SPECIAL REPORT

Health Literacy among Individuals with Disabilities: A Health Information National Trends Survey Analysis

Jenn Nguyen, PhD, MPH1; Lauren Gilbert, PhD, MPH, MA2

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ABSTRACT

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Introduction: Limited health literacy has been shown to be detrimental on health outcomes and the health care system, such as high rates of mortality and health care costs. A disability has been diagnosed in more than 19% of the US population, but the health literacy status of these individuals has yet to be adequately assessed.

Objective: To examine the health literacy concerns of a nationally representative sample of individuals with disabilities.

Methods: Data analysis using the Health Information National Trends Survey, a nationally representative survey sponsored by the National Cancer Institute. Descriptive analyses and χ^2 tests were conducted to examine the association between sociodemographics, disability status, and health literacy concerns. A weighted logistic regression model was performed to explore associations between disability status and each health literacy concern, controlling for sociodemographics.

Results: Results show 2 areas of concern for individuals with disabilities compared with those who did not report a disability: The effort to find needed information and being frustrated during the search for information. There was no difference detected between individuals with and without disabilities regarding being concerned about the quality of information found and believing that the information found was hard to understand.

Discussion: These findings do not support the notion that individuals with disabilities are more likely to experience health literacy difficulties than individuals without disabilities. However, accurately assessing and improving health literacy for the diverse group of individuals with disabilities requires tailored approaches and further attention.

Conclusion: Precise assessment of health literacy and disabilities is necessary to identify and address the unique concerns of this population.

INTRODUCTION

The US Census Bureau estimates that approximately 85.3 million individuals, or over 27% of the population, in the US have a disability. ^{1p2} This rate is expected to grow as the US population ages, with the current rate for people aged 65 years and older more than doubling. ² Individuals with disabilities are most likely to seek out health information to better communicate with their physician; learn about diet, exercise, and preventive health; and enhance their quality of health. ³ With the availability and incorporation of the Internet and mobile devices into our daily lives, the process of seeking health information has become ubiquitous. Those living with a disability are more likely than their nondisabled counterparts to use the Internet for health/medical information. ⁴ Yet, little is known

about the health literacy levels of disabled individuals and the experience of individuals with disabilities when they encounter medical information.

Health Literacy

Health literacy is defined as the ability to obtain, process, and understand basic health information to make appropriate health decisions. 5 Findings from the 2003 National Assessment of Adult Literacy showed that more than 77 million adults (or more than one-third of the population) struggle with basic health tasks, including following medication instructions or interpreting a pediatric immunization chart.6 Limited health literacy has been shown to be detrimental on health outcomes and the health care system, such as high rates of mortality and health care costs. Furthermore, the Institute of Medicine (now called the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine) presented overwhelming evidence linking limited health literacy and poorer health.7 Individuals with limited health literacy tend to neglect preventive health and health behaviors, possess less knowledge of health-promoting behaviors, and are more likely to have trouble navigating the health care system.8-10

Adequate and appropriate health literacy, a critical factor in health communication, is part of the health care continuum. Limited health literacy increases barriers to receiving adequate health care and, many times, results in poor health outcomes. It is estimated that inadequate health literacy is associated with annual health care expenditures approximating \$172 billion 11 and is seen as a contributing factor of health disparities. Per Yet, research on the impact of health literacy and health disparities has mainly been explored in racial/ethnic populations, and individuals with disabilities have traditionally been excluded.

Individuals with Disabilities

As defined by the Americans with Disabilities Act (ADA), an *individual with a disability* has a physical or mental impairment that substantially limits 1 or more major life activities. More than 115,000 males and 124,000 females older than age 18 years reported having a disability. The higher incidence among females is attributed to the greater number of women older than the age

Author Affiliations

¹ Mercer University College of Pharmacy, Atlanta, GA

² Mercer University School of Medicine, Macon, GA

Corresponding Author

Jennifer Nguyen, PhD, MPH (nguyen_jl@mercer.edu)

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of 65 years compared with men. Looking at race and ethnicity, Asians were least likely to report they had a disability (20.1%), followed by Hispanics (24.617.4%). African Americans were most likely to report a disability (34.9%), followed by those identified as other (33.2%) and non-Hispanic Caucasians (31.5%)¹

The most frequently reported disability involves difficulties with walking or climbing stairs, representing 12.6% of the civilian population aged 15 years and older in 2010. Another 6.3% of the population reported having a mental disability, with 1 or more conditions such as a learning, intellectual, or developmental disability. The third most common disability included difficulties seeing, hearing, or speaking (6.2%), followed by difficulties with different types of daily living activities, such as difficulties bathing, dressing, and eating (3.9%).¹

People with disabilities are more likely to report being in poor health compared with nondisabled people, ^{13,14} to engage in poor health behaviors, such as overeating and smoking, ^{13,15-17} and to have limited access to health care. ^{14,18} Individuals living with disabilities have health disparities that are unique to their circumstances. Research has shown that individuals with disabilities may have the greatest need for health literacy and health communication because they already face issues regarding access and poorer outcomes because of their disabilities. ^{14,18,19}

There are limited data that describe the health literacy concerns of individuals with disabilities, because of low priority, attention, and poor measurement. This study examines the health literacy concerns of a nationally representative sample of individuals with disabilities.

METHODS

Data Source

The data are from the Health Information National Trends Survey (HINTS) 4, Cycle 3.20 The HINTS is a nationally representative, cross-sectional survey of the American public's use of cancer-related information, including attitudes, beliefs, and behaviors. The survey contains items developed by subject matter experts or adapted from existing sources and then refined via cognitive testing. The survey was mailed from September 2013 through December 2013 to a stratified sample of residential addresses with a small monetary incentive. These addresses came from a database of addresses used by the Marketing Systems Group (Horsham, PA) and the group provided a random sample of addresses for survey mailings. The instructions specified that the adult in the household with the next birthday should be the person to complete the questionnaire. The overall response rate was 35.19%.²¹ Detailed information regarding development, design, and methods can be found elsewhere. 20,22 The HINTS 4 received institutional review board approval from the distribution agency (Westat, Rockville, MD) and was deemed exempt by the National Institutes of Health Office of Human Subjects. This particular cycle of HINTS is the only cycle to date that consists of items assessing a wide range of disabilities.²⁰

Participants

The sample included 3185 participants. Each participant received a full-sample weight and a set of 50 replicate weights. The

full-sample weight was used for 1) population and subpopulation calculation estimates and 2) ensuring valid inferences to the population, providing nonresponse and noncoverage biases correction. Replicate weights were used to compute standard errors (SEs).²⁰

Measures and Variables

Health Literacy

Health literacy was assessed with 4 items: "It took a lot of effort to get the information you needed"; "You felt frustrated during your search for information"; "You were concerned about the quality of the information"; and "The information you found was hard to understand." Participants endorsed the items on a scale from 1 (*strongly agree*) to 4 (*strongly disagree*). Each item was examined on its own. The 4 response categories were collapsed to dichotomize responses into agreement or disagreement of the statement.

Disability

Disability was assessed with 5 items. Participants responded to the following questions: 1) "Are you deaf or do you have serious difficulty hearing?"; 2) "Are you blind or do you have serious difficulty seeing, even wearing glasses?"; 3) "Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?"; 4) "Do you have serious difficulty walking or climbing stairs?"; and 5) "Do you have difficulty dressing or bathing?" An endorsement for any of the items resulted in being categorized as having a disability. Selection of a disability was not mutually exclusive, because respondents had the ability to endorse each disability statement as applicable. Furthermore, with discussion from experts, separation between a physical and mental disability was not possible based on the available data.

Sociodemographics

Standard measures assessed sample demographics, including age, race/ethnicity, education, relationship status, and income. Age was organized into 4 categories: 18 to 29 years, 30 to 49 years, 50 to 69 years, and 70 years or older. Education was also split into 4 categories: Less than high school degree, 12 years completed (high school diploma or equivalent), some college education or postsecondary technical training, and bachelor's degree or higher. Race/ethnicity was split into 4 categories: Non-Hispanic whites, non-Hispanic blacks, non-Hispanic other, or Hispanic. Annual household income was sorted into 5 categories: Less than \$20,000; \$20,000 to \$34,999; \$35,000 to \$49,999; \$50,000 to \$74,999; and \$75,000 or more. Relationship status was dichotomized into 2 categories: Partnered or single. Those who responded to "married" or "living as married" were considered to be partnered. The following responses were categorized as single: Divorced, widowed, separated, and single/never been married.

Statistical Analyses

Descriptive analyses and χ^2 tests were conducted to examine the association between sociodemographics, disability status, and each of the health literacy items. A weighted logistic regression model was performed to explore associations between disability status for each health literacy item (lot of effort, frustrated, concerned, and hard to understand), controlling for

sociodemographics. Data were analyzed using SAS version 9.4 (SAS Institute Inc, Cary, NC) to estimate SEs for the complex survey data and were weighted to adjust for nonresponsiveness, to adjust for oversampling, and to provide representative estimates of the US adult population.

RESULTS

Demographic Characteristics

Of the 3185 respondents, almost 24% (n = 759) reported a disability. Of those with a disability, most were white (65%), were middle aged (50-69 years; 33%), had a high school diploma or

Table 1. Weighted descriptive statistics Standard Characteristic Number (%) error Types of disability^{a,b} (n = 759) Deaf 236 (30.45) 2.76 Blind 149 (17.55) 2.17 Difficulty with decision making 300 (49.31) 2.95 442 (48.14) 2.81 Difficulty with walking Difficulty with dressing 118 (12.54) 1.65 2.45 Difficulty running errands 208 (23.17) Race/ethnicity (n = 639) 2.4 Non-Hispanic white 338 (64.87) Non-Hispanic black 134 (16.52) 2.17 1.94 Hispanic 125 (14.71) Other 42 (3.91) 1.04 Age, y (n = 744)18-29 32 (12.87) 3.13 30-49 136 (26.82) 2.67 50-69 338 (33.27) 2.31 ≥ 70 238 (27.04) 1.88 Education (n = 742) 2.36 Some high school or less 127 (19.29) High school diploma 234 (30.15) 2.57 Some post-high school training/college 243 (33.34) 2.78 College graduate 138 (17.23) 1.92 Annual household income, \$ (n = 627) < 20,000 327 (44.59) 3.06 20,000-34,999 107 (18.03) 2.14 35,000-49,999 88 (16.74) 2.17 50,000-74,999 71 (12.83) 2.00 ≥ 75,000 34 (7.83) 2.07 Sex (n = 742) 462 (53.84) 3.09 Women 3.09 Men 280 (43.16) Relationship status (n = 740) Married/partnered/living with someone 287 (53.17) 2.70 453 (46.84) Single/widowed/divorced 2.70

higher (81%), were in a relationship (53%), and had lower income (<\$20,000; 45%) (Table 1). The sample contained slightly more women than men (54%). The most reported disability was having difficulty with decision making (49%) followed by difficulty with walking (48%) (Table 1).

Health Literacy Variables Lot of Effort

The results from the weighted logistic regression, controlling for demographics, showed that respondents with a disability ($\beta = 0.27$, SE = 0.12, p = 0.03) and men compared with women ($\beta = 0.32$, SE = 0.15, p < 0.05) were more likely to endorse the

Table 2. Logistic regression model: Lot of effort							
Characteristic	β	SE (β)	OR (95% CI)	p value			
Disability							
No reported disability			Reference				
Yes, disability	0.27	0.12	1.7 (1.07-2.79)	0.03ª			
Race/ethnicity							
Other			Reference				
Non-Hispanic white	-0.28	0.12	0.86 (0.46-1.63)	0.03b			
Non-Hispanic black	0.09	0.21	1.25 (0.53-2.96)	0.66			
Hispanic	0.31	0.19	1.55 (0.69-3.50)	0.12			
Age, y							
18-29			Reference				
30-49	0.257	0.136	1.39 (0.71-2.75)	0.07			
50-69	0.085	0.120	1.17 (0.59-2.32)	0.49			
≥70	-0.269	0.173	0.82 (0.38-1.76)	0.13			
Sex							
Women			Reference				
Men	0.15	0.07	1.36 (1.01-1.83)	0.045a			
Education level							
Less than high school diploma			Reference				
High school diploma	0.288	0.124	1.24 (0.65-2.37)	0.03b			
Some college	-0.07	0.18	0.86 (0.38-1.95)	0.69			
College graduate or higher	-0.29	0.16	0.70 (0.32-1.54)	0.07			
Annual household income	e, \$						
< 20,000			Reference				
20,000-34,999	0.12	0.25	0.96 (0.47-1.95)	0.64			
35,000-49,999	-0.26	0.22	0.66 (0.33-1.33)	0.26			
50,000-74,999	0.17	0.189	1.01 (0.52-1.95)	0.38			
≥ 75,000	-0.20	0.17	0.71 (0.39-1.27)	0.25			
Relationship status							
Single/widowed/ divorced			Reference				
Married/partnered/living with someone	-0.12	0.10	0.78 (0.52-1.17)	0.23			

^a Indicates statistical significance (p < 0.05).

^a Selection of disability was not mutually exclusive; respondents had the ability to endorse each disability as applicable. Respondents were not required to answer all the items; variance regarding the number of responses for demographic variables was observed.

^b Because individuals could select multiple disabilities, there is some variance in the listed percentages.

 $^{^{\}mathrm{b}}$ Indicates p < 0.05 but is not statistically significant because of the inclusion of 1.0 in the 95% CI.

CI = confidence interval; OR = odds ratio; SE = standard error.

statement: "It took a lot of effort to get the information you needed" (Table 2).

Frustrated

A weighted logistic regression showed that individuals with a disability, controlling for demographics, were 1.81 times more likely to agree with the statement: "You felt frustrated during your search for the information," (β = 0.30, SE = 0.13, p = 0.03; Table 3).

Concerned about the Quality of the Information

Participants older than age 70 years were 0.40 times less likely than the youngest respondents (18- to 29-year-olds) to be concerned about the quality of information (β = -0.59, SE = 0.17, p = 0.001; Table 4). Hispanics, compared with those who self-identified as "other," were significantly more likely to be

Table 3. Logistic regression model: Frustrated Characteristic SE (B) OR (95% CI) p value Disability No reported disability Reference Yes, disability 0.30 0.13 1.81 (1.06-3.11) 0.03a Race/ethnicity Other Reference 0.99 (0.44-2.24) Non-Hispanic white 0.17 0.13 0.19 Non-Hispanic black 0.07 0.23 1.21 (0.52-2.88) 0.75 Hispanic -0.17 0.13 1.34 (0.72-2.50) 0.19 Age, y 18-29 Reference 30-49 0.30 0.16 1.26 (0.62-2.57) 0.07 50-69 0.08 0.14 1.01 (0.50-2.04) 0.58 ≥ 70 -0.44 0.22 0.60 (0.25-1.44) 0.05 Sex Women Reference 0.02 1.03 (0.71-1.51) Men 0.10 0.87 Education level Less than high school Reference diploma High school diploma 0.16 0.17 1.01 (0.40-2.54) 0.36 -0.12 0.19 0.77 (0.28-2.09) 0.53 Some college College graduate or -0.19 0.21 0.72 (0.25-2.08) 0.39 higher Annual household income, \$ < 20,000 Reference 20,000-34,999 0.44 0.24 1.33 (0.63-2.80) 0.08 0.25 -0.06 0.81 35,000-49,999 0.81 (0.36-1.83) 50,000-74,999 -0.01 0.19 0.85 (0.43-1.68) 0.97 -0.52 0.51 (0.26-1.05) 0.97 ≥ 75,000 0.20 Relationship status Single/widowed/ Reference divorced Married/partnered/ 0.07 0.09 1.14 (0.79-1.64) 0.48 living with someone

concerned about the quality of information (β = 0.39, SE = 0.18, p = 0.04; Table 4).

Too Hard to Understand

Individuals living in households with reported income of more than \$75,000 were 0.39 times less likely than individuals reporting household income of less than \$20,000 to report they encountered information that was too hard to understand ($\beta = -0.59$, SE = 0.23, p < 0.02; Table 5).

DISCUSSION

The results show that although some demographic groups have some concerns, individuals with disabilities are not statistically different compared with individuals without disabilities concerning health literacy and information seeking. The only

Table 4. Logistic regression model: Concerned about the quality of the information								
Characteristic	β	SE (β)	OR (95% CI)	p value				
Disability								
No reported disability			Reference					
Yes, disability	0.10	0.11	1.22 (0.77-1.92)	0.39				
Race/ethnicity								
Other			Reference					
Non-Hispanic white	-0.12	0.13	1.33 (0.75-2.35)	0.37				
Non-Hispanic black	0.13	0.16	1.70 (0.90-3.21)	0.43				
Hispanic	0.39	0.18	2.21 (1.14-4.29)	0.04ª				
Age, y								
18-29			Reference					
30-49	0.26	0.14	0.94 (0.54-1.63)	0.07				
50-69	0.003	0.10	0.72 (0.44-1.19)	0.98				
≥ 70	-0.59	0.17	0.40 (0.22-0.74)	0.001a				
Sex								
Women			Reference					
Men	0.17	0.09	1.40 (0.96-2.03)	0.08				
Education level								
Less than high school diploma			Reference					
High school diploma	-0.07	0.17	0.90 (0.42-1.90)	0.68				
Some college	0.04	0.17	1.00 (0.45-2.21)	0.83				
College graduate or higher	-0.01	0.17	0.96 (0.42-2.17)	0.97				
Annual household incon	ne, \$							
< 20,000			Reference					
20,000-34,999	-0.02	0.22	0.80 (0.40-1.61)	0.95				
35,000-49,999	-0.04	0.19	0.78 (0.42-1.45)	0.82				
50,000-74,999	0.13	0.18	0.92 (0.47-1.80)	0.49				
≥ 75,000	-0.28	0.16	0.62 (0.34-1.10)	0.09				
Relationship status								
Single/widowed/ divorced			Reference					
Married/partnered/ living with someone	-0.01	0.09	0.98 (0.68-1.42)	0.92				

 $^{^{\}rm a}$ Indicates statistical significance (p < 0.05).

a Indicates statistical significance (p < 0.05).

CI = confidence interval; OR = odds ratio; SE = standard error.

CI = confidence interval; OR = odds ratio; SE = standard error.

statements in which individuals with disabilities are more likely to endorse are: "It took a lot of effort to get the information you needed," and "You felt frustrated during your search for the information." Men with disabilities were more likely than women with disabilities to agree that it took a lot of effort to find needed information. Individuals older than age 70 years were less likely than individuals aged 18 to 29 years to be concerned about the quality of information, whereas Hispanics compared with individuals self-identified as "other" race/ethnicity were more likely to be concerned about information quality. Last, individuals with disabilities with a household income above \$75,000 compared with individuals in households with less than \$20,000 were more likely to agree that the information was hard to understand.

These findings, taken together, do not support the notion that there is an association between individuals with disabilities and health literacy difficulties. The main objectives of large nationally

Table 5. Logistic regression model: Information hard to understand							
Characteristic	β	SE (β)	OR (95% CI)	p value			
Disability							
No reported disability			Reference				
Yes, disability	0.18	0.14	1.43 (0.83-2.47)	0.19			
Race/ethnicity							
Other			Reference				
Non-Hispanic white	-0.01	0.17	0.72 (0.34-1.51)	0.94			
Non-Hispanic black	-0.42	0.27	0.48 (0.19-1.23)	0.12			
Hispanic	0.12	0.24	0.82 (0.33-2.05)	0.62			
Age, y							
18-29			Reference				
30-49	0.20	0.19	1.30 (0.68-2.49)	0.30			
50-69	0.06	0.13	1.13 (0.62-2.08)	0.67			
≥ 70	-0.18	0.19	0.89 (0.46-1.73)	0.34			
Sex							
Women			Reference				
Men	0.05	0.11	1.10 (0.70-1.74)	0.68			
Education level							
Less than high school diploma			Reference				
High school diploma	0.15	0.15	0.76 (0.35-1.65)	0.31			
Some college	-0.21	0.20	0.53 (0.20-1.39)	0.31			
College graduate or higher	-0.37	0.19	0.45 (0.18-1.14)	0.07			
Annual household income, \$							
< 20,000			Reference				
20,000-34,999	0.15	0.21	0.79 (0.41-1.52)	0.47			
35,000-49,999	-0.12	0.29	0.60 (0.26-1.39)	0.68			
50,000-74,999	0.14	0.21	0.78 (0.38-1.61)	0.50			
≥ 75,000	-0.59	0.23	0.39 (0.17-0.89)	0.02a			
Relationship status							
Single/widowed/divorced			Reference				
Married/partnered/living with someone	0.07	0.12	1.15 (0.71-1.86)	0.56			

^a Indicates statistical significance (p < 0.05).

representative surveys, such as the HINTS, are not to specifically measure health literacy or disabilities, resulting in a lack of sensitivity and precision. Although other scales and tools have been validated and used extensively, these are often not incorporated into these larger national surveys because it is not seen as practical or feasible. The demonstrated absence of differences between individuals with and without disabilities in this analysis could therefore be indicative that the measurements and items of the HINTS survey may not capture the nuances of health literacy difficulties and variations in this subgroup.

In 2017, the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine held a workshop titled, "People Living with Disabilities: Health Equity, Health Disparities, and Health Literacy." During the workshop, the discussants noted that despite comparable levels of health insurance status between individuals with disabilities and those without, adults with disabilities often have much poorer health outcomes. The experts noted that lack of data contribute to negative health outcomes and health disparities. Considering the many sources and outlets in which health information is now available, understanding the specific limitations (physical, mental, emotional) of individuals will be more salient, specifically in designing interventions. 10

Although physical and mental disabilities are commonly intertwined, there are distinct differences between mental and physical illnesses.^{24,25} Yet, many items and assessments do not parse whether encountered difficulties are because of mental or physical disabilities. For instance, the US Bureau of Labor Statistics included items in the American Community Survey that assess whether an individual has hearing issues; vision issues; difficulty walking or climbing stairs; difficulty dressing/ bathing; and difficulty concentrating, remembering, or making decisions.26 Because HINTS is also a government-sponsored survey, the included disabilities are the same. For this particular HINTS cycle, 23.8% of respondents self-reported a disability, yet the US disability prevalence rate in 2013 was only 10.8%.26 Items that parse differences in disabilities will provide content or context to disaggregate disabilities categorization and lead to a better understanding of this unique population.

In addition, health literacy is widely considered a dynamic construct, with constant evolutions and nuanced interpretations. There is no 1 correct definition for health literacy, with layers and multiple lenses dependent on individual and system-level factors. The Patient Protection and Affordable Care Act⁵ defines *health literacy* as the "degree to which an individual has the capacity to obtain, communicate, process, and understand health information and services in order to make appropriate health decisions." This definition encompasses a wide range of skills and resources, including information seeking.²⁷ As such, it is difficult to measure health literacy adequately and comprehensively. With at least 51 published instruments, researchers must carefully consider how to assess information seeking and health literacy.²⁸ Because of the time, space, and participant constraints of national surveys, these items are only a part of what health literacy is.

Furthermore, 3 fundamental assumptions must be considered when one appraises the health literacy needs for individuals with

CI = confidence interval; OR = odds ratio; SE = standard error.

disabilities. The first is that individuals with disabilities may differ in meaningful, significant, and undefined ways in terms of their healthy literacy needs. Second, the recognition of the unique barriers faced by individuals and communities with various disabilities must be addressed and highlighted. Finally, alleviating and overcoming these particular barriers can be empowering and may encourage active participation in and navigation of the complex health care system, which has been shown to result in more positive health outcomes.^{7,29}

CONCLUSION

Despite the results of this particular analysis, the evidence is limited on health literacy of individuals with any type of disabilities. Some research has highlighted the needs of individuals with intellectual and developmental disabilities in terms of general literacy and communication.^{28,30} However, most research on health literacy has ignored the needs of individuals with disabilities. Accurate assessment and improvement of health literacy for the diverse group of individuals with disabilities require tailored approaches and further attention. Future research can examine health literacy among these specific populations with tailored measurement tools for more valid and specific results. Targeted sampling efforts aimed at gathering more data on this population, as well as the different categories of disability (physical vs mental/emotional), would further illuminate the health literacy levels and needs. As national surveys are updated and fielded, the inclusion of nuanced and detailed measurements should be considered in future iterations to ensure precise and useful assessment and comparison. �

Disclosure Statement

The author(s) have no conflicts of interest to disclose.

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