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# Disability and Discussions of Health-Related Behaviors Between Youth and Health Care Providers

Elisabeth M. Seburg, M.P.H. [a,*], Barbara J. McMorris, Ph.D. [b], Ann W. Garwick, Ph.D., R.N. [b], and Peter B. Scal, M.D., M.P.H. [a,c]

[a] *Division of Epidemiology and Community Health, School of Public Health, University of Minnesota, Minneapolis, Minnesota*
[b] *School of Nursing, University of Minnesota, Minneapolis, Minnesota*
[c] *Department of Pediatrics, Medical School, University of Minnesota, Minneapolis, Minnesota*

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A B S T R A C T

**Purpose:** The purpose of this study was to examine the likelihood of discussing health-related behaviors with health care providers (HCPs), comparing youth with and without mobility limitations (MLs).
**Methods:** Analyses were conducted using baseline data from the MyPath study. Adolescents and young adults between the ages of 16 and 24 years completed a survey about their health care and health-related experiences. Analyses assessed the relationship between mobility status and discussing health-related behaviors with an HCP. Secondary analyses examined the extent to which adolescents and young adults' engagement in these behaviors was associated with these discussions.
**Results:** Overall, we found low rates of discussions about the following topics: substance use, sexual and reproductive health, healthy eating, weight, and physical activity. Adolescents and young adults with MLs were less likely to report discussing substance use and sexual and reproductive health, but were more likely to discuss healthy eating, weight, and physical activity than peers without MLs. Those adolescents and young adults who reported substance use had higher odds of discussing this topic and those who reported having sexual intercourse had higher odds of discussing sexual and reproductive health.
**Conclusions:** Results suggest mobility status and a young person's engagement in health risk and promoting behaviors are associated with the likelihood of discussing these behaviors with an HCP. It is important that HCPs view adolescents and young adults with MLs as needing the same counseling and guidance about health-related behaviors as any young person presenting him/herself for treatment.
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**IMPLICATIONS AND CONTRIBUTION**

Few adolescents and young adults—and especially few of those with mobility limitations (MLs)—discussed health-related behaviors with a health care provider. This community-based study confirms the need to develop and implement strategies to improve counseling in clinical settings, especially for youth with MLs.

Providing preventive counseling is a critical component of adolescent health services. Yet, many young people who experience difficulty with physical functioning because of a mobility limitation (ML) do not receive information or counseling regarding their health behaviors [1–3]. The low rates of routine counseling for health behaviors in this population are concerning for several reasons. Adolescents and young adults with MLs, similar to peers without disabilities, experience the physiologic and psychosocial changes of adolescence and engage in and establish health-related behavior patterns that influence their health trajectories across the life span [4,5]. In addition, the risk for poor health outcomes related to health risk behaviors may be amplified by the interaction between chronic condition, treatments, and behavior [3]. For

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* Address correspondence to: Elisabeth M. Seburg, M.P.H., HealthPartners Institute for Education and Research, 8170 33rd Ave S. Mail stop 23301A, PO Box 1524, Bloomington, MN 55440-1524.
*E-mail address:* Elisabeth.M.Seburg@HealthPartners.com (E.M. Seburg).

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example, alcohol use can influence bowel management among those with spina bifida [6], whereas recreational substance use can compromise effectiveness of medications prescribed for health conditions or symptom management [7].

Furthermore, low engagement in health promoting behaviors, such as eating a balanced, nutritious diet and engaging in regular physical activity, are associated with greater risk for obesity. Adolescents and young adults with MLs are at a higher risk for obesity than peers without disabilities [8,9]. In addition to increasing the risk for many chronic health conditions [10], obesity can negatively affect condition management and progression (e.g., pressure sores and muscle wasting) and limit a young person's capacity to perform self-care and activities of daily living [11].

Also of concern are the low rates of screening, counseling, and education about sexual and reproductive health for those with MLs. Similar to peers without disabilities, adolescents and young adults with MLs experience sexual development, engage in sexual activity, and have romantic and sexual relationships [12,13]. Likewise, these young people are exposed to negative health consequences associated with risky sexual behaviors [13]. Indeed, adolescents and young adults with disabilities experience greater risk of sexual abuse than those without disabilities [13]. Sexual development, sexuality, and reproductive health are relevant topics that should be routinely discussed and assessed in the health care setting for these young people [12].

As young people with MLs navigate their way through adolescence and the transition to adulthood, information and education about health behaviors should be viewed as important and relevant to their health and well-being. Health care providers (HCPs) are in a key position to provide screening, anticipatory guidance, and counseling regarding these behaviors, in the context of a young person's specific health condition [14]. The benefits of preventive counseling in a health care setting are well established, and young people themselves express a desire for this care [2,15,16]. However, provision of these services for adolescents and young adults with MLs remains persistently low. Studies have identified barriers to providing preventive counseling [17], such as time constraints [18], provider training [19], and provider perceptions of which young people would benefit from these services. However, further research is needed to examine the extent to which adolescents and young adults with MLs discuss these topics with their HCPs and the factors that influence the likelihood of these conversations.

The present study seeks to address research gaps using a community-based sample of adolescents and young adults, aged 16–24 years, with and without MLs. The study's first aim was to assess the impact of having a ML on the extent to which young people discuss health behaviors with their HCP. The second aim was to examine whether adolescents and young adults' own engagement in these behaviors is associated with the likelihood of talking to providers about sexual and reproductive health, substance use, healthy eating, and physical activity. This is the first study, to our knowledge, to investigate whether young people who are engaging in a particular behavior are more likely to discuss that behavior with an HCP.

## Methods

### *Participants*

Data are drawn from the baseline survey of the MyPath study, a prospective, longitudinal study of the health care and health-related experiences of a nonprobability, community-based sample of adolescents and young adults, collected between March 2011 and November 2012 in the upper Midwest region of the United States. To enroll adequate numbers of adolescents and young adults with and without MLs, separate recruitment strategies were used. Potential participants with MLs were recruited through targeted mailings sent from more than 120 study partners (HCPs, clinics, state agencies, school districts, colleges and universities, nonprofits and community organizations). Messages introduced the study and directed individuals to the research team to enroll. Our research team never had access to the names, contact information, or the number of individuals contacted; thus, we are unable to calculate a response rate. The cohort of participants without MLs was recruited through mailings to households in a five-state region (Minnesota, Wisconsin, Iowa, South Dakota, and North Dakota) with a high likelihood of having a 16- to 24-year-old living in the home. The list was purchased from Genesys Sampling Systems (Horsham, PA). Adult participants and parents of minors provided informed consent, and minors provided assent. Institutional review boards from the participating sites (when appropriate) approved study procedures.

Baseline data consisted of responses to the MyPath questionnaire (available for completion online, paper, and telephone) from 786 adolescents and young adults. All participants were between the ages of 16 and 24 years at the time of enrollment; those who did not speak English or did not have the cognitive ability to complete the survey were excluded. For this analysis, the analytic sample comprised 557 participants (287 with MLs and 270 without MLs) who reported having seen an HCP in the 6 months before completing the survey.

### *Measures*

Participants responded to questions assessing gender, age, ethnicity, race, and parent education level. Race was dichotomized into white or nonwhite; highest education level achieved by either parent was also dichotomized (college graduate or not a college graduate). In the present study, ML status was defined by self-report of having any of three specific conditions (spina bifida, cerebral palsy, or muscular dystrophy) and/or reporting any ML as measured by an adaption of the Gross Motor Functioning Classification System (GMFCS) [20]. The GMFCS self-report youth version is a tool for categorizing the gross motor functioning of youth based on the way they usually engage in each activity assessed. Thus, it assesses functioning within youths' environmental context reflecting the lived experience rather than gross motor assessment of capacity in a clinic setting. Youth are asked to select the GMFCS category that best describes their functioning. The five categories range from the most limited ("I have difficulty sitting on my own and have difficulty achieving any voluntary control of movement") to the least ("Can walk on my own without using walking aids but am limited in speed, balance and coordination") [20]. For this study, we provided a sixth category representing youth who perceive no limitation in their mobility. The survey assessed whether participants had a usual source of care and health insurance and the type of HCP they usually saw for checkups or if sick or hurt.

Questions about specific health behaviors were adapted for the study from the Centers for Disease Control and Prevention Youth Risk Behavior Survey [21] and the Minnesota Student Survey [22]. Participants responded to questions regarding use of alcohol, cigarette, and marijuana use during the past 30 days

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