

Oral presentation

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## Survey of individuals with spina bifida in Maryland, USA, 2004

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### Background

The Chesapeake-Potomac Spina Bifida Association (CPSBA) conducted a survey of individuals with spina bifida (SB) in Maryland during the first half of 2004 in order to assess their current status and unmet needs. The survey was sponsored by the Maryland State Office of Genetics and Children with Special Health Care Needs (OGCSHCN). The findings of this survey are to be used to inform programs and services and to identify the most important self-perceived challenges faced by individuals with spina bifida in the areas of health, education, daily living and employment and to determine areas of unmet service need.

### Materials and methods

A survey questionnaire composed of structured and semi-structured questions was developed with input from CPSBA, two regional SB centers, and OGCSHCN. Surveys were to be completed by the individual with SB or a caregiver. Prospective survey participants were identified using merged contact data from the two SB centers, two local chapters of the Spina Bifida Association of America and CPSBA (a regional affiliate), and OGCSHCN. Surveys were mailed to 644 potential survey participants. Of those, 125 (19.4%) returned the survey.

### Results

Of respondents, 49.6% were female, 73% were White, 7% Hispanic, 15% African-American, 2.4% Other. Mean age was 17.2 years with 15% aged birth to 5 years, 22% were 6–12 yrs, 34% were 13–21 yrs, and 22% were 22–59 yrs. Self-reported diagnosis was myelomeningocele in 80%, 81% were shunted, and 33.6% were totally wheelchair dependent for mobility. The top 3 problems across all age

groups were lack of control of bowels (74%), lack of control of bladder (72%), and public ignorance about SB (71%). Other problems reported by more than 50% included lack of recreation/sports activities, inadequate social life, emotional stress among family members, lack of information about resources, cost of medical equipment and supplies and cost of health care services not covered by insurance. Of individuals 18 years and older (N = 54), 68% completed high school, 24% went on to some college, and 11% obtained a college degree, yet 39% were totally unemployed. Common health problems included pressure ulcers, depression, and obesity. Self-perceived overall quality of life was excellent in 31%, good 48%, fair 17%, and poor 1%.

### Conclusion

Individuals with SB are aging. Most have good or excellent quality of life yet there are a number of common challenges that have not yet been overcome including continence, social and community integration.