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Youth with Spina Bifida and Transitions: Health and Social Participation in a Nationally Represented Sample

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Objective To describe outcomes and identify factors that affect social participation in youth and young adults with spina bifida.

Study design Prospective data from a nationally representative survey of youth and young adults with disabilities were analyzed. The WHO ICF framework was used with participation as the dependent category and (a) body function/structure; (b) activities; (c) personal factors; and (d) environment as independent categories.

Results A nationally representative sample of 130 youth with spina bifida (mean age 15 years) representing 5171 individuals with spina bifida was followed up for 4 years. The general health of the sample declined over the 4-year study period. Although each outcome using the WHO ICF model had its own pattern of factors that related to it, being Latino or not speaking English at home was negatively associated with each of the outcomes.

Conclusion The general health of individuals with spina bifida declines during adolescence and early adulthood. Social participation is affected by many factors, and each outcome appears to have its own set of factors that affect it. Future interventions to improve health, well-being, and social participation in adults with spina bifida will need to address factors in all domains. *(J Pediatr 2010;157:584-8)*.

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Recent studies have shown that adolescents and young adults with spina bifida have a lower- than-expected rate of independence, employment, attendance in post-secondary education, and are more isolated compared with peers without spina bifida. For example, Barf et al[1] found that at a mean age of 21 years, only 16% of Dutch adolescents with spina bifida were living independently; 53% of those who completed their education did not have a regular job, and 71% did not have a partner. In another Dutch study of adults with spina bifida who ranged in age from 21 to 32 years,[2] 60% were employed and 20% of these were in a sheltered workplace. In a Swedish study,[3] 38% of young adults with spina bifida were employed. In a study of youth and adults with cerebral palsy, spina bifida, and acquired brain injury, Young et al[4] found that 61% of adults were living with their parents and 55% of adults were employed. In a cohort study of adolescents with spina bifida from Chicago,[5] 49% were attending or had graduated from college at the time of the study. In an earlier study,[6] only 8% of adolescents with spina bifida from Arkansas had graduated from a 2- or 4-year college. Dicianno et al[7] reported significant social isolation in adults with spina bifida.

The health status of adolescents and young adults with spina bifida has been a concern as well. Verhoef et al[8] found that quality of life scores of young adults with spina bifida were below those of an age-matched population group in 6 of the 8 domains. This difference was largest for physical functioning. In a study comparing adolescents with spina bifida, acquired brain injury, and cerebral palsy, only 42% of adults reported “excellent” or “very good” health; the lowest health scores were reported by adults with spina bifida.[4]

Because the factors that affect “success” in adulthood are uncertain, programs to optimize transitions from adolescence to adulthood and to maintain the health and well-being of adults remain unsupported by evidence. The objectives of this study were to describe outcomes and to identify factors that affect social participation in a nationally representative sample of youth and young adults with spina bifida. The long-term goal of this research is to acquire insights that will help to develop and guide interventions to maximize social participation of individuals with spina bifida.

Methods

The World Health Organization’s (WHO) International Classification of Functioning, Disability, and Health (ICF) framework was used as a model to provide insights into the health and well-being of the sample.[9,10] The 6 categories used in

ICF	International Classification of Functioning, Disability, and Health
LD	Learning disability
NLTS2	National Longitudinal Transition Study 2
WHO	World Health Organization

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this model (and examples related to spina bifida) include the following: (1) health condition (spina bifida, hydrocephalus); (2) body function and structure (paraplegia, upper extremity function, learning disability); (3) activities (mobility, self care, and performance of school-related tasks); (4) participation (social contacts, work, and independence); (5) environment (physical, social, cultural, or institutional; eg, language spoken at home, parental support, and support in school); and (6) personal (sex, age, race/ethnicity, and socioeconomic status).

This was a prospective cohort study of a nationally representative sample of adolescents with spina bifida. Data from the National Longitudinal Transition Study 2 (NLTS2) were analyzed. This is an ongoing survey from the U.S. Department of Education of youth and young adults in the United States who were classified by their school districts as having a disability. The reliability of responses to the NLTS2 questions was verified through pretesting. Validated questions from other national surveys with the general population and from the first NLTS were also used.[11] The NLTS2 does not include data on adolescents who are not classified. All data in the NLTS2 are de-identified; this study was, therefore, exempted by the Upstate Medical University IRB.

Students classified as having a disability were randomly selected from local education agencies, which were stratified by geographic region, district size, and district/community wealth. Students who participated were ages 13 through 16 and in at least 7th grade on December 1, 2000 (wave 1). Wave 1 was completed in 2001; wave 2 was conducted in 2003, and wave 3 in 2005. This study evaluates data from the parental interviews obtained during waves 1 and 3, as well as interviews with the individuals themselves at wave 3. When outcomes (eg, health status) were compared in this study between waves 1 and 3, the same source of data was used (in this case parental interview). Adolescents in this study had been identified by their district as having spina bifida. Data were weighted to reflect the sampling strategy. When race and ethnicity were determined, parents were first asked if their child (youth) was Hispanic, Latino, or of other Spanish origin, and then were asked about his or her race. The results of formal psychoeducational testing were not included in the data. Therefore we could not obtain scores of intelligence. We used whether the child had been classified as having a learning disability as a proxy for cognitive abilities. We considered using rates of grade retention as a measure of intelligence. However, different schools use different criteria for this; in addition, in some schools children with spina bifida are enrolled in special education classes whereas in other schools children with a similar intellectual profile would be placed in a regular or inclusion classroom, thus making comparisons difficult to interpret. Whether the individual had shunted hydrocephalus was not noted.

Findings are reported as weighted frequencies and means that are population estimates for students who were classified with spina bifida. The χ^2 test and analysis of variance were used for comparisons among discrete and continuous variables, respectively. Logistic regression was used for multifactor analyses. Structural equation modeling was not used because the total number of individuals was too small for the number of comparisons. To identify variables to be used in the logistic regression equations, correlation matrices using variables from the WHO ICF categories of Body Function and Structure, Activities, Environment and Personal Factors [independent variables] and Participation [dependent variables] were examined. Independent variables having a Pearson correlation coefficient (r) whose absolute values were greater than 0.2 with a specific dependent variable were entered stepwise into the logistic regression equation for that dependent variable. SPSS 16.0[12] (SPSS Inc., Chicago, Illinois) was used for data analysis.

Results

A total of 130 subjects with spina bifida were identified and followed up for 4 years; they represent a weighted sample of 5171 individuals (**Table I**). The mean age at the time of enrollment (wave 1) was 15.3 years, with a range of 13 to 17; 94% were enrolled in a regular school, and 4% were in a school that only served students with disabilities; 93% had an Individual Education Program. At wave 1, 26% of parents disagreed or strongly disagreed that their youth was getting needed support/services from the school. By wave 3, 92% had graduated from high school or had received an equivalency diploma.

At wave 1, 40% of teens were diagnosed with at least 1 other disability (eg, problem with vision), 23% with 2 other disabilities, and 5% with 3 or more. This information was not obtained at wave 3. Four percent had been diagnosed with a seizure disorder or epilepsy. Forty-five percent had ever been held back a grade; 47% reported being teased, and 24% reported that they had been bullied at school. In wave 1, 21% had been classified as having a learning disability (LD), with 22% being classified as such in Wave 3; all the individuals identified with LD in wave 1 had LD in wave 3.

Computer use at home was assessed because it is a measure of environmental resources, as well as a means to increase social networking.[13] At wave 1, 78% reported that they had a computer in the home. Computer use was reported as follows: 94% to access the Internet, 93% for games, 88% for homework, and 65% for electronic mail (E-mail) and

Table I. Demographic factors of sample (Wave 1); n = 130

Mean age as of 7/15/01 (Mean [CI$_{95}$])	15.27 years [15.24, 15.31]
Mean income	$39 030 [$38 286, $39 773]
Variable (weighted)	
Female	2253 (44%)
Latino	985 (19%)
White	3209 (62%)
African-American	830 (16%)
Below poverty level	1181 (26%)
Household receives any benefits	2238 (47%)
Primary health insurance	
Private	2635 (52%)
Government	2469 (48%)