

Developmental Pediatrics

Title: PARTICIPATION AMONG YOUTH WITH SPINA BIFIDA

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Background: The goal of this study was to understand patterns of participation among youth with spina bifida (SB) while assessing how participation relates to key child and caregiver demographics and bladder and bowel needs.

Method: Youth with SB and their caregivers were interviewed using a structured questionnaire and the Children's Assessment of Participation and Enjoyment, which measures participation for children with disabilities according to 55 activities that fall into two domains: informal (e.g., doing puzzles) and formal (e.g., doing team sports). Each activity is measured on 5 dimensions: diversity, frequency, with whom, where, and enjoyment. Paired t-tests were used to compare rates of informal and formal participation, and non-parametric statistics were used to conduct subgroup comparisons.

Results: 27 youth were interviewed: 63% female, 70% Caucasian, mean age was 11.52 years (range 6-18). Thirty-three percent had a motor level of L2 or higher and 67% fell between L3 and L5. Fifty percent used a wheelchair as their primary means of mobility. Youth participated more often in informal than formal activities ($p < .001$), but when participating in formal activities they participated with a more diverse group of people ($p < .001$) further away from home ($p < .001$). Youth enjoyed formal activities more than informal activities ($p < .001$). There were no significant associations of participation with gender, age, primary means of mobility, or disability severity. However, caregivers who had some college exposure had children who participated more often in activities overall ($p = .021$); and youth whose caregivers reported that bowel needs do not prevent their child's participation, participated with a more diverse group of people ($p = .009$).

Conclusion: This study provides an initial understanding of participation among youth with SB. Future research should investigate how offering more formal opportunities for participation and providing caregivers with more education may impact participation among youth with disabilities.