

Participation in home, extracurricular, and community activities among children and young people with cerebral palsy

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AIM Participation in home, extracurricular, and community activities is a desired outcome of rehabilitation services for children and young people with cerebral palsy (CP). The purpose of this study was to investigate the effect of age and gross motor function on participation among children and young people with CP.

METHOD Five hundred participants (277 males, 223 females) were grouped by age and Gross Motor Function Classification System (GMFCS) level. There were 291 children aged 6 to 12 years and 209 young people aged 13 to 21 years. There were 128 participants in GMFCS level I, 220 in levels II/III, and 152 in levels IV/V. Participants completed the Children's Assessment of Participation and Enjoyment to measure number of activities (diversity) and how often they were performed (intensity) in the past 4 months.

RESULTS Children had higher overall participation diversity and intensity than young people ($p < 0.001$). Children and young people in GMFCS level I had the highest overall participation, followed by children and young people in levels II/III and IV/V. Children had higher participation in recreational ($p < 0.001$) but not formal (such as team sports or clubs) or physical activities. Children ($p < 0.01$) and young people ($p < 0.001$) in level I had the highest participation in physical activities; diversity and intensity were generally low.

INTERPRETATION The findings provide evidence of the effect of age and gross motor function on participation of children and young people with CP. Low participation in physical activities may have implications for fitness and health, especially for children and young people in GMFCS levels IV and V.

Participation is the context in which children develop skills and competences, experience socialization, and foster initiative and self-efficacy.^{1,2} Participation is defined in the International Classification of Functioning, Disability and Health as 'involvement in life situations'.³ For people with disabilities, meaningful and intrinsically motivated leisure activities foster mental and physical health benefits, provide opportunities for social relationships, and may improve quality of life.⁴ Successful participation in daily activities, therefore, is considered an optimal outcome of pediatric rehabilitation services.⁵

Differences in participation have been reported between children with and without physical disabilities. Children with physical disabilities often demonstrate more passive patterns of activity and are more likely to experience social isolation and loneliness.^{6,7} Children with physical disabilities participate in less diverse leisure activities that take place more at home, spend more time on quiet activities, and are involved in fewer social and physical activities.⁷ Imms et al.⁸ compared children

aged 10 to 12 years of age with and without cerebral palsy (CP) and found those with CP had higher participation in arts and crafts and playing electronic games. Adolescents with CP preferred less structured and less intense physical activities than peers without disabilities.⁹

Age and gross motor function influence both intensity and type of participation of children and young people with physical disabilities.^{10,11} Among 427 children and adolescents aged 6 to 15 years with physical disabilities, the number of leisure activities and how often activities were performed were lower in adolescents aged 12 years or older and differed according to type of activity.^{10,11} Compared with children, young people participated less in recreational and more in social activities.¹⁰

A positive relationship has been reported between gross motor function and participation in daily activities.¹²⁻¹⁴ Among children with physical disabilities, functional ability was identified as a predictor of intensity of participation in formal (involving rules, a coach, or instructor) and informal

(involving little or no planning, and often child-initiated) leisure activities.¹⁵ Among adolescents with CP, younger age and higher gross motor function are associated with increased physical activity.⁹

The purpose of this study was to investigate the effect of age and gross motor function on participation in home, extra-curricular, and community activities among children and young people with CP. We were interested in identifying differences in diversity and intensity of participation between children of 6 to 12 years of age and young people aged 13 to 21 years, grouped by Gross Motor Function Classification System (GMFCS) level.¹⁶ We hypothesized that: (1) children would have a higher diversity and intensity of participation in formal, physical, and recreational activities; (2) young people would have a higher diversity and intensity of participation in informal and social activities; (3) children who walked in all environmental settings (level I) would have the highest overall diversity and intensity of participation; and (4) young people with limited self-mobility (levels IV and V) would have the lowest overall diversity and intensity of participation.

METHOD

Participants

A sample of convenience was recruited from six Shriners Hospitals for Children (Chicago, IL; Erie, PA; Lexington, KY; Sacramento, CA; Philadelphia, PA; and Springfield, MA, USA) and the Kluge Children's Rehabilitation Center, Charlottesville, VA, USA. All children with CP receiving services were eligible if they did not have a concomitant illness or health condition that might affect participation. Ethical approval was provided by the institutional review board of each institution. Parents or guardians, and young people aged 18 to 21 years old, provided consent; children and adolescents 7 to 17 years old provided informed assent.

The sample included 500 children and young people (277 males, 223 females) with a diagnosis of CP. Two hundred and ninety-one children were aged between 6 and 12 years (mean age 9y 8mo, SD 2y) and 209 young people were between 13 and 21 years old (mean age 16y 2mo, SD 2y 3mo). The number of participants in each GMFCS level varied from 71 to 128. The characteristics of the participants are described in Table I.

Measures

Gross Motor Functional Classification System

The GMFCS¹⁶ is a five-level system for children with CP aged up to 12 years. A classification is made on current performance of gross motor function in daily activities, emphasizing mobility and sitting. The preliminary version of the 12- to 18-year-old age band of the expanded and revised GMFCS was used to classify all participants over 12 years of age.¹⁷ The GMFCS has evidence of content, construct, discriminative validity, and interrater reliability.¹⁶

Children's Assessment of Participation and Enjoyment

The Children's Assessment of Participation and Enjoyment (CAPE)¹⁸ measures participation in leisure activities exclusive

of the mandated school curriculum during the past 4 months in children and young people aged 6 to 21 years. The CAPE includes 55 activities and is completed as a questionnaire or by interview. Each activity is categorized by domain (Formal, Informal) and type (Recreational, Physical, Social, Skill-Based, Self-Improvement; Table II). The child is asked whether an activity was performed during the past 4 months, and for each activity performed, how often, with whom, where, and the level of enjoyment.

The diversity score is calculated by adding the number of activities performed. The seven response options for how often an activity was performed range from one time in the past 4 months to one time a day or more. The intensity score is calculated by adding the 'how often' scores and dividing by the total number of possible activities. The resulting intensity score varies from 0 to 7. Evidence of internal consistency, test-retest reliability, content validity, construct validity, and convergent and discriminate validity of the CAPE has been reported.¹⁸

After consultation with the CAPE authors, guidelines were developed for parent assistance in recall of the number of times an activity was performed in the past 4 months, where, and with whom. To assist young children with the 4-month period, specific events that occurred 4 months ago were provided as a reference. Permission was obtained from the publisher to display the picture card for each of the 55 activities on a laptop computer and record responses electronically.

Procedure

A cross-sectional analytical design was used. At each hospital, data were collected by between one and three research assistants. Most research assistants were health professionals experienced in providing services to children and families with CP. Before data collection, the research assistants received a procedural manual and attended a 2-day workshop to learn the procedures. After instruction in the GMFCS, interrater reliability was examined using a criterion videotape. Each assessor classified a minimum of 11 children and demonstrated a percentage agreement of greater than 80%. To ensure data fidelity, tele-

Table I: Characteristics of children and adolescents with CP (n=500)

| Characteristic | 6-12y (n=291) | 13-21y (n=209) |
|--------------------------|---------------|----------------|
| Mean age, y:mo (SD) | 9:8 (2:0) | 16:2 (2:3) |
| GMFCS level, n (%) | | |
| I | 74 (25) | 54 (26) |
| II/III | 69/61 (24/21) | 57/33 (27/16) |
| IV/V | 45/42 (16/14) | 26/39 (12/19) |
| Sex, n (%) | | |
| Male | 169 (58) | 108 (52) |
| Female | 122 (42) | 101 (48) |
| Ethnic background, n (%) | | |
| Caucasian | 231 (79) | 142 (68) |
| African-American | 19 (7) | 21 (10) |
| Hispanic/Latino | 21 (7) | 21 (10) |
| Other | 20 (7) | 25 (12) |

CP, cerebral palsy; GMFCS, Gross Motor Function Classification System.

Table II: Examples of the Children's Assessment of Participation and Enjoyment domain and activity type items

| Types | Formal domain (15 items) | Informal domain (40 items) |
|-----------------------------|---|--|
| Recreational (12 items) | | Playing board or card games Doing crafts, drawing or coloring Playing computer or video games Bicycling, in-line skating or skateboarding |
| Physical (13 items) | Doing martial arts Racing or track and field Doing team sports Participating in school clubs | Doing water sports Playing nonteam sports Hanging out Going to a party Going on a full-day outing Dancing |
| Social (10 items) | | |
| Skill-based (10 items) | Swimming Taking art (or music) lessons Participating in community organizations | |
| Self-improvement (10 items) | Doing a religious activities | Reading Going to the public library Doing a chore Doing volunteer work |

conferences were scheduled at 3-month intervals and a second workshop was held at the midpoint of data collection.

The CAPE was completed by interviewing the child using either the custom-designed computer display or the picture cards and coding sheets that are typically used. Parent assistance or parent proxy was allowed as needed. Assistance was provided to children or parents who had difficulty with reading or marking responses. Two hundred and nine (42%) children and young people completed the CAPE without parental assistance, 147 (29%) received parental assistance, and the CAPE was completed by parent proxy for 144 (29%) children and young people.

Data analysis

Participants were grouped by age (6–12y and 13–21y) and GMFCS level (I, II/III, and IV/V). The decision to combine levels II/III and IV/V was based on the results of a study of performance of physical activities by children and young people with CP.¹⁹ Children and young people in level I had the highest performance, whereas performance of physical activities by children and young people in levels II/III and IV/V approximated each other.

Statistical analyses were performed using the SPSS for Windows software program, version 15.0 (SPSS, Chicago, IL, USA). Descriptive statistics for diversity and intensity of participation were computed, including the percentage of activities performed. All data were examined for distribution shape. For variables with symmetrical distributions, two-way analyses of variance (ANOVAs) were used to examine the effect of age and GMFCS level on overall participation and for each activity domain and type. For variables with asymmetrical distributions, median tests were used. Data screening indicated that both diversity and intensity distributions for Formal domain activities and for Physical and Skill-based activity types were asymmetrical.

Diversity and intensity scores were analyzed separately. For overall participation, a probability of $p \leq 0.05$ was used for statistical significance. For activity domains and types, a probability

of $p \leq 0.01$ was used for statistical significance. For the results of the ANOVAs, two-sided post-hoc analysis of significant effects was performed using Tukey's method for multiple comparisons. The criterion used for significance for the multiple comparison tests was $p \leq 0.01$.

RESULTS

Mean and median scores for those variables with skewed distributions for participation diversity and intensity are reported in Tables III and IV. Among children (6–12y) with CP, 23 (8%) did not perform any activities in the Formal domain, 34 (12%) did not perform any Physical activities, 35 (12%) did not perform any Skill-based activities, and five (2%) did not perform any Self-improvement activities. Among young people with CP, 24 (12%) did not perform any activities in the Formal domain, 30 (14%) did not perform any Physical activities, 46 (22%) did not perform any Skill-based activities, and one (0.5%) did not perform any Self-improvement activities.

A summary of the significant effects of age and GMFCS level on participation is presented in Table V. Variables tested using the median test are indicated. The interaction effects were not significant; therefore, only significant main effects and post-hoc analyses are reported. For overall participation, the effects of age and GMFCS level were significant. Children had higher mean scores for diversity ($p < 0.001$) and intensity ($p < 0.001$) than young people. Children and young people in level I had the highest mean scores, followed by children and young people in levels II/III, followed by those in levels IV/V.

Activity domain

For the formal domain, children and young people in level I had higher median scores for diversity ($p < 0.01$) and intensity ($p < 0.001$) than those in levels II/III and levels IV/V ($p < 0.001$). Children and young people in levels II/III had higher scores than those in levels IV/V for both diversity ($p < 0.01$) and intensity ($p < 0.01$). For the Informal domain, the effect of age and GMFCS level were significant. Children had higher mean scores for diversity ($p < 0.001$) and intensity ($p < 0.001$) than

Table III: Children's Assessment of Participation and Enjoyment diversity scores for children and adolescents with CP (*n*=500)

| Activity domain/type | GMFCS level | 6–12y | | | | 13–21y | | | |
|-----------------------------|-------------|----------|----------------------------|----------------|-------|----------|----------------------------|----------------|-------|
| | | <i>n</i> | Mean (SD) | % ^a | Range | <i>n</i> | Mean (SD) | % ^a | Range |
| Overall (55 items) | I | 74 | 27.9 (6.2) | 51 | 14–40 | 54 | 24.5 (7.3) | 45 | 7–40 |
| | II/III | 130 | 25.0 (6.2) | 46 | 12–41 | 90 | 23.2 (6.4) | 42 | 11–39 |
| | IV/V | 87 | 21.8 (7.5) | 40 | 7–41 | 65 | 18.5 (7.0) | 34 | 4–33 |
| Formal (15 items) | I | 74 | 3.6 (2.0) 3.0 ^b | 24 | 0–9 | 54 | 3.1 (2.1) 3.0 ^b | 20 | 0–9 |
| | II/III | 130 | 2.7 (1.6) 3.0 ^b | 18 | 0–7 | 90 | 2.4 (1.7) 2.0 ^b | 16 | 0–8 |
| | IV/V | 87 | 2.2 (2.0) 2.0 ^b | 15 | 0–12 | 65 | 2.0 (1.6) 2.0 ^b | 13 | 0–6 |
| Informal (40 items) | I | 74 | 24.3 (5.1) | 61 | 13–35 | 54 | 21.5 (5.8) | 54 | 7–34 |
| | II/III | 130 | 22.3 (5.4) | 56 | 10–36 | 90 | 20.8 (5.3) | 52 | 10–33 |
| | IV/V | 87 | 19.6 (6.4) | 50 | 6–35 | 65 | 16.6 (6.0) | 41 | 4–29 |
| Recreational (12 items) | I | 74 | 9.2 (2.0) | 77 | 4–12 | 54 | 6.6 (2.5) | 55 | 1–12 |
| | II/III | 130 | 8.6 (2.2) | 72 | 3–12 | 90 | 7.0 (2.0) | 59 | 2–12 |
| | IV/V | 87 | 7.4 (2.7) | 61 | 2–12 | 65 | 5.6 (2.4) | 47 | 1–10 |
| Physical (13 items) | I | 74 | 3.6 (2.2) 3.5 ^b | 28 | 0–10 | 54 | 3.6 (2.4) 3.0 ^b | 28 | 0–10 |
| | II/III | 130 | 2.8 (2.0) 3.0 ^b | 21 | 0–8 | 90 | 2.6 (2.0) 2.0 ^b | 20 | 0–11 |
| | IV/V | 87 | 2.1 (1.8) 2.0 ^b | 16 | 0–7 | 65 | 1.6 (1.6) 1.0 ^b | 12 | 0–6 |
| Social (10 items) | I | 74 | 7.0 (2.0) | 70 | 2–10 | 54 | 7.1 (1.7) | 71 | 4–10 |
| | II/III | 130 | 6.7 (2.0) | 67 | 1–10 | 90 | 7.0 (1.8) | 70 | 3–10 |
| | IV/V | 87 | 6.7 (1.8) | 66 | 2–10 | 65 | 6.2 (2.2) | 62 | 1–10 |
| Skill-based (10 items) | I | 74 | 2.4 (1.5) 2.0 ^b | 24 | 0–7 | 54 | 2.0 (1.6) 2.0 ^b | 20 | 0–6 |
| | II/III | 130 | 2.0 (1.2) 2.0 ^b | 20 | 0–5 | 90 | 1.7 (1.4) 1.0 ^b | 17 | 0–6 |
| | IV/V | 87 | 1.9 (1.6) 2.0 ^b | 19 | 0–8 | 65 | 1.5 (1.3) 1.0 ^b | 15 | 0–5 |
| Self-improvement (10 items) | I | 74 | 5.7 (1.8) | 57 | 0–10 | 54 | 5.1 (1.8) | 51 | 2–9 |
| | II/III | 130 | 4.9 (1.7) | 49 | 1–9 | 90 | 4.9 (2.1) | 49 | 1–10 |
| | IV/V | 87 | 3.8 (2.0) | 38 | 0–8 | 65 | 3.7 (1.8) | 37 | 1–8 |

^aPercentage of total activities performed. ^bMedian scores. CP, cerebral palsy; GMFCS, Gross Motor Function Classification System.

Table IV: Children's Assessment of Participation and Enjoyment intensity scores for children and adolescents with CP (*n*=500)

| Activity domain/type | GMFCS level | 6–12y | | | 13–21y | | |
|-----------------------------|-------------|----------|----------------------------|---------|----------|----------------------------|---------|
| | | <i>n</i> | Mean (SD) | Range | <i>n</i> | Mean (SD) | Range |
| Overall (55 items) | I | 74 | 2.5 (0.6) | 1.3–3.9 | 54 | 2.2 (0.7) | 0.7–3.7 |
| | II/III | 130 | 2.2 (0.6) | 0.9–3.8 | 90 | 2.0 (0.6) | 1.0–3.8 |
| | IV/V | 87 | 2.0 (0.7) | 0.5–3.5 | 65 | 1.6 (0.6) | 0.4–2.9 |
| Formal (15 items) | I | 74 | 1.1 (0.7) 0.9 ^a | 0.0–2.7 | 54 | 1.0 (0.7) 0.9 ^a | 0.0–2.7 |
| | II/III | 130 | 0.8 (0.5) 0.7 ^a | 0.0–2.1 | 90 | 0.7 (0.6) 0.7 ^a | 0.0–3.3 |
| | IV/V | 87 | 0.7 (0.6) 0.4 ^a | 0.0–3.2 | 65 | 0.6 (0.5) 0.5 ^a | 0.0–2.1 |
| Informal (40 items) | I | 74 | 3.0 (0.7) | 1.7–4.8 | 54 | 2.6 (0.8) | 0.9–4.3 |
| | II/III | 130 | 2.7 (0.7) | 1.2–4.4 | 90 | 2.5 (0.7) | 1.3–4.3 |
| | IV/V | 87 | 2.4 (0.8) | 0.5–4.3 | 65 | 2.0 (0.8) | 0.5–3.9 |
| Recreational (12 items) | I | 74 | 4.2 (1.0) | 1.3–6.0 | 54 | 2.8 (1.1) | 0.6–5.0 |
| | II/III | 130 | 4.0 (1.2) | 1.3–6.2 | 90 | 3.1 (1.1) | 1.1–5.9 |
| | IV/V | 87 | 3.4 (1.3) | 0.8–6.8 | 65 | 2.5 (1.2) | 0.5–4.3 |
| Physical (13 items) | I | 74 | 1.3 (0.8) 1.4 ^a | 0.0–3.8 | 54 | 1.3 (1.0) 1.0 ^a | 0.0–3.9 |
| | II/III | 130 | 0.9 (0.7) 0.8 ^a | 0.0–2.6 | 90 | 0.8 (0.7) 0.6 ^a | 0.0–3.5 |
| | IV/V | 87 | 0.7 (0.6) 0.6 ^a | 0.0–2.5 | 65 | 0.5 (0.5) 0.5 ^a | 0.0–2.2 |
| Social (10 items) | I | 74 | 3.1 (1.0) | 0.6–5.2 | 54 | 3.3 (1.0) | 1.4–5.5 |
| | II/III | 130 | 2.8 (1.0) | 0.7–5.1 | 90 | 3.1 (0.9) | 0.9–5.0 |
| | IV/V | 87 | 2.8 (0.8) | 0.8–4.6 | 65 | 2.7 (1.0) | 0.7–5.5 |
| Skill-based (10 items) | I | 74 | 1.1 (0.8) 1.1 ^a | 0.0–3.5 | 54 | 1.0 (0.8) 0.7 ^a | 0.0–3.1 |
| | II/III | 130 | 0.9 (0.6) 0.8 ^a | 0.0–2.7 | 90 | 0.7 (0.7) 0.6 ^a | 0.0–2.9 |
| | IV/V | 87 | 0.9 (0.8) 0.8 ^a | 0.0–4.8 | 65 | 0.7 (0.6) 0.6 ^a | 0.0–2.3 |
| Self-improvement (10 items) | I | 74 | 2.9 (0.9) | 0.0–5.0 | 54 | 2.7 (1.0) | 0.5–5.7 |
| | II/III | 130 | 2.5 (0.9) | 0.4–5.1 | 90 | 2.5 (1.2) | 0.2–5.4 |
| | IV/V | 87 | 1.9 (1.0) | 0.0–4.1 | 65 | 1.8 (0.9) | 0.4–4.2 |

^aMedian scores. CP, cerebral palsy; GMFCS, Gross Motor Function Classification System.

young people. Children and young people in level I and levels II/III had higher mean scores for diversity ($p<0.001$) and intensity ($p<0.001$) in Informal domain activities than those in levels IV/V.

Activity type

For Recreational activities, the effects of age and GMFCS level were significant. Children had higher mean scores for diversity ($p<0.001$) and intensity ($p<0.001$) than young people.

Table V: Effect of age and GMFCS level on participation of children and adolescents with CP (*n*=500)

| | Diversity | | | Intensity | | |
|------------------|-------------|---------------------|---------------------|-------------|---------------------|---------------------|
| | Main effect | Post hoc | | Main effect | Post hoc | |
| | | Group | <i>p</i> | | Group | <i>p</i> |
| Overall | Age | 6–12y>13–21y | <0.001 | Age | 6–12y>13–21y | <0.001 |
| | GMFCS | I>II and III | <0.01 | GMFCS | I>II and III | 0.001 |
| | | I>IV and V | <0.001 | | I>IV and V | <0.001 |
| | | II and III>IV and V | <0.001 | | II and III>IV and V | <0.001 |
| Domain | | | | | | |
| Formal | GMFCS | I>II and III | <0.01 ^a | GMFCS | I>II and III | <0.001 ^a |
| | | I>IV and V | <0.001 ^a | | I>IV and V | <0.001 ^a |
| | | II and III>IV and V | <0.01 ^a | | II and III>IV and V | <0.01 ^a |
| Informal | Age | 6–12y>13–21y | <0.001 | Age | 6–12y>13–21y | <0.001 |
| | GMFCS | I>IV and V | <0.001 | GMFCS | I>IV and V | <0.001 |
| | | II and III>IV and V | <0.001 | | II and III>IV and V | <0.001 |
| Activity types | | | | | | |
| Recreational | Age | 6–12y>13–21y | <0.001 | Age | 6–12y>13–21y | <0.001 |
| | GMFCS | I>IV and V | <0.001 | GMFCS | I>IV and V | <0.001 |
| | | II and III>IV and V | <0.001 | | II and III>IV and V | <0.001 |
| Physical | GMFCS | I>II and III | <0.01 ^a | GMFCS | I>II and III | <0.001 ^a |
| | | I>IV and V | <0.001 ^a | | I>IV and V | <0.001 ^a |
| | | II and III>IV and V | <0.001 ^a | | II and III>IV and V | <0.01 ^a |
| Social | | | | GMFCS | I>IV and V | 0.001 |
| Skill-based | Age | 6–12y>13–21y | <0.001 ^a | Age | 6–12y>13–21y | <0.01 ^a |
| | GMFCS | I>IV and V | <0.001 ^a | | | |
| Self-improvement | GMFCS | I>IV and V | <0.001 | GMFCS | I>II and III | <0.01 |
| | | II and III>IV and V | <0.001 | | I>IV and V | <0.001 |
| | | | | | II and III>IV and V | <0.001 |

^aMedian test. GMFCS, Gross Motor Function Classification System; CP, cerebral palsy.

Children and young people in level I and levels II/III had higher mean scores for diversity than those in levels IV/V. For Physical activities, children and young people in level I had higher median scores for diversity ($p<0.01$) and intensity ($p<0.001$) than those at levels II/III, and in diversity ($p<0.001$) and intensity ($p<0.001$) than those at levels IV/V. Children and young people in levels II/III had higher median diversity ($p<0.001$) and intensity ($p<0.01$) than those in levels IV/V. For Social activities, the effect of GMFCS level was significant for intensity. Children and young people in level I had higher mean scores for intensity than those in levels IV/V. For Skill-based activities, children had higher median scores for intensity ($p<0.01$) but not diversity than young people. Children and young people in level I had higher median scores for diversity ($p<0.001$) but not intensity than those in levels IV/V. For Self-improvement activities, the effect of GMFCS level was significant. Children and young people in level I and levels II/III had higher mean scores for diversity and intensity than those in levels IV/V. Children and young people in level I had a higher mean score for intensity of Self-improvement activities than those in levels II/III.

DISCUSSION

Children had higher diversity and intensity of overall participation and, as hypothesized, higher participation in recreational activities than young people. The hypotheses that children would have higher participation in formal and physical activities and that young people would have higher participation in social activities were not supported. The results support the hypothesis that children and young people in level

I have higher diversity and intensity of overall participation than those in levels II/III and IV/V. Children and young people in level I had more intensity and diversity of participation in Formal and Physical activities than those in levels II/III and levels IV/V, and more intensity of Self-improvement activities. The finding that participation was highest among children and young people in level I is consistent with previous findings for performance of physical activities of children and young people (11–17y) with CP.¹⁹

Activity preference is an important consideration when assisting children and young people with CP to find appropriate and personally satisfying activities in which to participate. The higher participation in recreational activities by children may reflect age-related preferences. Some of the recreational activities on the CAPE, such as doing puzzles, pretend or imaginary play, and playing with things or toys, appear more suited for children than young people. Activity preference was reported to predict participation of children with physical disabilities.¹⁵ There was insufficient time to ask children and young people to complete the Preferences for Activities of Children,¹⁸ a companion measure to the CAPE, to identify age-related preferences.

The finding that social participation did not differ between children and young people with CP may reflect the relatively high participation reported by both age groups. We hypothesized that young people with CP would have higher social participation, based on the findings that young people with physical disabilities identified involvement in social and sports activities as priority areas²⁰ and participated more in social activities than younger children with physical disabilities.¹⁰

However, preference for more solitary activities has been reported for young people without disabilities.²¹ The extent to which young people with CP perform desired social activities with friends and other nonfamily members outside the home was not investigated but warrants further study. The choice of whether or not to engage in group or solitary pursuits may not only be dependent on personal preference but also on complex factors beyond the control of children and young people with CP, such as societal, transportation, and accessibility barriers.^{22–24}

The low diversity and intensity of participation in physical activities among the children and young people may have implications for health and fitness, especially for young people in levels IV and V. A decline in physical activity has been reported among young people without physical disabilities.^{25,26} The finding that participation in physical activities did not differ between children and young people with CP may reflect the low participation by both age groups. Children and young people participated on average between 12% and 28% in the physical activities on the CAPE (Table III). Furthermore, 14% of children and 18% of young people reported that they did not perform any of the physical activities during the past 4 months. Our finding that children and young people in levels I to III had higher participation in physical activities than children and young people in levels IV and V is similar to the results of an Australian study in which children with CP in levels I to IV had a higher diversity and intensity in physical activities than children in level V.⁸ Collectively, the findings suggest that the ability to walk and perform motor abilities such as running and jumping may increase opportunities but are not essential for participation in physical activities. Children and young people in levels IV and V who require extensive activity accommodation and the physical assistance of another person appear to be at greatest risk for secondary impairments associated with a lack of physical activity.

The CAPE provides a valuable ‘snapshot’ of participation in home, extracurricular, and community activities; however, diversity and intensity scores should be interpreted carefully based on how they are scored and calculated. Higher diversity and intensity of overall participation are not necessarily desired outcomes of intervention for individuals with CP. Participation in one or two new activities, or increased frequency of participation in one or two activities, is likely to result in only a small change in score on the CAPE. If, however, these activities are important to the child, this may have a large impact on their quality of life. The method used to calculate

intensity of participation does not differentiate between the number of activities performed and how often each activity is performed. The same intensity score may be obtained through frequent participation in a few activities or infrequent participation in many activities. When using the CAPE in clinical practice, it may be useful to examine both diversity and intensity scores to obtain a more complete picture of the individual’s participation.

The limitations of the study are important considerations when interpreting the results. Participants were selected from seven children’s hospitals across the USA; however, they are a sample of convenience which may not be representative of the population of children and young people with CP. Participation is a multidimensional construct involving physical, social, and psychological aspects. We only reported the activities that children and young people with CP did over a 4-month period and how often they participated. A mixed method approach is recommended for future research. Synthesis of data from standardized measures and in-depth interviews would provide insights into the experiences of children and young people with CP, which was not possible in our study.

The results have implications for services, interventions, and supports for children and young people with CP that optimize participation. Health professionals such as physical therapists are encouraged to involve children and young people actively in planning and sustaining regular physical activity. Therapists have a role in sharing information on community programs and coordination of services with community organizations. Therapists can problem-solve with children, young people, and families to identify solutions for barriers to participation. This might involve consultation with educators, instructors, and coaches on activity accommodations and environmental modifications that enable participation in recreation and sports activities. A desired outcome is the ability of children and young people with CP to derive similar benefits from participation as their peers who do not have disabilities.

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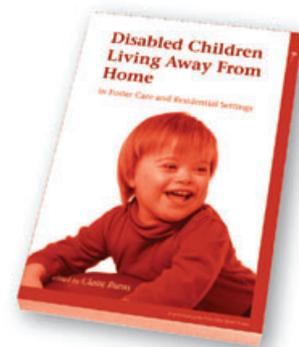
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