How Does Participation of Youth With Spina Bifida Vary by Age?

Erin H. Kelly PhD, Haluk Altıok MD,
Julie A. Gorzkowski MSW, LSW, Jennifer R. Abrams MSW, LSW,
Lawrence C. Vogel MD

Published online: 30 November 2010
© The Association of Bone and Joint Surgeons® 2010

Abstract

Background Youth with disabilities are at risk for decreased participation in community activities. However, little is known about participation at different developmental periods of childhood and adolescence among youth with spina bifida (SB) or whether child, family, and SB-associated factors influence participation.

Questions/purposes Our cross-sectional study examined participation among youth with SB and assessed how participation differs between youth ages 2–5, 6–12, and 13–18; how participation relates to child (gender) and family (caregiver marital status, education, and employment) characteristics; and how participation relates to

SB-related factors (motor level, hydrocephalus, ambulation, medical issues, and bladder/bowel needs).

Patients and Methods Sixty-three youth ages 2–18 years and/or their caregivers completed age-appropriate measures of participation for youth with disabilities. The patients had an average age of 9.52 years (SD = 5.22), 83% had a shunt, 34% had a motor level of L2 or higher, and 66% L3 or lower.

Results A comparison of youth ages 2–5 (n = 19), 6–12 (n = 21), and 13–18 (n = 23) revealed older youth participated less in recreational, physical, and skill-based activities. Caregiver employment facilitated participation in social activities. Youth who did not have a shunt participated more often in physical and skill-based activities. Youth without recent major medical issues participated more often in physical and social activities. More caregivers reported bladder and bowel needs as barriers to participation for youth ages 6–12 than those ages 2–5 or 13–18.

Conclusions Participation of youth with SB varies by age and across child and caregiver factors and should be understood in a developmental and situational context.

Each author certifies that he or she has no commercial associations (eg, consultancies, stock ownership, equity interest, patent/licensing arrangements, etc) that might pose a conflict of interest in connection with the submitted article.

This work was funded by Shriners Hospitals for Children®, grant 9143 (LCV).

Each author certifies that his or her institution approved the human protocol for this investigation, that all investigations were conducted in conformity with ethical principles of research, and that informed consent for participation in the study was obtained.

This work was performed at Shriners Hospitals for Children®, Chicago, IL, USA; University of Illinois at Chicago, Chicago, IL, USA; and Rush University, Chicago, IL, USA.

E. H. Kelly (✉), H. Altıok, J. A. Gorzkowski,
J. R. Abrams, L. C. Vogel
Shriners Hospitals for Children®, 2211 North Oak Park
Avenue, Chicago, IL 60707-3392, USA
e-mail: ekelly@shrinenet.org

E. H. Kelly
University of Illinois at Chicago, Chicago, IL, USA

H. Altıok, L. C. Vogel
Rush Medical College, Chicago, IL, USA

Introduction

The World Health Organization defines participation as “involvement in life situations” [28] which, for children, “includes domains of learning..., communication, home life, school life, social life, relationships, and leisure and recreation” [18]. Participation has been discussed as key to life success and happiness [18, 27]. For youth, participation has the potential to contribute to life satisfaction and preparation for critical adult roles [8, 17, 24]. Despite this, research indicates low levels of participation among youth

with disabilities. Particular to spina bifida (SB), youth are not “engaging in the full range of adolescent activities needed to make a successful transition to adulthood” [7]. One study reported 63% of young people with SB had difficulties in daily activities and 59% in social roles [5]; another that 72% of youth reported no participation in structured and 63% in unstructured activities [10]; and yet another that only 30% of young people ages 10 to 32 years reported participating in structured community activities such as volunteer opportunities, sports, and church programs at least weekly [2]. Specific to physical activity, youth with SB participate less than comparison youth [4, 22, 23, 25, 26].

A variety of factors relate to participation. One study found sports participation was not associated with “disease-related” factors (including ambulation, hydrocephalus, and functional independence), but rather with family support and perceived athletic competence and physical appearance [6]. Another study found a higher level of ambulation correlates with daily physical activity [4]. Among youth with varied complex disabilities, patterns of participation are related to family resources and child age, gender, and functioning [11, 14]. Child functioning has been linked to specific aspects of participation in that physical functioning relates to physical participation, social competence to social participation, and cognitive and communicative functioning to both [11]. Evidence also suggests aspects of executive functioning are related to physical activity among young people with SB [22].

Although there is growing body of information on participation, current work addresses participation among older children, adolescents, and young adults and does not document participation among children younger than age 6 nor changes across childhood and adolescence. Furthermore, little is known about how participation among youth with SB varies by child and family characteristics or disorder-specific factors. Understanding how participation relates to these factors can help facilitate successful interventions aimed at fostering participation. We presume participation varies based on children’s age and gender, that increased participation would be associated with greater family resources, and that participation would be higher for higher-functioning youth and lower for those with more SB-related issues.

We therefore asked (1) does participation differ between young children (ages 2–5) with SB, school-aged youth (ages 6–12), and adolescents (ages 13–18); (2) does participation relate to child and family characteristics, including the child’s gender and caregiver’s marital status, education, and employment; and (3) does participation relate to SB-related factors, including motor level, hydrocephalus, mobility, medical issues, and bladder and bowel functioning?

Patients and Methods

In this cross-sectional study, English-speaking youth with SB who were receiving care at Shriners Hospitals for Children®—Chicago between January 2008 and June 2009 were recruited. Sixty-four youth ages 2 to 18 years and/or their primary caregivers agreed to participate, but one youth was dropped from the current analyses because of incomplete data. The 63 remaining youth had an average age of 9.52 years ($SD = 5.22$), 52% were male, 83% had a shunt, 33% had a motor level of L2 or higher and 65% L3 or lower, and 56% did some walking (independently, with assistance, or in conjunction with using a wheelchair). Seventy-six percent of caregivers were mothers; 59% were married; 59% had some college experience; and 51% were employed. Twenty-five percent of caregivers reported their child had experienced a major medical issue that affected participation in the 4 months before the interview; and 29% and 37% of caregivers reported bladder and bowel needs kept their child from participating, respectively (Table 1). Depending on the child’s age, we asked youth and/or caregivers to complete relevant survey measures. The study protocol was reviewed by the local Institutional Review Board, and youth and caregivers completed age-appropriate consent and/or assent forms.

A study-specific questionnaire was completed by the caregiver and included questions on the child’s gender; the caregiver’s marital status (married/not married), education (college experience/none), and employment (employed in some capacity/not employed); the presence of hydrocephalus (presence of a shunt); the child’s primary means of mobility (some ambulation/none); whether the child recently had any major medical issues or hospitalizations that affected their participation; and whether bladder and bowel needs keep them from participating.

We administered the Children’s Assessment of Participation and Enjoyment (CAPE) [12] to youth ages 6–18 years; it includes 55 items that measure participation for children with disabilities. The CAPE includes five activity types, but four were selected for the current analyses to draw comparisons with the participation measure used for the younger children: recreation, physical, social, and skill-based (see Appendix). The CAPE measures five dimensions of each activity (diversity, intensity, with whom, where, and enjoyment), but for the purposes of comparison with the young child’s measure, we included only the intensity dimension here. Intensity measures how often youth participate in activities on the following scale: 1 = once in the past 4 months; 2 = twice in the past 4 months; 3 = once a month; 4 = two to three times a month; 5 = once a week; 6 = two to three times a week; and 7 = once a day or more. If a child engages in an activity, that activity is given an intensity rating. Intensity

Table 1. Demographic characteristics

Characteristic	Youth overall (n = 63)	Ages 2–5 years (n = 19)	Ages 6–12 years (n = 21)	Ages 13–18 years (n = 23)
Age, mean years (SD)	9.52 (5.22)	3.53 (1.12)	8.57 (2.42)	15.35 (1.77)
Gender, percent male	52%	58%	43%	57%
Motor level [†] *				
Percent L2 or higher	33%	21%	33%	43%
Percent L3 or lower	65%	74%	67%	57%
Shunt* (%)	83%	58%	91%	96%
Primary means of mobility* (%) ambulating)	56%	68%	52%	48%
Caregivers [†]				
Percent mothers	76%	84%	86%	61%
Percent fathers	14%	11%	5%	26%
Percent others	5%	–	9%	3%
Marital status [†] (%) married)	59%	53%	76%	48%
Education [†] (%) at least some college)	59%	47%	76%	52%
Employment [†] (%) employed in some capacity)	51%	37%	43%	70%
Major medical issue impacting participation in the past 4 months [†] (% type of issue)	25%	21%	38%	17%
Bladder needs keep child from participating* (% reasons why)	29%	26%	52%	9%
	unable to manage bladder needs independently (12 youth), lack of private space to catheterize (8), unable to transfer independently (3), fear of having an accident (2), complications as a result of bladder problems (2), lack of support from others (1) (7 caregivers cited multiple reasons)	unable to manage bladder needs independently (4 youth), lack of private space to catheterize (2), unable to transfer independently (2), (2 caregivers cited multiple reasons)	unable to manage bladder needs independently (7 youth), lack of private space to catheterize (5), complications as a result of bladder problems (2), unable to transfer independently (1), fear of having an accident (1), lack of support from others (1) (5 caregivers cited multiple reasons)	pressure sore (2 youth), surgery (3) (1 caregiver cited multiple reasons) unable to manage bladder needs independently (1 youth), lack of private space to catheterize (1), fear of having an accident (1)

Table 1. continued

Characteristic	Youth overall (n = 63)	Ages 2–5 years (n = 19)	Ages 6–12 years (n = 21)	Ages 13–18 years (n = 23)
Bowel needs keep child from participating* (%), reasons why	37% fear of having an accident (13 youth), unable to manage bowel needs independently (13), lack of private space to do a bowel program (6), complications as a result of bowel problems (4), unable to transfer independently (2) (9 caregivers cited multiple reasons)	11% unable to manage bowel needs independently (2 youth), lack of private space to do a bowel program (1), unable to transfer independently (1) (1 caregiver cited multiple reasons)	57% unable to manage bowel needs independently (7 youth), fear of having an accident (7), lack of private space to do a bowel program (2), complications as a result of bowel problems (4), unable to transfer independently (1) (5 caregivers cited multiple reasons)	39% fear of having an accident (6 youth), unable to manage bowel needs independently (4), lack of private space to do a bowel program (3) (3 caregivers cited multiple reasons)

* Missing data for one child (2% of overall sample); † missing data for three children (5%); ‡ missing data for four children (6%).

scores for each activity are then summed and divided by the total number of items listed in that category, creating intensity subscale scores for each activity type. Intensity scores therefore take into account amount of time spent participating and variety of activities, because youth who participate very frequently in only one activity may have a lower score than youth who participate less frequently in many activities. Past administrations of the CAPE have demonstrated acceptable test-retest reliability and content and construct validity [11, 12].

Participation for youth ages 2 to 5 years was measured with the Assessment of Preschool Children's Participation (APCP) [19]. This instrument was completed by caregivers and assesses participation diversity, frequency and intensity across activities in the following domains: play, active physical recreation, social, and skill development (see Appendix). For the purposes of comparison with the CAPE, we included only the intensity dimension; intensity measures how often youth participate on the same scale as specified previously for the CAPE. Information on validity and reliability of the APCP is currently unavailable.

We reviewed medical records to determine each child's motor level (L2 or higher/L3 or lower).

Descriptive statistics were used to assess levels of participation. For group comparisons, we compared the CAPE recreational, physical, social, and skill-based questions with the APCP play, active physical, social, and skill development questions. Because of differences in the target age groups for each measure, the CAPE and APCP items differ, but two of the study coauthors independently agreed that each set of items contributes to a valid assessment of recreational, physical, social, and skill-based participation for the age group assessed. Furthermore, the APCP was patterned after the CAPE, and the instrument authors have declared a strong conceptual linkage among the physical, social, and skill-based subscales. Average intensity scores for each category were used for each participant.

Because of small sample sizes, we incorporated non-parametric statistics, and medians were used as measures of central tendency for all measures [20]. Within-group analyses were conducted using the Friedman test, in which the four intensity scores (recreational, physical, social, skill-based) were compared for each of the three age groups. We then conducted post hoc analyses to locate differences where significant Friedman tests resulted (the Siegel and Castellan approach, where $p = 0.004$). Between-group analyses were conducted using the Kruskal-Wallis test. We conducted followup tests with Mann-Whitney U, and the Dunn procedure was used to correct for multiple comparisons ($p = 0.003$). Daily activities were those with median participation scores of 7.00, indicating at least half of the youth who reported participating in that activity participated once a day or

more. Differences in participation by child, family, and SB-specific characteristics were assessed using the Mann-Whitney U test.

Missing data on the following variables resulted from incomplete information in medical records or caregiver surveys: motor level (2%, $n = 1$), mobility (2%, $n = 1$), caregiver marital status (6%, $n = 4$), caregiver education and employment (5%, $n = 3$), major medical issues (5%, $n = 3$), whether bladder and bowel issues prevent participation (2%, $n = 1$), and presence of a shunt (2%, $n = 1$). In addition, two and 11 youth did not participate in any physical or skill-based activities, respectively, so these youth did not have intensity scores for those activity types. As a result, analyses were not always conducted with 63 participants; group sizes are presented throughout.

Results

We found between-group differences in youth participation scores for recreational, physical, and skill-based activities (Table 2). Two to 5 year olds participate more often in physical and skill-based activities than all other youth, and 2 to 5 and 6 to 12 year olds participate in recreational activities more than 13 to 18 year olds. Within-group analyses yielded differences in participation among all three age groups and youth overall (Table 2). Youth overall participated more often in recreational activities than physical, social, or skill-based activities and in social activities more than physical or skill-based activities. Youth ages 2 to 5 years participated more often in recreational activities than either physical or social activities. Youth ages 6 to 12 and 13 to 18 years participated more often in recreational and social activities than physical or skill-based activities. On a daily basis, youth ages 2 to 5 years engage more often in recreational

and skill development activities, whereas older youth engage more often in recreational and social activities (Table 3).

Participation did not differ by child gender, caregiver marital status, or caregiver education. However, youth whose caregivers were employed participated more often in social activities (Table 4). There was no relationship between child's age and child gender, caregiver marital status, or caregiver education. However, child's age was related to caregiver employment in that caregivers of youth ages 13 to 18 years (70%) were more likely to be employed than those of youth ages 2 to 5 (37%) or 6 to 12 (43%) years (chi square = 6.84, $p = 0.033$).

Participation did not differ by child's motor level, ambulation, or bladder and bowel issues. However, youth who did not have a shunt participated more often in physical and skill-based activities. Furthermore, youth without recent major medical issues participated more often in physical and social activities (Table 5). Child age was not associated with motor level, ambulation, or recent medical issues but was associated with presence of a shunt in that more youth in the older groups (6–12 = 91%, 13–18 = 96%) had a shunt than youth ages 2–5 (58%) (chi square = 9.93, $p = 0.007$). Bladder and bowel needs limiting participation were more commonly reported for youth ages 6 to 12 years (52% and 57%, respectively) than those ages 2 to 5 years (26% and 11%, respectively) or 13 to 18 years (9% and 39%, respectively) (chi square = 10.19, $p = 0.006$ for bladder; chi square = 8.87, $p = 0.012$ for bowel). Because of the increased frequency of reported bladder and bowel needs among youth 6 to 12 years, relationships between these factors and participation were explored. Among youth 6 to 12 years, bladder needs were not related to participation; however, bowel issues limited their involvement in physical and social activities (Table 6).

Table 2. Median (range) participation intensity scores by child age

Activity type	Chi square (Kruskal-Wallis) for between-groups test	Youth overall ($n = 63$)	Ages 2–5 ($n = 19$)	Ages 6–12 ($n = 21$)	Ages 13–18 ($n = 23$)
Chi square for within-groups test	–	69.05*	27.06*	35.88*	34.35*
Recreational	19.77*	3.56 (0.92–6.00), $n = 63$	4.33 (1.89–6.00), $n = 19$	3.83 (2.25–5.58), $n = 21$	2.83 (0.92–4.67), $n = 23$
Physical	16.64*	1.31 (0.15–4.50), $n = 61$	2.80 (0.50–4.50), $n = 19$	0.92 (0.15–2.23), $n = 19$	1.08 (0.23–2.69), $n = 23$
Social	3.47	2.90 (0.30–4.90), $n = 63$	2.54 (0.64–4.73), $n = 19$	2.90 (0.30–4.60), $n = 21$	3.20 (0.70–4.90), $n = 23$
Skill-based	28.21*	1.40 (0.10–4.93), $n = 52$	3.60 (0.73–4.93), $n = 19$	0.70 (0.10–3.70), $n = 17$	0.70 (0.10–2.60), $n = 16$

* $p < 0.001$.

Table 3. Daily activities engaged in by youth

Activity	Percentage of youth who endorsed this activity (number)	Category of activity
Youth 2–5 years		
Playing with toys	100% (19)	Recreational
Listening to a story	100 (19)	Skill development
Doing pretend or imaginary play	90 (17)	Recreational
Helping around the house	90 (17)	Skill development
Watching TV or a video	84 (16)	Recreational
Listening to music	79 (15)	Social
Picking out books, movies, DVDs, or CDs	79 (15)	Skill development
Playing with pets	53 (10)	Recreational
Youth 6–12 years		
Watching TV or a rented movie	100 (21)	Recreational
Listening to music	91 (19)	Social
Playing with things or toys	81 (17)	Recreational
Doing pretend or imaginary play	76 (16)	Recreational
Entertaining others	52 (11)	Social
Racing or track and field	5 (1)	Physical
Youth 13–18 years		
Watching TV or a rented movie	91 (21)	Recreational
Listening to music	91 (21)	Social
Playing with computer or video games	87 (20)	Recreational
Talking on the phone	87 (20)	Social
Playing with pets	83 (19)	Recreational
Taking care of a pet	48 (11)	Recreational
Learning to sing	26 (6)	Skill-based
Doing snow sports	4 (1)	Physical

Table 4. Median (range) participation intensity scores by child and family characteristics

Activity type	Child gender		Caregiver marital status		Caregiver education		Caregiver employment	
	Boys (n = 33)	Girls (n = 30)	Not married (n = 22)	Married (n = 37)	No college (n = 23)	At least some college (n = 37)	Not employed (n = 28)	Employed in some capacity (n = 32)
Recreational	3.44	3.82	4.17	3.50	3.25	3.83	3.50	3.83
	(0.92–6.00)	(1.25–6.00)	(1.17–6.00)	(0.92–6.00)	(1.75–6.00)	(0.92–6.00)	(1.17–6.00)	(0.92–6.00)
	n = 33	n = 30	n = 22	n = 37	n = 23	n = 37	n = 28	n = 32
Physical	1.54	1.00	1.20	1.27	1.35	1.15	1.27	1.15
	(0.15–4.50)	(0.23–3.80)	(0.46–3.80)	(0.15–4.50)	(0.23–3.80)	(0.15–4.50)	(0.38–3.80)	(0.15–4.50)
	n = 33	n = 28	n = 21	n = 36	n = 22	n = 36	n = 26	n = 32
Social	2.70	3.05	3.20	2.70	2.82	2.73	2.24 ¹	3.20 ¹
	(0.73–4.90)	(0.30–4.60)	(1.27–4.50)	(0.30–4.73)	(0.70–4.73)	(0.30–4.50)	(0.30–3.91)	(1.40–4.73)
	n = 33	n = 30	n = 22	n = 37	n = 23	n = 37	n = 28	n = 32
Skill-based	1.30	1.93	1.20	1.40	2.00	1.30	1.62	1.40
	(0.10–4.93)	(0.10–3.93)	(0.10–4.93)	(0.10–4.47)	(0.40–4.47)	(0.10–4.93)	(0.10–4.93)	(0.10–4.47)
	n = 27	n = 25	n = 19	n = 30	n = 18	n = 31	n = 24	n = 25

Numeric superscripts indicate pair is significantly different, $p < 0.001$.

Table 5. Median (range) participation intensity scores by spina bifida-related factors

Activity type	Child motor level		Child shunt		Child mobility		Child recent medical issue		Child bladder needs as a barrier to participation		Child bowel needs as a barriers to participation	
	L2 or higher (n = 21)	L3 or lower (n = 41)	No shunt (n = 10)	Shunt (n = 52)	No walking (n = 27)	Some walking (n = 35)	No recent issues (n = 44)	Recent issues (n = 16)	No (n = 44)	Yes (n = 18)	No (n = 39)	Yes (n = 23)
Recreational	3.25 (1.25–6.00)	3.89 (0.92–6.00)	3.50 (1.89–6.00)	3.58 (0.92–6.00)	3.25 (1.17–6.00)	3.83 (0.92–6.00)	3.53 (0.92–6.00)	3.50 (1.92–5.67)	3.53 (0.92–6.00)	3.60 (2.00–6.00)	3.67 (0.92–6.00)	3.25 (1.17–6.00)
Physical	n = 21	n = 41	n = 10	n = 52	n = 27	n = 35	n = 44	n = 16	n = 44	n = 18	n = 39	n = 23
	1.42 (0.15–3.80)	1.27 (0.23–4.50)	2.22 ¹ (1.10–4.50)	1.08 ¹ (0.15–3.80)	1.23 (0.15–4.50)	1.31 (0.23–4.00)	1.31 ^a (0.15–4.50)	0.65 ^a (0.23–2.80)	1.20 (0.15–4.50)	1.46 (0.38–3.80)	1.31 (0.15–4.50)	1.08 (0.23–3.50)
Social	n = 20	n = 40	n = 10	n = 50	n = 27	n = 33	n = 42	n = 16	n = 43	n = 17	n = 39	n = 21
	3.00 (0.70–4.90)	2.82 (0.30–4.73)	2.55 (1.55–4.60)	3.00 (0.30–4.90)	2.55 (0.64–4.90)	3.00 (0.30–4.73)	3.00 ^b (0.70–4.73)	2.24 ^b (0.30–4.90)	2.86 (0.64–4.90)	2.81 (0.30–4.73)	2.82 (0.64–4.73)	2.90 (0.30–4.90)
Skill-based	n = 21	n = 41	n = 10	n = 52	n = 27	n = 35	n = 44	n = 16	n = 44	n = 18	n = 39	n = 23
	1.25 (0.10–4.47)	1.40 (0.10–4.93)	3.67 ^c (0.70–4.47)	1.15 ^c (0.10–4.93)	1.20 (0.10–4.47)	2.27 (0.10–4.93)	1.35 (0.10–4.93)	1.00 (0.30–3.70)	1.50 (0.10–4.47)	1.05 (0.30–4.93)	2.27 (0.10–4.47)	0.80 (0.10–4.93)
	n = 16	n = 35	n = 9	n = 42	n = 21	n = 30	n = 34	n = 15	n = 37	n = 14	n = 34	n = 17

Numeric superscripts indicate pair is significantly different, $p < 0.01$; alpha subscripts indicate pair is significantly different, $p < 0.05$.

Discussion

Participation is key to child development, contributing to life satisfaction but also preparing one for future roles [8, 17, 24]. However, youth with disabilities participate in fewer activities and less often than children without disabilities [13]. Understanding factors related to participation across development can help target youth in need of intervention. The present study examined how participation of youth with SB changed with age and explored whether child, family, and SB-related characteristics influenced participation.

Our study had several limitations. First, the data were cross-sectional. Although comparisons between age groups begin to create a developmental understanding of participation, longitudinal data are needed for more definitive conclusions. Second, the sample size was small, possibly making it difficult to detect subgroup differences (eg, how motor level or bowel/bladder needs influence participation). Furthermore, the sample was restricted to English-speaking patients receiving care at one hospital and therefore may not be representative of the population of youth with SB. Participation is likely related to cultural expectations and norms; past research found participation of youth with cerebral palsy was influenced by where they live [9]. Future research should explore these connections with a larger, more diverse sample. Third, different measures of participation were used for younger and older youth. Although efforts were made to ensure these measures were comparable, this difference may compromise the ability to make reliable comparisons between groups. Furthermore, participation was proxy (caregiver)-reported among youth 2 to 5 years but self-reported for those 6 to 18 years. Future research may consider standardizing procedures by having caregivers report participation for all youth; however, the accuracy of parent report may change with the child's age because older youth tend to have more freedom in participation. Also related to differences in the two measures, only the intensity dimension of participation could be used as a point of comparison. Intensity is only one aspect of participation and includes some inherent limitations itself (eg, youth must endorse at least one activity to receive an intensity score). Future research should examine how other dimensions of participation change across developmental stages. Fourth, future measurement efforts should move beyond relying on self-report alone, because both youth and caregiver participants may experience recall bias. Fifth, the APCP has not been established as reliable or valid, although psychometric properties on the APCP are forthcoming according to the instrument authors. Although this measure was patterned after the more established CAPE, results from the youngest participants should be interpreted with caution. Sixth, data

Table 6. Median (range) participation scores assessing relationships between bladder and bowel needs and participation among youth ages 6 to 12 years

Activity type	Child bladder needs as a barrier to participation		Child bowel needs as a barriers to participation	
	No (n = 10)	Yes (n = 11)	No (n = 9)	Yes (n = 12)
Recreational	4.42 (3.00–5.58) n = 10	3.75 (2.25–5.42) n = 11	4.25 (2.58–5.58) n = 9	3.79 (2.25–5.42) n = 12
Physical	0.92 (0.15–2.23) n = 9	0.88 (0.38–1.69) n = 10	1.54 (0.15–2.23) ^a n = 9	0.65 (0.23–1.46) ^a n = 10
Social	3.20 (1.60–4.60) n = 10	2.50 (0.30–3.60) n = 11	3.20 (1.80–4.60) ^b n = 9	2.40 (0.30–3.60) ^b n = 12
Skill-based	0.90 (0.10–3.70) n = 9	0.70 (0.30–1.30) n = 8	1.10 (0.10–3.70) n = 9	0.70 (0.40–1.30) n = 8

Alpha subscripts indicate pair is significantly different, $p < 0.05$.

on medical issues and bladder and bowel needs were reported by caregivers; it is possible some of these data were inaccurate because of misperceptions. Future research should corroborate findings with information from medical records. Finally, no data from able-bodied youth currently exist to serve as a comparison group for the CAPE or APCP. Although the CAPE authors have published limited data collected from youth without disabilities, the activity scales compared in the current study were not included [13]. Future research should investigate how youth with SB fare regarding participation as compared with their able-bodied peers.

Findings revealed youth ages 2 to 5 years participate more often in physical and skill-based activities than older youth. The preschool years are a time of intense cognitive and social-emotional learning [1], which may account for differences in skill-based participation. Decline in physical activity with increased age may indicate the start of a trend found in research that youth with disabilities participate less in physical activities than able-bodied peers [3, 16]. School age may therefore be an appropriate time for interventions encouraging physical participation. Youth participation also differed by age group: recreational participation was lower and social participation higher among older youth. These differences seem developmentally appropriate because younger youth tend to engage in more playing and older youth more social activities [11]. Overall, youth participated less often in physical and skill-based activities than recreational or social activities, as reflected by two daily activities shared by all groups: TV viewing and listening to music. This is consistent with previous findings that children with disabilities spend more time in quiet recreation-type activities [3].

Caregiver employment was related to social participation. Employment may require caregivers to expose their children to more situations, including childcare and extended social networks. Additionally, income from

employment may enable caregivers to facilitate their child's participation. Alternatively, this finding may be explained by the fact that caregivers of older youth (ages 13–18 years) were more likely to be employed, and older youth demonstrate more involvement in social activities [11]. In contrast to past research [11, 14], child's gender was not related to participation. Furthermore, caregiver education and marital status were not related to participation. Future research should examine the importance of these factors among larger samples of youth with SB.

Although motor level and ambulation were not related to participation, hydrocephalus affected participation in physical and skill-based activities. Youth with hydrocephalus are more likely to experience cognitive delay, which may affect participation. However, cognitive challenges put these youth in particular need of physical participation, because individuals with cognitive impairments disproportionately experience health complications like obesity [21]. This finding may also be explained by age differences; more youth in the older group had a shunt, and older youth participated less often in physical and skill-based activities. Future work should investigate this relationship and, if needed, bolster participation opportunities among youth with hydrocephalus. Decreased physical and social participation were associated with major medical issues in the sample overall and bowel issues among children 6 to 12 years. These dimensions of participation might be expected to be affected by medical and bowel issues, because these complications may prevent youth from being physically able to participate or may create embarrassment in social situations.

This study has implications for researchers measuring participation and clinicians working with youth with SB. First, both instruments incorporated here measured how much youth participate. However, youth may have varying degrees of satisfaction with their participation; one child may prefer to participate very intensely in one activity,

whereas another may prefer a wider variety of activities. Further research should identify optimal levels of participation for youth. Second, these data contribute to existing literature highlighting rates of participation among youth with SB. Although comparable CAPE data from youth without disabilities are not available, a comparison of mean intensity scores from youth ages 6 to 14 in the current sample to published data from 427 youth ages 6 to 14 with a variety of physical disabilities (including SB) [15] suggests the current sample may be participating less in recreational (3.75 versus 4.16), physical (1.01 versus 1.76), and social (2.89 versus 3.21) activities. Youth with SB may therefore be in particular need of encouragement and support by multidisciplinary rehabilitation teams through technical assistance, resources, and actual opportunities to “practice” participating. Finally, bladder and bowel needs were more often barriers for youth ages 6 to 12 years. This is the usual age when youth with SB are learning to be independent in bladder and bowel management; extra supports may therefore be needed to help youth meet their toileting needs during this transition time to facilitate their participation.

Acknowledgments We thank the youth and their caregivers who participated in this research.

Appendix

See Table 7

Table 7. Activities listed in the Children’s Assessment of Participation and Enjoyment (CAPE)* and Assessment of Preschool Children’s Participation (APCP)

CAPE activities	APCP activities
<i>Recreational/play activities</i>	
Doing puzzles	Doing pretend or imaginary play
Playing board or card games	Building forts or tents
Doing crafts, drawing, or coloring	Collecting things
Collecting things	Playing with pets
Playing computer or video games	Playing with toys
Playing with pets	Creating a craft project
Doing pretend or imaginary play	Exploring
Playing with things or toys	Watching TV or a video
Going for a walk or a hike	Playing a musical instrument
Playing on equipment	
Watching TV or a rented movie	
Taking care of a pet	
<i>Physical activities/active physical recreation</i>	
Doing martial arts	Interacting with nature
Racing or track and field	Dancing

Table 7. continued

CAPE activities	APCP activities
Doing team sports	Going for walks
Participating in school clubs	Riding a bicycle, tricycle, or scooter
Bicycling, in-line skating, or skateboarding	Doing water activities
Doing water sports	Doing snow activities
Doing snow sports	Playing on playground equipment
Playing games	Playing physical games
Gardening	Gardening
Fishing	Doing team sports
Doing individual physical activities	
Playing nonteam sports	
Doing a paid job	
<i>Social activities</i>	
Talking on the phone	Playing dress up
Going to a party	Playing board or card games
Hanging out	Playing computer games
Visiting	Going to the movies
Entertaining others	Going to a live event
Going to the movies	Going on a full or half-day outing
Going to a live event	Going to a party
Going on a full-day outing	Attending a play group
Listening to music	Having someone over to play
Making food	Baking or cooking
	Listening to music
<i>Skill-based activities/skill development</i>	
Swimming	Helping around the house
Doing gymnastics	Building things
Horseback riding	Painting
Learning to sing	Drawing and coloring
Taking art lessons	Cutting and pasting
Learning to dance	Doing a puzzle
Playing a musical instrument	Taking swimming lessons
Taking music lessons	Doing gymnastics
Participating in community organizations	Participating in religious activities
Dancing	Listening to stories
	Picking out books, movies, DVDs, or CDs
	Learning to dance
	Taking music lessons
	Reading/looking at books
	Participating in community organizations

*Children’s Assessment of Participation and Enjoyment (CAPE). Copyright © 2004 NCS Pearson, Inc. Adapted and reproduced with permission of publisher, NCS Pearson, Inc. All rights reserved. “Children’s Assessment of Participation and Enjoyment” and “CAPE” are trademarks in the United States and/or other countries of Pearson Education, Inc or its affiliates.

References

- Bernstein DA, Roy EJ, Scull TK, Wickens CD. *Psychology*. 2nd ed. Boston: Houghton, Mifflin and Company; 1991.
- Boudos RM, Mukherjee S. Barriers to community participation: teens and young adults with spina bifida. *J Pediatr Rehabil Med*. 2008;1:303–310.
- Brown M, Gordon WA. Impact of impairment on activity patterns of children. *Arch Phys Med Rehabil*. 1987;68:828–832.
- Buffart LM, Roebroek ME, Rol M, Stam HJ, van den Berg-Emons RJ. Triad of physical activity, aerobic fitness and obesity in adolescents and young adults with myelomeningocele. *J Rehabil Med*. 2008;40:70–75.
- Buffart LM, Van den Berg-Emons RJG, Van Meeteren J. Lifestyle, participation, and health-related quality of life in adolescents and young adults with myelomeningocele. *Dev Med Child Neurol*. 2009;51:886–894.
- Buffart LM, van der Ploeg HP, Bauman AE, Van Asbeck FW, Stam HJ, Roebroek ME, van den Berg-Emons RJG. Sports participation in adolescents and young adults with myelomeningocele and its role in total physical activity behaviour and fitness. *J Rehabil Med*. 2008;40:702–708.
- Buran CF, Sawin KJ, Brei TJ, Fastenau PS. Adolescents with myelomeningocele: activities, beliefs, expectations, and perceptions. *Dev Med Child Neurol*. 2004;46:244–252.
- Caldwell LL, Gilbert AA. Leisure, health and disability: a review and discussion. *Can J Commun Ment Health*. 1990;9:111–122.
- Hammal D, Jarvis SN, Colver AF. Participation of children with cerebral palsy is influenced by where they live. *Dev Med Child Neurol*. 2004;46:292–298.
- Johnson KL, Dudgeon B, Kuehn C, Walker W. Assistive technology use among adolescents and young adults with spina bifida. *Am J Public Health*. 2007;97:330–336.
- King GA, Law M, King S, Hurley P, Hanna S, Kertoy M, Rosenbaum P. Measuring children's participation in recreation and leisure activities: construct validation of the CAPE and PAC. *Child: Care, Health and Development*. 2007;33:28–39.
- King GA, Law M, King S, Hurley P, Rosenbaum P, Hanna S, Kertoy M, Young N. *Children's Assessment of Participation and Enjoyment & Preferences for Activities of Children: Manual*. San Antonio, TX: Harcourt Assessment, Inc; 2004.
- King G, Petrenchik T, Law M, Hurley P. The enjoyment of formal and informal recreation and leisure activities: a comparison of school-aged children with and without physical disabilities. *Int J Disabil Dev Education*. 2009;56:109–130.
- Klaas SJ, Kelly EH, Gorzkowski JA, Homko E, Vogel LC. Assessing patterns of participation and enjoyment in pediatric spinal cord injury. *Dev Med Child Neurol*. 2010;52:468–474.
- Law M, King G, King S, Kertoy M, Hurley P, Rosenbaum P, Young N, Hanna S. Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Dev Med Child Neurol*. 2006;48:337–342.
- Longmuir PE, Bar-Or O. Factors influencing the physical activity levels of youths with physical and sensory disabilities. *Adapted Physical Activity Quarterly*. 2000;17:40–53.
- Lyons RF. Meaningful activity and disability. Capitalizing upon the potential of outreach recreation networks in Canada. *Can J Rehabil*. 1993;6:256–265.
- Morris C. Measuring participation in childhood disability: how does the capability approach improve our understanding? *Dev Med Child Neurol*. 2009;51:92–94.
- Petrenchik T, Law M, King G, Hurley P, Forhan M, Kertoy M. *Assessment of Preschool Children's Participation*. Hamilton, Ontario, Canada: CanChild Centre for Childhood Disability Research, McMaster University; 2006.
- Pett MA. *Nonparametric Statistics for Health Care Research: Statistics for Small Samples and Unusual Distributions*. Thousand Oaks, CA: Sage Publications, Inc; 1997.
- Rimmer JH, Braddock D, Fujiura G. Prevalence of obesity in adults with mental-retardation—implications for health promotion and disease prevention. *Mental Retardation*. 1993;31:105–110.
- Roebroek ME, Hempenius L, Van Baalen B, Hendriksen JGM, Van Den Berg-Emons HJG, Stam HJ. Cognitive functioning of adolescents and young adults with meningomyelocele and level of everyday physical activity. *Disabil Rehabil*. 2006;28:1237–1242.
- Schoenmakers MAGC, de Groot JF, Gorter JW, Hillaert JLM, Helden PJM, Takken T. Muscle strength, aerobic capacity and physical activity in independent ambulating children with lumbosacral spina bifida. *Disabil Rehabil*. 2009;31:259–266.
- Simeonsson RJ, Carlson D, Huntington GS, McMillen JS, Brent JL. Students with disabilities: a national survey of participation in school activities. *Disabil Rehabil*. 2001;23:49–63.
- van den Berg-Emons HJ, Bussmann JB, Brobbel AS, Roebroek ME, van Meeteren J, Stam HJ. Everyday physical activity in adolescents and young adults with meningomyelocele as measured with a novel activity monitor. *J Pediatr*. 2001;139:880–886.
- van den Berg-Emons HJ, Bussmann JBJ, Meyerink HJ, Roebroek ME, Stam HJ. Body fat, fitness and level of everyday physical activity in adolescents and young adults with meningomyelocele. *J Rehabil Med*. 2003;35:271–275.
- Whiteneck GG. Measuring what matters: key rehabilitation outcomes. The 44th Annual John Stanley Coulter Lecture. *Arch Phys Med Rehabil*. 1994;75:1073–1076.
- World Health Organization. *International Classification of Functioning, Disability, and Health*. Geneva: World Health Organization; 2001.