varied from 4% (heart condition) to 53% (visual impairment). The diagnoses and conditions reported are consistent with the definition of CP.¹ Family income was fairly evenly distributed and varied from less than \$15,000 to more than \$100,000 per year.

Measures

Children's Assessment of Participation and Enjoyment. The Children's Assessment of Participation and Enjoyment (CAPE)³² is a 55-item measure of participation in leisure and recreational activities designed for completion by children and youth of 6 to 21 years of age. The CAPE is completed by a questionnaire or structured interview and parent assistance is permitted. Five dimensions of participation are rated for each item: whether the activity was done during the past 4 months and, for each activity done, how of-

ten, with whom, where, and level of enjoyment. Each item is categorized by activity domain (formal or informal) and activity type (recreational, physical, social, skill-based, or self-improvement). *Formal activities* refer to activities structured by adults that involve rules or goals (eg, organized sports, art lessons), and *informal activities* refer to activities involving little or no planning that often are initiated by the child (eg, playing non-team sports, reading). Examples of items for each activity type are provided in Table 2. A score can be calculated for each of the 5 dimensions of participation. The diversity score is the number of activities performed in the past 4 months. The intensity score is the total ratings for how often each activity was performed divided by the total number of items. The "With Whom," "Where," and enjoyment scores are the total ratings for each dimension divided by the diversity score. The response options for the 3 dimen-

sions analyzed in this study are presented in Table 3.

Evidence of reliability and validity of the CAPE have been reported previously.^{25,32} Test-retest stability was examined in 48 children. The intra-class correlation coefficients (ICCs) were .75 for the overall diversity score, .72 for the overall intensity score, and .65 for the overall enjoyment score. Construct validity was examined using correlation analysis. Intensity and enjoyment scores correlated significantly with environmental, family, and child variables, in expected ways. Predictions also were supported with respect to differences in mean scores for boys and girls and younger and older children. Agreement between scores when the CAPE was completed by questionnaire versus structured interview was high for intensity (ICC=.82-.99) and moderate for enjoyment (ICC=.47-.78). The reader is referred to an appraisal of the CAPE for more information.³³

Table 3.

Response Options for Diversity (Number of Activities Performed) and "With Whom" and "Where" Dimensions of the Children's Assessment of Participation and Enjoyment (CAPE)³²

Activity Performed?	With Whom?	Where?
0 No	1 Alone	1 At home
1 Yes	2 With family (parents, brothers, sisters)	2 At a relative's home
	3 With other relatives (grandparents, aunts, uncles, cousins)	3 In your neighborhood
	4 With friends	4 At school (but not during classes)
	5 With others (instructors, other individuals, or multiple types of people)	5 In your community
		6 Beyond your community

Gross Motor Function Classification System. The GMFCS³⁴ is a 5-level system for children with CP ages 12 years or younger. A classification is made based on current performance of gross motor function in daily activities with emphasis on mobility and sitting. The preliminary version of the 12- through 18-year-old age band of the expanded and revised GMFCS³¹ was used to classify participants over the age of 12 years. The GMFCS has evidence of content, construct, and discriminative validity and interrater reliability.^{31,34}

Procedure

A prospective cross-sectional analytic design was used. At each hospital, data were collected by 1 to 3 research assistants. The research assistants were primarily health care professionals experienced in providing services to children with CP. They included physical therapists, occupational therapists, a nurse, a psychologist, and a social worker. Research assistants who were not health care professionals were selected to collect data based on their positive interpersonal and communication skills.

Prior to data collection, the research assistants received a procedural manual and attended a 2-day workshop to learn the procedures. Following instruction in the GMFCS, interrater reliability was examined using a criterion videotape. Each research assistant classified a minimum of 11 children and achieved agreement of >80% with the criterion rating. To ensure data fidelity, teleconferences were scheduled at 3-month intervals, and a second workshop was held at the midpoint of data collection.

The CAPE was completed by interview using either a custom-designed display on a computer monitor or the standard picture cards and scoring form. Permission was obtained from the publisher to display the pic-

ture card for each of the 55 activities on a laptop computer and to record responses electronically. Guidelines were developed for parent assistance in recall of the number of times an activity was done in the past 4 months and where and with whom the activity was done. The researcher provided assistance to children or parents who had difficulty with reading or entering responses. If a child or youth was unable to communicate whether or not each activity was done, the CAPE was completed by parent proxy.

The CAPE was completed independently by 32% of the children and 56% of the youth. The CAPE was completed by a parent for 34% of the children and 22% of the youth. Sixty-three percent of the children and youth in level I, 49% of the children and youth in levels II and III, and 13.2% of the children and youth in levels IV and V completed the CAPE independently. The CAPE was completed by a parent for 59.2% of the children and youth in levels IV and V.

Data Analysis

Participants were grouped by age (ages 6-12 years and 13-21 years), sex, and GMFCS level (I, II and III, and IV and V). The 2 age bands were selected to permit comparisons between children and youth. The decision to combine GMFCS levels II and III and levels IV and V was based on previous research.^{35,36} In a study of performance of physical activity of children and youth with CP (ages 11-17 years), the mean score on the Activity Scales for Kids³⁵ was highest for participants in level I, and scores of participants in levels II and III and participants in levels IV and V were similar to each other.³⁶ Orlin et al³⁷ found a similar relationship between GMFCS level and CAPE scores for diversity and intensity of participation in their study.

The overall percentage of activities done with friends or other non-family members (friends and others) and the percentage of activities done with friends and others for each of the 5 activity types were calculated for each participant as follows. First, the diversity score was determined by summing the number of activities done in the past 4 months (Tab. 3). Second, the number of activities done in which the "With Whom" dimension score was 4 or 5 was summed (Tab. 3). Third, the sum of scores of 4 and 5 for the "With Whom" dimension was divided by the diversity score, and the ratio was multiplied by 100. For example, 1 child reported having done 20 of the 55 activities in the past 4 months. Five activities were done with friends, 3 activities were done with others (non-family members), and 12 activities were done alone, with family members, or with other relatives. The overall percentage of activities done with friends and others was $(5 + 3)/20 \times 100 = 40\%$.

The overall percentage of activities done outside the home and the percentage done outside the home for each of the 5 activity types were calculated as follows. The number of activities done in which the "Where" dimension score was 3 through 6 (Tab. 3) was summed, divided by the diversity score, and multiplied by 100. In the previous example, the child did 3 activities at school (extracurricular), 2 activities in his neighborhood, and 5 activities in the community, and 10 activities were done either at home or at a relative's home. The overall percentage of activities done outside the home was $(3 + 2 + 5)/20 \times 100 = 50\%$. The use of percentages instead of absolute numbers of activities enabled comparisons across participants with different diversity scores for overall activities and among 5 activity types with different numbers of items.

Statistical analysis was performed using SPSS for Windows, version 16.0.* Among the 500 participants, 50 (10%) did not do any activities with friends and others. Logistic regression was performed to determine if the adjusted odds of not participating in an activity with friends and others differed by age, sex, or gross motor function level.

Three-way analyses of variance (ANOVAs) were computed to analyze the effect of age, sex, and gross motor function level on the overall percentage of activities done: (1) with friends and others and (2) outside the home. *Post hoc* analysis of significant effects was performed using Bonferroni corrections for pairwise comparisons. The significance level for all analyses was $P=.05$. The data for the 450 participants who did at least 1 activity with friends and others and the 497 participants who did at least 1 activity outside the home were used for the ANOVAs. The distribution of "With Whom" scores was positively skewed; therefore, natural logarithmic transformation was performed prior to statistical analysis. The "Where" scores of the 497 participants who did at least 1 activity outside the home had a normal distribution.

Friedman 2-way ANOVA by ranks was used to analyze whether the percentage of activities done with friends and others and the percentage of activities done outside the home differed among the 5 activity types. The distributions of scores for activity types were positively skewed. The high number of 0 scores precluded transformation of data; therefore, nonparametric statistics were used. *Post hoc* analyses were performed using the Wilcoxon signed-rank test. The significance level for the Friedman test was

* SPSS Inc, 233 S Wacker Dr, Chicago, IL 60606.

Table 4.

Analysis of Whether the Odds That Children and Youth Who Did Not Do Any Activities With a Friend or Other Non-Family Member (n=50) Differed Based on Age, Sex, and Gross Motor Function Level^a

Variable	OR	95% CI	P
Age (y)			
6-12	1.0		
13-21	0.9	0.5-1.7	.73
Sex			
Male	1.0		
Female	1.2	0.7-2.3	.47
GMFCS level			
I	1.0		
II/III	4.6	1.4-15.8	.02
IV/V	8.2	2.4-27.7	.001

^a OR=adjusted odds ratio, CI=confidence interval, GMFCS=Gross Motor Function Classification System.

$P=.05$ and for the *post hoc* Wilcoxon test was $P=.01$.

Role of the Funding Source

Funding support for this study was provided by Shriners Hospitals for Children (COS #9197).

Results

The results of the logistic regression are presented in Table 4. Among the 50 children and youth who did not do any activities with friends and others, 3 were in level I, 22 were in levels II and III, and 25 were in levels IV and V. The numbers represent 2%, 10%, and 16% of the participants in each group, respectively. The adjusted odds of children and youth not doing any activities with friends and others in the past 4 months differed for gross motor function level but not age or sex. Compared with children and youth in level I, children and youth in levels IV and V were 8.2 times ($P=.001$) more likely to not do any activities with friends and others and children and youth in levels II and III were 4.6 times ($P=.02$) more likely to not do any activities with friends and others.

Effect of Age, Sex, and Gross Motor Function Level

Descriptive statistics for the CAPE are presented in Table 5. The mean number of activities done by the entire sample was 23.7; on average, children and youth did 43% of the 55 activities on the CAPE. The mean number of activities done varied from a low of 18.5 (34%) for youth in levels IV and V to a high of 27.9 (51%) for children in level I.

The results of the ANOVAs are presented in Table 6. The mean percentage of activities done with friends and others differed based on age and gross motor function level. The effect of sex and the interaction effects were not significant. Youth did a higher percentage of activities with friends and others (30.3%) than children (20.2%, $P<.001$). Children and youth in level I did a higher percentage of activities with friends and others (29.8%) compared with children and youth in levels II and III (22.9%, $P<.001$) and in levels IV and V (21.5%, $P<.001$).

The mean percentage of activities done outside the home differed by

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Table 5.

Mean Number of Activities Done (Diversity Score) and the Mean Percentage of Activities Done With Friends and Others and Outside the Home for Children and Youth With Cerebral Palsy Grouped by Age and Gross Motor Function Level (Gross Motor Function Classification System [GMFCS])

	GMFCS Level	6-12 y			13-21 y			Total		
		n	Mean	SD	n	Mean	SD	n	Mean	SD
No. of activities done (n=500)	I	74	27.9	6.2	54	24.5	7.3	128	26.5	6.9
	II/III	130	25.0	6.2	90	23.2	6.4	220	24.3	6.4
	IV/V	87	21.8	7.5	65	18.5	6.9	152	20.4	7.4
	Total	291	24.8	7.0	209	22.1	7.2	500	23.7	7.2
% activities done with friends and others (n=450)	I	71	25.2%	12.5%	54	35.8%	19.7%	125	29.8%	16.8%
	II/III	118	19.1%	11.5%	80	28.5%	17.2%	198	22.9%	14.8%
	IV/V	72	17.0%	10.5%	55	27.3%	15.2%	127	21.5%	13.7%
	Total	261	20.2%	11.9%	189	30.3%	17.7%	450	24.4%	15.4%
% activities done outside the home (n=497)	I	74	40.3%	10.9%	54	45.5%	14.5%	128	42.5%	12.8%
	II/III	130	34.2%	11.9%	89	36.8%	13.5%	219	35.2%	12.6%
	IV/V	86	35.6%	11.2%	64	44.8%	16.9%	150	39.5%	14.6%
	Total	290	36.1%	11.7%	207	41.5%	15.4%	497	38.4%	13.6%

age and gross motor function. The effect of sex and the interaction effects were not significant. Youth did a higher percentage of activities outside the home (41.5%) than children (36.1%, $P < .001$). Children and youth in level I (42.5%) and in levels IV and V (39.5%) did a higher percentage of activities outside the

home compared with children and youth in levels II and III (35.2%, $P < .001$). The difference in the percentage of activities done outside the home between children and youth in level I and in levels IV and V was not significant ($P > .01$).

Effect of Activity Type

The mean number of activities that were done and percentages of activities done with friends and others and outside the home for each activity type are presented in Table 7. On average, children and youth participated in 67.7% of social activities, 63.3% of recreational activities, and 46.9% of self-improvement activities. There was only 21% of physical and 19% of skill-based participation by children and youth for related activities.

The percentage of activities done with friends and others differed by activity type ($\chi^2 = 190.4$, $df = 4$, $P < .001$). *Post hoc* analysis indicated that the percentage of activities done with friends and others was highest for physical (37.1%) and skill-based (34.9%) activities, followed by social activities (23.5%), and was lowest for self-improvement (16.0%) and recreational (14.8%) activities ($P < .01$).

The percentage of activities done outside the home differed by activity type ($\chi^2 = 319.8$, $df = 4$, $P < .001$). The mean percentage of activities done outside the home was highest for

Table 6.

Three-Way Analyses of Variance: Effect of Age, Sex, and Gross Motor Function Level (Gross Motor Function Classification System [GMFCS]) on the Mean Percentage of Activities Done With Friends and Others and Outside the Home by Children and Youth With Cerebral Palsy

Main Effects/Interactions	% Activities Performed With Friends and Others (n=450)		% Activities Performed Outside the Home (n=497)	
	F ^a	Paired Comparisons	F ^b	Paired Comparisons
Age	35.65 ^c	6-12 y < 13-21 y ^c	22.80 ^c	6-12 y < 13-21 y ^c
Sex	0.02		0.79	
GMFCS level	9.05 ^c	I > II/III ^c I > IV/V ^c	12.84 ^c	I > II/III ^c IV/V > II/III ^d
Age × sex	0.00		1.84	
Age × GMFCS level	0.74		2.84	
Sex × GMFCS level	0.64		2.35	
Age × sex × GMFCS level	0.58		0.60	

^a $df = 1,438$ for age; $df = 2,438$ for GMFCS level.

^b $df = 1,485$ for age; $df = 2,485$ for GMFCS level.

^c $P < .001$.

^d $P < .01$.

Table 7.

Mean Number of Activities Done (Diversity Score) and Mean Percentage of Activities Done With Friends and Others and Outside the Home by Children and Youth With Cerebral Palsy for Each Activity Type

	Recreational (12 Items)		Physical (13 Items)		Social (10 Items)		Skill-Based (10 Items)		Self- Improvement (10 Items)	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
No. of activities done (n=500)	7.6	2.6	2.7	2.1	6.8	1.9	1.9	1.4	4.7	2.0
% activities done (n=500)	63.3%	21.3%	20.7%	16.2%	67.7%	19.2%	19.2%	14.4%	46.9%	19.9%
% activities done with friends and others (n=450)	14.8%	17.6%	37.1%	36.9%	28.3%	23.5%	34.9%	37.9%	16.0%	19.0%
% activities done outside the home (n=497)	20.0%	16.1%	48.3%	39.5%	40.1%	19.4%	45.4%	40.4%	47.8%	21.9%

physical (48.3%), self-improvement (47.8%), and skill-based (45.4%) activities, followed by social activities (40.1%), and was lowest for recreational activities (20.0%) ($P < .01$).

Discussion

Children and youth with CP differed in social and community participation based on gross motor function level and age, but not sex. For the entire sample, social and community participation were highest for physical and skill-based activities and lowest for recreational activities. Several limitations should be considered when interpreting the results. The operational definitions reflect the content and construct of the CAPE and, consequently, do not encompass all aspects of social and community participation. In particular, we did not address social engagement, the nature of relationships, and involvement with friends and other non-family members while doing an activity.³⁸ The activities analyzed were limited to the 55 items on the CAPE. The CAPE was completed by parent proxy for 59.2% of the children and youth in levels IV and V, indicating that they were more likely to have problems in communication, cognition, or both. Consequently, differences in social and community participation cannot be attributed

only to gross motor function level. Although the sample was large and there was a wide geographical distribution, we do not know the extent that the participants are representative of children and youth with CP.

Children and youth with CP who walk without restrictions (level I) did the highest percentage of activities with friends and other non-family members. Children and youth in level I have the ability to run and jump, which may enable social participation in physical activities and sports. Conversely, children and youth who do not walk (levels IV and V) were more likely not to have done any activities with friends and others in the past 4 months. A relationship between mobility and social participation has been documented for children and youth with CP; however, mediating factors are not well understood.³⁹ Reduced speed, endurance, and efficiency of walking may limit the ability of children and youth in levels II and III to keep up with peers, especially outdoors and in the community.

The finding that children and youth in levels IV and V did a percentage of activities outside the home similar to that of children and youth in level I is encouraging and may reflect a con-

certed effort by family members. Previously, Palisano et al⁴⁰ reported that parents of children and youth in levels IV and V were more likely to express a need for help in locating camps and sports, recreational, social, and leisure activities than parents of children and youth in level I and levels II and III. In a qualitative study of 15 families, parents were characterized as making extraordinary efforts to promote a social life for their adolescent with a disability. Almost all parents enrolled their adolescent in recreational activities, often those especially for young people with disabilities.⁴¹ Transportation to accommodate a wheelchair, attending the activity to assist their child, instruction of others on accommodations, and activity modifications are resources family members may need to enable their children's participation when they require physical assistance for mobility and self-care.

The mean percentage of activities done outside the house by the child and youth in our study varied from 35.2% to 42.5%. Mactavish et al⁴² analyzed family recreation patterns of 65 families who have a child with a disability. Sixty percent of parents reported that family recreation occurred with equal frequency at home

and in the community, 29% reported that most family recreation took place at home, and 11% reported that most family recreation occurred in the community. In comparison, Orthner and Mancini⁴³ reported that among families of children without disabilities, family recreation occurred most often at home and less frequently in the neighborhood and community.

The findings that youth did a higher percentage of activities with friends and others and outside the home than children are consistent with life span development. Forming new and more mature relationships with peers of both sexes is an accomplishment that characterizes adolescence.⁴⁴ At first glance, the results appear to contradict studies in which participation was lower in youth than in children.^{18-20,26} We previously reported that among the participants in the present study, children had a higher diversity and intensity of participation than youth.³⁷ The aim of the present study, however, was not to quantify age-related differences in how many and how often activities were done. Rather, we were interested in the percentage of activities that were done with friends and others and outside the home. Time did not permit asking participants to complete the Preferences for Activities of Children (PAC),³² a companion measure to the CAPE. Consequently, the extent that the activities done in the past 4 months reflect what the children and youth would have preferred to do is not known.

Females and males did not differ in social and community participation. Our results do not corroborate differences reported between females and males with and without disabilities.²²⁻²⁵ Similar to the results for age, the discrepancy may reflect the aims of our study. Our primary interest was to quantify whether females

and males differed in the percentage of activities done with friends and others and outside the home rather than differences in the types of activities done by females and males. Comparison of scores for domains, activity types, and items on the CAPE would provide a more in-depth analysis of differences between males and females.

Although not an aim of the study or analyzed statistically, descriptive data for activity types suggest that for children and youth with CP, the number of activities done is not an indicator of social and community participation. Children and youth did the highest percentage of physical and skill-based activities with friends and others and outside the home, activity types where they did only 20.7% and 19.2% of the activities. Conversely, although the participants did 63.3% of recreational activities and 67.7% of social activities, they were more likely to do these activities by themselves, with members of their family, and at home. Many recreational activities on the CAPE, such as playing computer or video games, are well suited to do alone. Social activities such as going to a party or movie may be done with family members and relatives. Given the descriptive data, we caution against assumptions about activity types where social and community participation should be encouraged.

Implications for Physical Therapy

Self-sufficient mobility, or getting from place to place without relying on other people, is desirable for social and community participation. Children and youth with CP who walk without restrictions and perform gross motor tasks such as running and jumping did more activities with friends and others. Children and youth who are able to run and jump may benefit from instruction and practice of physical activities

and sports that they are interested in performing. Most children with CP, however, do not walk without restrictions.⁴⁵ For children and youth who are capable of walking with limitations (levels II and III), an issue is whether physical therapy interventions to improve walking and gross motor function generalize to social and community participation.

Powered mobility is an option for self-sufficient mobility for children and youth with CP who are unable to walk or when walking is not effective for social and community participation. Parents of children with disabilities, however, identified environmental barriers that restrict use of powered mobility, including the size of rooms, availability of transportation to accommodate a wheelchair, and durability of the wheelchair when used outdoors.⁴⁶ Mobility also includes transporting oneself via riding a bicycle, driving a car, or using transportation to move around as a passenger in a bus.⁶ Youth with physical disabilities have consistently indicated that the lack of accessible and reliable transportation is an obstacle to participation.^{30,39,46} Notable from the perspective of youth who use wheelchair-accessible public transportation is the inability to go places and do things in a spontaneous manner that is typical of socialization among youth.⁴⁷ Collectively, the findings support a team approach to selection of assistive technology and the importance of problem solving to minimize barriers to powered mobility and other means of transportation.

Physical therapists are encouraged to provide services to children and youth with CP in a manner that promotes social self-efficacy. This approach includes involving children and youth in identifying priorities for social and community participation, making choices, and participating in real-world experiences. We ad-

vocate for strength-based ecological and experiential approaches to learning that build on the abilities and interests of children and youth. Ecological and experiential approaches are based on the principle that real-world experiences optimize the development of life skills such as self-knowledge, communication, interpersonal relationships, problem solving, and daily living and work skills.^{48,49}

Physical therapists have an important role as consultants in supporting social and community participation of children and youth with CP. Strategies include linking children, youth, and families to community supports, enhancing knowledge of community opportunities, and creating individualized opportunities and experiences. Information about community programs is a common need expressed by families.^{40,50-52} Limited knowledge of community programs has been associated with fewer opportunities for participation.⁵³ Therapists are encouraged to share information about leisure, recreational, and social activities, sports programs, and camps with children, youth, and families. Direct consultation with educators, instructors, and coaches is recommended to address issues related to accessibility, activity accommodations, and assistive technology. Social and community participation involves interaction of the person and environment. Observation of a child or youth during a community activity enables the therapist to evaluate physical, social, and attitudinal features that facilitate or restrict participation.

Physical therapists have a role as advocates for environments that enable social participation of children and youth with CP. Advocacy might involve providing educational materials to the community, serving on an advisory board of an agency or organization, and meeting with local and

state policymakers. Whiteneck et al⁵⁴ proposed that accessibility, accommodation, resource availability, social support, and equality are characteristics of environments that foster social participation of people with disabilities. Their perspective is supported by parents of young children with physical disabilities who encouraged service providers to change the environment, not the child.⁵⁵

Further research is recommended to understand personal and environmental factors that are determinants of social and community participation of children and youth with CP. Participation is a multidimensional construct involving personal experiences.^{56,57} Mixed-methods designs⁵⁸ involving quantitative and qualitative methods are well suited for this area of inquiry. We perceive successful social participation as physical, social, and psychological engagement in an activity that is enjoyable and that promotes self-efficacy. Research is needed to identify factors that facilitate social and community participation desired by children and youth with CP.

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