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ORIGINAL ARTICLES

# 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;■:■-■)*.

See editorial, p ■■■

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 $\chi^2$ 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%) |

chatting. Thirty-three percent of the families belonged to any support groups for people with disabilities, and 45% had received funds from the Supplemental Security Income program in the previous 2 years.

At wave 3, the mean age of the sample was 19.3 years [$19.26 < CI_{95} < 19.33$]; 79% of the adolescents lived with their parents; 76% had been competitively employed or attended postsecondary school within the previous 2 years, and 36% had held a job in the previous 12 months, and 27% had any postsecondary education since high school. Twenty percent of females and 14% of males reported ever having had sexual intercourse; 6% reported having smoked a cigarette, and 20% reported having used any alcohol in the previous 30 days.

**Figure 1** shows the change in general health between waves 1 and 3. The percent reporting excellent health decreased from 29% in wave 1 to 11% in wave 3, and the percent reporting fair or poor health increased from 8% to 25% ($\chi^2 = 761$, df = 9, $P < .001$). In wave 1, those who were Latino reported 32% excellent health, compared with 12% for those who were non-Latino ($P < .01$); by wave 3, 8% of those who were Latino reported excellent health compared with 9% for non-Latinos ($P > .10$). Numbers were not sufficient to examine the effect of insurance status on change in general health. At wave 1, 36% of parents reported that their insurance company would not pay for at least 1 aspect of care; the most commonly cited category for which insurance refused to pay (90%) was for special equipment.

Because the NLTS2 does not include children who are not classified by their school district, the conditions of asthma, learning disability and cerebral palsy were chosen for comparison. **Table II** compares several outcomes at Wave 3 for adolescents enrolled in the NLTS2 who had cerebral palsy, spina bifida, asthma, and LD. Adolescents with cerebral palsy had the lowest employment rate (23%), and those with learning disability had the highest rate (78%).

Logistic regression was used with factors from wave 3 reflecting participation in the WHO ICF model used as dependent variables in the equations, and factors from wave 1 reflecting Body Function & Structure, Activities, Environment and Personal Factors were used as independent variables. **Table III** (available at www.jpeds.com) shows the results from the logistic regression analyses. For example, when the dependent variable was *Spent time with friends or going on dates*, “Has hobbies, special interests or reads” was positively associated (odds ratio 1.9), and the following variables (odds ratio) were all negatively associated: “Takes prescription medication” (0.67), “Has problem with communication” (0.11), “Latino” (0.18), and “Trouble using arms or hands” (0.09). **Figure 2** (available at www.jpeds.com) shows the WHO ICF model for spina bifida with the variables from one of the logistic regression equations inserted.

**Table II.** Comparison of several outcomes with young adults who have cerebral palsy, asthma, and learning disability

| | Cerebral Palsy | Spina Bifida | Asthma | Learning Disability | Total |
|---|---|---|---|---|---|
| Competitively employed within the past 2 years* | 23% | 39% | 73% | 78% | 76% |
| Spent time with friends or going on dates† | 12% | 15% | 16% | 38% | 37% |
| Has driver’s license or learner’s permit‡ | 26% | 30% | 60% | 70% | 68% |

*$\chi^2 = 14460$, df = 3, $P < .001$.
†$\chi^2 = 7253$, df=3, $P < .001$
‡$\chi^2 = 20550$, df = 3, $P < .001$

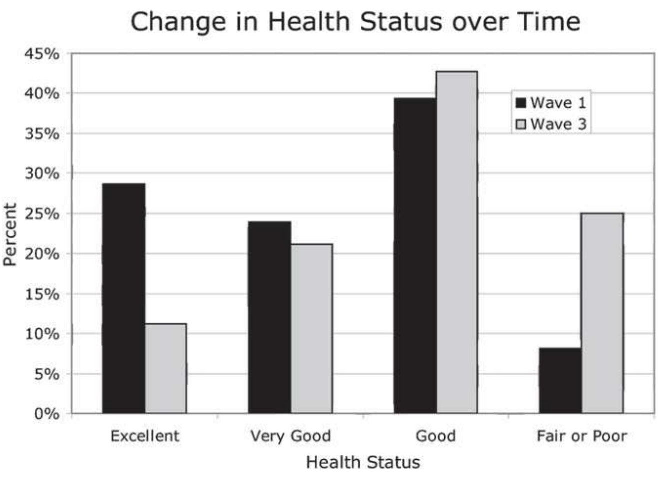

**Figure 1.** Change in the general health of the sample from Wave 1 to Wave 3, a 4-year span.

## Discussion

Individuals with spina bifida have physical disabilities, and most have learning disabilities as well[14]; therefore they are at increased risk for having difficulties with activities and participation. Adolescents and young adults with spina bifida in this longitudinal, nationally representative study were less likely to be competitively employed, spend time with friends, go on dates, or have a driver’s license or learner’s permit than adolescents with learning disabilities or asthma. These findings are consistent with previous studies that have found that adolescents with spina bifida are more isolated and have a lower-than-expected rate of independence, employment, and attendance in postsecondary education.[1-6,15]

In the United States, 41% of high school freshman and 85% of high school seniors hold down regular jobs either during the school year or during summer months.[16] The implications of limited early job experience on workforce readiness, long-term employment, economic status, and social functioning in adulthood are profound. In 2004, employment rates for the 14 million adults in the United States who had a disability (8% of adults ages 18 to 64 years) were substantially lower than for adults who did not have a disability (19% vs 77%). Related to this finding, adults who had a disability had a rate of poverty that is substantially higher than that of the population without disabilities (28% vs 9.2%).[17]

It is worrisome that the general health of the participants declined between waves 1 and 3. Health and well-being typically do not decline so dramatically during adolescence and young adulthood in individuals without spina bifida. Previous studies have documented declining health among adults with spina bifida. For instance, in a recent survey more than 50% (17/32) of adults had worse ambulation than expected for their neurologic level.[18] Renal damage is progressive and occurs in more than 30% of adults with spina bifida.[19] Preventable secondary conditions such as decubitus ulcers and obesity are common.[9] Olsson et al[20] have documented that adolescents continue to need long-term follow-up by urologists, neurosurgeons, orthopedists, therapists, orthotists, and others, but finding experts who are willing and able to take care of adults can be a challenge and "finding programs that can coordinate such complex care is even more difficult." All the individuals in this study had insurance. However, it is important to remember that in the United States nearly 30% of adolescents aged 18 to 29 years (with and without disabilities) have no insurance.[21] In addition, adolescents with spina bifida are more likely to be publicly insured. In this study, 48% had government insurance. It is likely that the decline in general health is occurring for several reasons, including the lack of coordinated health care, decreased formal social involvement as individuals leave school—with lower levels of fitness and possible depression from isolation—and deterioration from neurologic complications (like tethered spinal cord) that are not being addressed in a timely fashion.

As shown in the logistic regression equations, outcomes at Wave 3 that fall in the WHO ICF category of "Participation" are significantly affected by factors at an earlier age (wave 1) in the other WHO categories (Body Function and Structure, Activities, Environment, and Personal Factors). Volunteering was selected as an outcome because of the studies, which showed that taking care of others and volunteering can be a protective factor against adverse long-term outcomes.[22] They found that teens engaged in required helpfulness were more resilient and felt more empowered and confident about themselves. In this study, volunteering was positively associated with being above poverty, having the head of household employed, and being female; it was negatively associated with use of mobility aids and being Latino.

Being Latino or not speaking English at home had adverse effects on all the outcomes evaluated. In addition, those who were Latino had a greater decline in general health status. This finding may be related to being culturally different, or may be related to lower English proficiency. Others[23,24] have shown that being Latino or being limited in English proficiency can adversely affect access to care and health outcomes. Therefore interventions to optimize communication with those who are Latino or do not speak English fluently may improve outcomes. This is especially important because one of the goals of intervention is to encourage self-directed (autonomous) care for adolescents in addition to parent-directed care. An alternative explanation for some of the findings is that Latino individuals do not have the same regard for outcomes (like obtaining a driver's license) as non-Latinos. Therefore obtaining a license or achieving some of the other outcomes may not receive the same kind of commitment from people in these cultural groups.

Although communication is not often examined in individuals with spina bifida, in this study having problems with communication was negatively associated with 3 of the outcomes (being competitively employed, having a driver's license, and spending time with friends). Identifying problems with communication and intervening to improve it, for example with social skills groups or individual speech and language therapy, may help individuals with spina bifida with their social participation. In general, each outcome had its own pattern of independent factors that were associated with it and included factors relating to body function and structure (such as use of mobility aids), activities (like using arms or hands), and environment (like receiving services/ support at school).

Family income and education were associated with 2 of the outcomes. This is consistent with the findings from a Canadian study,[25] which showed that children's participation was less varied in families reporting lower income, and lower respondent parent education.

In this study, the diagnosis of spina bifida was made by the school district and confirmed by parents. Although the diagnosis of spina bifida is usually clear cut, the validity of classification by a school district has not been compared with diagnosis at a medical facility. It is possible, therefore, that children with less severe spina bifida were not classified by their district. Whether or not an individual had shunted hydrocephalus was not indicated; nor were specific measures of cognition recorded. Therefore we had to use a proxy, learning disability, for cognition. All the children in the National Longitudinal Transition Study 2 (NLTS2) have a disability. Thus no comparison group without a disability was available. On the other hand, this was a representative sample of 130 adolescents with spina bifida, representing 5171 individuals, who were followed up longitudinally for 4 years. This allowed a comparison of outcomes at the last evaluation with variables from 4 years earlier.

Future interventions to improve outcomes in adults with spina bifida will need to address factors in all domains and not just focus on medical factors. The WHO International Classification of Functioning, Disability, and Health (ICF) Model of Functioning and Disability provides insights into the health and well-being of individuals with spina bifida. ■

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**Table III.** Results of logistic regression analyses

| Characteristic (Wave 1) | Odds Ratio | 95% CI | *P* value |
|---|---|---|---|
| Dependent Variable: "Participated in volunteer/community service in the past 12 months" | | | |
| Above poverty | 27.5 | 14.5-52.2 | <.001 |
| Head of household employed | 5.8 | 3.9-8.7 | <.001 |
| Female | 2.4 | 1.9-3.1 | <.001 |
| Uses mobility aids | 0.28 | 0.18-0.44 | <.001 |
| Latino | 0.014 | 0.007-0.03 | <.001 |
| Dependent Variable: "Spent time with friends or going on dates" | | | |
| Has hobbies, special interests or reads | 2.21 | 1.79-2.74 | <.001 |
| Has problem with communication | 0.15 | 0.12-0.17 | <.001 |
| Latino | 0.22 | 0.17-0.28 | <.001 |
| Classified as learning disabled | 0.23 | 0.19-0.27 | <.001 |
| Trouble using arms or hands | 0.41 | 0.34-0.50 | <.001 |
| Takes prescription medication | 0.69 | 0.59-0.82 | <.001 |
| Dependent Variable: "Has a driver's license/learner's permit" | | | |
| Has a computer in the home | 7.42 | 4.90-11.25 | <.001 |
| Male | 3.21 | 2.58-4.00 | <.001 |
| Has problem with communication | 0.017 | 0.011-0.026 | <.001 |
| Latino | 0.431 | 0.289-0.641 | <.001 |
| Classified as learning disabled | 0.442 | 0.313-0.622 | <.001 |
| Dependent Variable: "Competitively employed or attending post-secondary education" | | | |
| English spoken at home | 9.1 | 5.0-16.7 | <.001 |
| Education of head of household | 6.1 | 4.7-7.9 | <.001 |
| Social cooperation score | 1.6 | 1.4-1.9 | <.001 |
| Has problem with communication | 0.03 | 0.02-0.05 | <.001 |
| Dependent Variable: "Shopping/hanging out at the mall or cafes/coffee shops or just driving around with someone" | | | |
| Reads books or has other hobbies | 7.86 | 5.10-12.19 | <.001 |
| English spoken at home | 6.07 | 4.08-9.04 | <.001 |
| Receiving enough services/support at school | 4.72 | 4.00-5.58 | <.001 |
| Male | 3.14 | 2.63-3.74 | <.001 |
| Classified as learning disabled | 0.233 | 0.196-0.277 | <.001 |

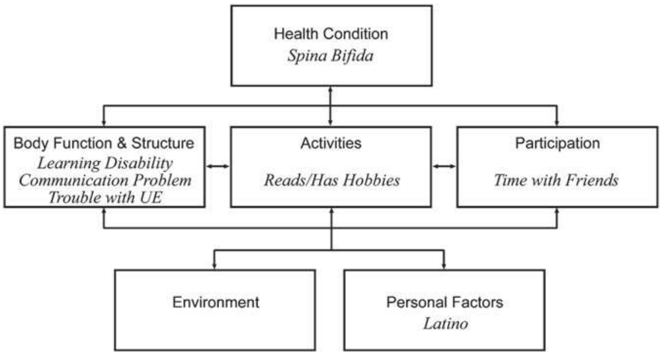

**Figure 2.** ICF model for the outcome: "Spends time with friends or going on dates." All the factors had a negative effect on the outcome except for having hobbies, which had a positive effect. Taking prescription medications, an index of severity, is not shown in the diagram and also had a negative effect.