The Digital Divide in Public E-Health: Barriers to Accessibility and Privacy in State Health Department Websites

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Abstract: State health departments have placed a tremendous amount of information, data, and services online in recent years. With the significant increase in online resources at official health sites, though, have come questions concerning equity of access and the confidentiality of electronic medical materials. This paper reports on an examination of public health department websites maintained by the 50 state governments. Using a content analysis of health department sites undertaken each year from 2000 to 2005, we investigate several dimensions of accessibility and privacy: readability levels, disability access, non-English accessibility, and the presence of privacy and security statements. We argue that although progress has been made at improving the accessibility and confidentiality of health department electronic resources, there remains much work to be done to ensure quality access for all Americans in the area of public e-health.

Key words: Internet, e-health, state governments, accessibility, confidentially, privacy, health literacy, disability, geographic variation.

S tate health departments have placed a tremendous amount of information, data, and services online in recent years. In Massachusetts, for example, visitors to the Department of Health and Human Services can use electronic forms to determine eligibility for assistance programs, to request American Sign Language interpreters, to renew professional licenses, to file medical claims, or to see data on provider care programs. The Pennsylvania Department of Health has a medical information clearinghouse covering major diseases, a list of nurses, and forms where visitors can register for emergency medical services courses. Several states, including California, New York, and Michigan, post consumer friendly data online, with the aim of allowing residents to compare quality and performance across hospitals, physicians, nursing homes, and other health care providers.^{1,2,3} Figures 1 and 2 provide screenshots of the home pages of the health department sites in Tennessee and California, respectively.

With the rapid increase in online resources at official health sites, though, have

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INSERT FIGURES 1 AND 2 ABOUT HERE

come questions concerning the quality of the information made available. Indeed, evidence suggests the quality of online health information varies widely along several dimensions, including accuracy, completeness, consistency, and readability.^{4,5,6} The quality of online information notwithstanding, there is also growing concern regarding equity of access and confidentiality of electronic medical materials. One third of the American population lacks Internet access.⁷ Due to disparities in access to digital technology, members of underserved groups are less likely to use the Internet, to visit various websites, or to have broadband capabilities. This is reflected in the results of one nationally representative survey, which indicates that 70% of Whites go online compared with 57% of African Americans.⁷ Whereas 89% of college graduates have access to the Internet, moreover, only 61% of high school graduates and 29% of those who did not graduate from high school have. These more general digital disparities are also reflected in health care, with African Americans, less well educated individuals, and those with lower incomes being much less likely to use home computers to acquire health or medical information from the Internet.8

From a social and political standpoint, therefore, there is growing pressure for policymakers to provide equitable access to quality online information and services. Indeed, advocacy groups representing those with little education, low literacy, and limited English proficiency have lobbied to ensure fair access to medical information on the Internet.⁹ Legally, equity is mandated for particular groups. This is reflected in the provisions of several federal statutes, including The Workforce Investment Act of 1998, which amended Section 508 of the Rehabilitation Act of 1973, to require that government agencies "develop, procure, maintain, or use electronic and information technology to ensure that Federal employees and members of the public with disabilities have access to and use of information and data, comparable to that of the employees and members of the public without disabilities."¹⁰ It is also reflected in the Americans with Disabilities Act of 1990, which extended federal civil rights protections in the areas of employment, transportation, public accommodations, and (most relevantly for our purposes) telecommunications beyond racial and ethnic minorities to include individuals with disabilities.

There are also economic incentives for improving accessibility. In order to reach the economies of scale necessary to make technology cost effective, governments must boost the number of website visitors. Anything that limits traffic weakens the long-term economic rationale for electronic or e-government, the term commonly used to refer to the provision of government-sponsored information and services through the Internet and other digital mechanisms.^{11,12}

At the same time, there is growing public concern about the privacy, security, and accessibility of government websites.¹³ In a 2003 national poll undertaken by the non-profit Council for Excellence in Government, the concerns voiced most frequently about e-government by respondents were terrorists making use of online information (32%), having less personal privacy (24%), hackers breaking into personal computers (19%), and people without Internet service getting less government service (13%).¹⁴ If citizens do not have confidence in public websites, they are not likely to make use of electronic resources.¹⁵

In this paper, we investigate the accessibility, privacy, and security of public e-health focusing on the health department websites maintained by the 50 state governments in the United States. We examined trend data for the chief public health agency in every state from 2000 to 2005. Typically, this was the department of health (or public health), although some states had a combined health and human services department. Each website was assessed for readability, disability access, non-English translation, privacy and security, and regional variation in each of these characteristics. Overall, we found that state health departments made progress over time on several of these dimensions, but that many public agencies continue to fall far short of fair and equitable e-health accessibility and confidentiality. There also are wide variations across regions, which make geographic disparities a concern for policymakers as well.

Readability. Literacy is the ability to read and understand information from text and other written formats. Three types of literacy have been assessed nationally: prose, document, and quantitative. Prose literacy refers to the ability to search, comprehend, and use continuous texts (e.g., editorials, news stories, brochures); document literacy to the ability to search, comprehend, and use noncontinuous texts (e.g., job applications, maps, tables, labels); and quantitative literacy to the knowledge and skills required to perform quantitative tasks (e.g., computing a tip, completing an order form, balancing a checkbook).¹⁶ The latest statistics rank performance on each of these tasks into four categories, with *below basic, basic, intermediate*, and *proficient* indicating the ability to perform progressively more complex and challenging literacy activities.

According to the most recent national survey, a significant proportion of American adults rank at the basic or below basic levels in each literacy area (prose (43%), document (34%), and quantitative (55%)).¹⁷ Not only is literacy a general problem in the United States, there also are troubling differences in literacy by race, ethnicity, education, and income. Minorities and those with limited educations and incomes typically have more difficulty comprehending texts than their counterparts. Take prose literacy, for example. At 32%, a smaller proportion of Whites score at basic/below basic literacy than Blacks (67%) or Hispanics (74%).¹⁷ Furthermore, literacy levels rise steadily with educational attainment, with 52% of high school graduates scoring at the basic/below basic levels compared with just 11% of those having at least some graduate work. A similar trend appears from the vantage point of employment status, with full time workers receiving higher average prose literacy scores (285 on the 0 to 500 scale used) than part time workers (281), unemployed workers (269), and non-workforce participants (255).

Poor literacy is a particular concern in the area of health due to the sensitivity of medical information and the importance of good health to quality of life and general well-being. As health departments put more information and services online, electronic resources must be made understandable to a wide range of consumers. This imperative is especially salient given growing evidence documenting significant health illiteracy and its relationship to cost, quality, and access.^{18–20} Health literacy has been defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make

appropriate health decisions" (p. vi).²¹ If official health websites are written at too high a level for visitors to comprehend, the technology revolution will not reach its full potential as a public health information tool.

Failure to write documents in a comprehensible way may also make it more difficult for state officials to address social, political, and economic inequities. A number of researchers have evaluated written communications from health warning labels, brochures, forms, and instructions to medical diagnoses to see if they are written at a widely understandable level.²¹ Results indicate that pamphlets and educational materials are frequently too complicated for the populations they are targeting. Indeed, a review of 216 published articles on health literacy by the Council on Scientific Affairs found widespread evidence of health illiteracy and clear links between poor literacy and inadequate understanding of medical treatments.²² Often, this research has documented racial disparities and other types of class-based barriers in medical comprehension.^{23–25} Although Medicaid enrollees on average read at approximately the 5th-grade level, most health care information is written at the 10th-grade level or higher.²⁶

Disability access. Another aspect of accessibility involves disability. U.S. Census figures for 2003 indicate that 49.7 million Americans have a long-lasting physical impairment. This includes 9.3 million with a disability involving sight or hearing, 21.2 million with a condition that limits basic physical activities, 12.4 million with a physical, mental, or emotional condition limiting learning or remembering, 6.8 million with a condition causing problems dressing or bathing, and 18.2 million with a condition making it difficult to go outside the home.²⁷

Given the fact that 19.3% of the American population suffers from one or more physical impairment,²⁷ it is critical that government web designers endeavor to ensure the accessibility of e-health resources, regardless of problems of sight, hearing, or movement. For example, for the visually impaired, it is crucial to have the right color contrasts in website texts and backgrounds so that people with limited vision can read what is on the computer screen. In addition, it is important to have text equivalent *alt* tags on images so that software used by the visually impaired which converts text to audio signals knows that a picture of the Capitol (or any other object) is of that building (or object). For individuals with hearing impairments, websites must display procedures for using Text Telephones (TTY) or Telecommunications Devices for the Deaf (TDD). These tools allow deaf individuals to communicate with government officials through text display devices. They require agencies to have designated phone numbers that the hearing-impaired can call, where both parties have access to TTY/TDD machines. For those with mobility constraints, data tables must be written in clear and hierarchical ways so that software programs can make sense of online information. Specialized software for those with mobility impairments help those individuals navigate complex databases and documents, through such means as voice commands or eye movements. Failure to have well-designed website features may drive potential users away and limit the traffic at the health site.

Non-English translation. Language accessibility is another major potential barrier to Internet access. Nearly 18% of the American population speaks a language

other than English at home. Of these, 45% have limited English proficiency; that is, they report speaking English only *well, not well,* or *not at all* as opposed to *very well.*²⁸ Lack of English proficiency raises questions regarding the ability of these individuals to make use of e-health resources. In some parts of the country, the portion of residents with limited English proficiency can rise to nearly one fifth of the population. The percentage with limited English proficiency ranges from less than 1% in West Virginia to more than 20% in California.²⁸ Whereas 14.3% of the population living in the West speaks English less than very well, 8.7% of the population in the Northeast does, followed by 6.6% in the South and 4% in the Midwest. Lack of English proficiency is especially high in certain metropolitan areas such as New York City (22%), Elizabeth, New Jersey (36.8%), Miami, Florida (47.1%), and East Los Angeles, California (51.9%).

The presence of so many people in the United States who have limited English proficiency represents a major challenge for health care providers, making it difficult for medical professionals who only speak English to communicate with these individuals and for non-English proficient speakers to comprehend health care information in English, whether in person or through the Internet, with potentially adverse consequences for health care access and outcomes. This is reflected in the findings of one study, which found that in a nationally representative sample Spanish-speaking Latino patients were significantly less likely than non-Latino White patients to have physician or mental health visits, influenza vaccinations, or mammograms during the previous year.²⁹ It is also reflected in the results of another study which found that Spanish-speaking Latinos reporting at least one physician visit during the previous three months had 22% fewer physician visits, on average, than non-Latinos whose native language was English.³⁰

Privacy and security. Privacy and security are major concerns of many web users. In a 2003 national survey undertaken by the non-profit Council for Excellence in Government, confidentiality worries were at the top of the list of problems Americans saw with government websites.¹⁴ People expressed fear over the privacy of online transactions and the dangers associated with confidential information stored online.

These issues represent a particular worry in the public health area because of the sensitivity of medical data. With state health sites increasing their number of online transactions, citizens fear security breaches that will compromise their private information. Among other things, information a person may wish to keep confidential includes his or her Social Security number, address, phone number, credit card numbers, income, medical status, and requests for services. Because of stigma, some people may be especially concerned that others find out that they have applied for public assistance. Well-publicized disclosures at some medical hospitals have intensified these concerns and placed privacy and security center-stage in e-health.³¹

Regional disparities in accessibility, privacy, and security. The United States exhibits considerable cross-regional variation in health policy and market characteristics.³² It also exhibits considerable regional variation in Internet access. Whereas 39% of Americans living in urban/suburban areas have high-speed Internet access,

for example, only 24% of rural Americans have.³³ In general, the proportion of Internet users is largest in the West (53%) and smallest in the South (41%), with the Midwest (47%) and Northeast (43%) falling in between.³⁴ At 5.3, moreover, the average number of hours individuals spend on the Internet per week in the West is nearly two hours greater than in the South (3.6) and one hour greater than in both the Midwest (4.1) and Northeast (4.2). It is one thing, therefore, to look at the overall situation on accessibility and confidentiality, but another to determine whether there are variations across geographic areas. Even if there has been progress in disability access or more attention devoted to privacy and security, it does not mean that all areas share in those improvements. There may be big differences between geographic areas that have consequences for public e-health.

Methods

Using a content analysis of the website maintained by each state's health department for the years studied, we investigated different dimensions of accessibility and privacy: readability levels, non-English accessibility, disability access, and the presence of privacy and security statements. Non-English accessibility and the presence of privacy and security statements were examined over a six-year period, 2000–2005. Because we did not start measurement on disability access and readability levels until later, we assess those characteristics over three years, 2003–2005. One of the principal problems with content analysis is that it often relies on subjective determination. To limit the degree of subjectivity involved in our analyses, we used automated software to evaluate readability levels and disability access. We also limited the degree of subjectivity involved in our other two areas by simply requiring coders to observe the presence or absence of non-English language materials and/or translation software and statements on privacy and security. Each website was examined by a single reviewer. Two reviewers were used each year.

To assess readability, we used a test of the grade-level readability of the first page of each health site. Our procedure was to employ the Flesch-Kincaid method. The Flesch-Kincaid test is a standard reading tool evaluator and is the one used by the United States Department of Defense. It is computed by dividing the average sentence length (number of words divided by number of sentences) by the average number of syllables per word (number of syllables divided by the number of words).³⁵ Its central premise is that many citizens' comprehension of the written word is limited to sentence structures and words that are neither complex nor lengthy. The algorithm for calculating reading level is included in Microsoft Word, which calculates the grade level for a particular portion of text based on the Flesch-Kincaid statistic it generates.

In order to determine how accessible state health websites were to the physically impaired, we scanned the first page of each website using Watchfire's BobbyTM software on usability (see www.Watchfire.com for format). This assessment tool scans online properties for a number of features designed to improve usability for different kinds of impairments. To assess whether a website was accessible to the

disabled, we took the attributes identified by Bobby[™] and applied the Priority Level One standard recommended by the World Wide Web Consortium (W3C) (www .w3.org). This is the minimum standard for website accessibility recommended by disability advocates. It checks for compliance with a variety of accessibility features such as text equivalents for audio, video, or pictures; the ability to generate text in a format for Braille displays or speech synthesizers; the use of effective color backgrounds; information that conveys the layout and structure of text/data; and adaptability to voice commands or head/eye movements. State health department websites were judged to be either in compliance or not in compliance based on the results of this test.

Evaluating the home page of each website is a conservative examination of readability and disability access. Since the home page is the portal through which users reach all other information, we suppose that webmasters prioritize home page readability and access before other portions of their websites. To the extent that we identify problems, therefore, those problems would probably be judged more severe if we delved deeper into the websites than we have done here.

To evaluate language access, we looked at whether state health websites provided information in languages other than English or had links to common translation software that would facilitate understanding. We began with each site's home page but searched further when non-English language materials were not readily observable. When such material was there, it was almost always in Spanish. Although it was beyond the scope of the present study to assess the completeness or accuracy of translations, typically the health department websites only provided a handful of key documents in a language or languages other than English. Translated documents accessible from the health department website were far more common than links to translation software. Like our assessments of readability and disability access, our assessment of non-English language accessibility was conservative since only a small portion of a state site need have been translated for us to count that site as being language accessible.

To evaluate privacy and security, we searched sites for any mention of a privacy and/or security policy. These were often found at the bottom of the home page in an *About Us*, privacy, or copyright section. We searched deeper into a website's content when such statements were not readily observable. We also examined the quality of health department privacy policies. In doing so, we determined whether the privacy statement prohibits commercial marketing of visitor information; use of cookies, which automatically create electronic profiles of website visitors; disclosure of personal information without the prior consent of the visitor; or disclosure of visitor information to law enforcement agents.

To examine the possibility that there are big differences correlating with geography that have consequences for e-health, we broke down the 2005 state health department measures of accessibility, privacy, and security by U.S. Census region (Northeast, Midwest, South, and West).

Results

Readability findings. To see whether the findings concerning readability discussed earlier held up for public e-health, we used the Flesch-Kincaid test to assess government health department websites in each of the 50 states for 2003, 2004, and 2005. As shown in Table 1, the average grade readability level of state health websites was 11.2th grade in 2003, 10.6th grade in 2004, and 10.9th grade in 2005. Seventy percent of sites in 2003, 50% in 2004, and 62% in 2005 were written at the 12th grade level. Only 6% in 2003, 16% in 2004, and 20% in 2005 fell at the eighth grade level or below, the reading level of half the American public.³⁶

Based on this analysis, it is clear that many state health sites are written well above the comprehension level of the average American. This makes it difficult for many people to use these sites to acquire timely health information, to compare health care providers, or to access online medical services. If past studies are to be believed, poor understanding of governmental websites may lead to unfavorable medical outcomes down the road.²²

Disability access findings. Our findings using Watchfire's Bobby[™] software show that in 2003, 30% of the state health department sites were accessible to the disabled, while 40% were compliant in 2004 and 42% met the W3C accessibility test in 2005. Although the trendline indicates some progress on disability access, it also is clear that the majority of state health websites are not accessible to the physically-impaired.

These results raise fundamental issues of justice and equity in public e-health. If medical sites are not accessible to the millions of visually, hearing, or physicallyimpaired individuals, this limits the benefits of electronic health resources for that

Table 1.

PERCENTAGE OF STATE HEALTH DEPARTMENT WEBSITES FALLING WITHIN READABILITY GRADE LEVELS

group of Americans. People in particular need of up-to-date and accurate health care information appear least able to share in the benefits of online government resources.

Non-English translation findings. In 2000, only 10% of state health sites provided any kind of non-English materials. The numbers were not much better over the next two years. Eight percent of state health department sites in 2001 had language translation and 10% had it in 2002. However, the level of non-English translations rose rapidly after 2002. In 2003, 32% of state health websites had medical information in languages other than English. This number increased to 44% in 2004 but dropped down to 34% in 2005, possibly because some agencies continued to take materials, such as information about anthrax or the spread of contagious diseases, off-line for security reasons.³⁷

Similar to the numbers for disability access, then, these numbers suggest that web designers are making progress at narrowing the access gap for those with limited English proficiency, but still have a long way to go before equal access is obtained. At the national level, statutes concerning elections require that communities with non-English speaking populations exceeding 5% must provide ballots in the native language of that group.³⁸ This is also true of federal education policy, which requires that students with limited English proficiency be eligible for services at the same level as other students.³⁹ Our results indicate that if standards such these were applied to state health departments, many states would not meet them.

Privacy and security findings. As shown in Table 2, there have been major improvements in state health department websites providing privacy and security statements outlining how these issues are addressed in terms of electronic information. In 2000, only 8% of health departments had an online privacy policy and only 4% had a security policy. However, by 2005, these numbers had grown to 86% for privacy policies and 62% for security policies. This growth in privacy and security policies likely reflects implementation of Title II of the Health Insurance Portability Act (HIPA) of 1996, which established privacy rights and controls through standards governing the use of patient information, in addition to security standards protecting the confidentiality, availability, and integrity of protected information.⁴⁰ All covered entities but small health plans had to comply with privacy standards by April 2003 and with security standards by August 2005.

As shown in Table 3, we found major improvements in the quality of health

Table 2.

PERCENTAGE OF STATE HEALTH DEPARTMENT SITES HAVING PRIVACY AND SECURITY POLICIES

	2000	2001	2002	2003	2004	2005
Privacy policies	8	32	46	68	76	86
Security policies	4	22	38	46	50	62

Table 3.

	2001 (%)	2002 (%)	2003 (%)	2004 (%)	2005 (%)
Prohibit commercial marketing	14	48	42	52	82
Prohibit cookies	16	4	16	18	26
Prohibit sharing personal information	12	42	44	38	80
Share information with law enforcement	—	40	44	42	76

QUALITY OF STATE HEALTH DEPARTMENT WEBSITE PRIVACY STATEMENTS

department privacy policies over the last few years. In 2001, only 14% of state health websites prohibited the commercial marketing of information provided by visitors, 16% prohibited cookies, and 12% banned the sharing of personal information without prior consent. However, by 2005, the quality of privacy policies had improved. Eighty-two percent had policies prohibiting the commercial marketing of visitor information. Twenty-six percent prohibited the use of cookies or individual profiles. Eighty percent said they did not share personal information, a marked increase from 38% during the previous year. This is in contrast to 76% which said they could disclose visitor information to law enforcement agents, up from 42% a year earlier. Together with the increase in states unwilling to share personal information with other entities, the increase in states willing to disclose information to law enforcement agencies reflects, in part, effects of the Patriot Act and the *9-11 Commission Report*.^{41,42}

Regional disparities in accessibility, privacy, and security: Findings. As shown in Table 4, there were major disparities in accessibility, privacy, and security by geographic area. The South was best in terms of having state health websites that were readable (23% of its sites at the 8th grade or less), while Western states were the worst at 15%. Southern states also were the most likely (at 62%) to provide disability access to their websites, while the West was the least likely (23%). And on non-English language accessibility, the South and West were most likely to provide non-English websites (38% each), compared to the Midwest (29%) and Northeast (30%). This latter finding reflects, in part, the large number of Spanish speakers in the Southwestern United States. While 29.4% percent of the population living in the West speaks a language other than English at home, 20% of the population in the Northeast does so, 15% in the South, and 9.4% in the Midwest.⁴³

On the dimensions of privacy and security, Midwestern states (100% of state health department websites) were most likely to have privacy policies, while the South was least likely (77%). With respect to security, the Midwest had the highest percentage of security policies (71%), while the South had the lowest (46%).

In short, it matters where one lives for access to e-health. There was no single region that was strong on all areas of accessibility, privacy, and security. Rather,

Table 4.

	Readable at 8th grade (%)	Provide for disabled access (%)	Provide for language access (%)	Have privacy policies (%)	Have security policy (%)
Northeast	20	50	30	80	70
Midwest	21	36	29	100	71
South	23	62	38	77	46
West	15	23	38	85	62

REGIONAL DISPARITIES IN ACCESSIBILITY, PRIVACY, AND SECURITY AT STATE HEALTH WEBSITES, 2005

there were substantial variations from region to region in how public health officials were able to provide access to electronic resources, stemming, in part, from differences in the bureaucratic, fiscal, and political contexts within which they work.⁴⁴ Even with improvements in access to e-health over time, there remain areas that lag behind the overall trend.

Discussion

According to Section 508 of the Rehabilitation Act, government agencies are required to provide equal access regardless of physical impairment. Courts and policymakers have interpreted this to apply not just to bricks and mortar government but also to electronic government. Part of the hope is that all citizens will share equally in the benefits of digital technology. Indeed, according to one authority, technology should enable "more than 90% of all households [to be] successful users of information and communications services" (p. 85).⁴⁵ Based on that standard, public e-health clearly has a long way to go. Regardless of whether one looks at accessibility linked to literacy, physical impairment, or language skills, state health department websites must make much more progress than they have to date. The level at which public health sites are written represents a major accessibility barrier as does the failure of many government sites to be usable by the disabled or those who do not speak English.

National data reveal that only 22% of the disabled have access to the Internet,⁴⁶ despite the fact that there is software for the visually, hearing, and physicallyimpaired that converts information to audio, text, or other kinds of electronic signals, thereby enabling those who cannot see, hear, or move well to access website content. However, sites must be designed in a way to allow these software programs to function properly. While images need *alt* text labels that identify the nature of the picture, for example, data tables must be set up in a clear and hierarchical manner. Unless websites are configured in such a way that all Americans can share in the benefits of new technology, the advantages of the Internet in terms of information and service availability will be denied to those unable to take advantage of conventional online resources.

One step toward closing the digital divide in public e-health is to reduce regional variation in accessibility, privacy, and security. Whereas Southern states tend to host more accessible websites, Midwestern states tend to place more emphasis on confidentiality. Although interstate differences contribute to existing inequities, they also suggest an opportunity for progress. Clearly, some states perform better than others and this is not just true with respect to e-health, but it is true with respect to use of the Internet more generally. Among the top performing states in e-government are Massachusetts, Texas, Indiana, Tennessee, California, Michigan, Pennsylvania, New York, and Kentucky.⁴⁴ Though values, fiscal capacity, and the extent of bureaucratic intransigence contribute to geographic variation in e-government, leading states can serve as models against which other states judge their performance. This interstate benchmarking between laggard and innovative states has been shown to create pressures that spur the diffusion of public policies and governmental practices nationally.⁴⁷ If combined with positive Federal incentives, which have been shown to promote more rapid diffusion of innovations,⁴⁸ the current gap in public e-health between information haves and have-notes could be closed.⁴⁹ In the meantime, inaccessible websites hurt the underprivileged and make it difficult to justify the investment in technology that has taken place in state governments around the country. Unless these concerns are addressed, public e-health will remain the domain of highly educated and affluent individuals who speak English and do not suffer from physical impairments.

Notes

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