

## INNOVATION REPORT

# Self-Reported Accommodation Needs for Patients with Disabilities in Primary Care

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**Background:** People with disabilities experience barriers to engaging with health care due to inaccessible social and physical environments at primary care clinics. Despite legal mandates, identification and provision of necessary accommodations for this population at primary care clinics are poor. The objective of this cross-sectional study was to assess patient-reported disability status and accommodation needs among patients at a primary care clinic.

**Methods:** An electronic health record–based Disability and Accommodations Questionnaire assessing disability status, types, and accommodation needs was developed by subject matter experts at Michigan Medicine and the University of Michigan Council for Disability Concerns. The questionnaire underwent multiple rounds of reviews and revisions before its use in clinical settings. A paper-based questionnaire was administered to all patients presenting for a wellness-based visit at an academic health system primary care clinic in southeast Michigan. Data were collected between March 2022 and August 2022.

**Results:** Approximately 13% of the 541 patients self-reported a disability, with 54.2% indicating at least one needed accommodation. The most commonly reported disabilities were mental health and hearing-related disabilities, by 4.8% and 4.6% of patients, respectively. The most frequently requested accommodations were communication- or language-based (for example, presence of an American Sign Language interpreter, assistive listening devices), cognitive-based (for example, inclusion of a support person with care decisions), and mobility-based (for example, assistance with transfers).

**Conclusion:** The Disability and Accommodations Questionnaire helped identify the presence of a disability, its types, and any requested accommodations requested at a primary care health center.

In 2016 more than 60 million Americans reported having a disability.<sup>1</sup> People with disabilities (PWD) struggle with significant health disparities, including worse health outcomes, decreased satisfaction with medical care, and poorer access to diagnostic, preventive, and primary care services.<sup>2,3</sup> A recent study indicated that 59.3% of physicians lacked confidence in their ability to provide equal quality care for PWD, highlighting a significant knowledge gap.<sup>4</sup> The Americans with Disabilities Act of 1990 (ADA) and Section 1557 of the Affordable Care Act (ACA) mandate that public and private health care facilities provide equal access to services for PWD. Section 4302 of the ACA also states that there should be a set of uniform data collection standards for inclusion in surveys used in health care, including those with disabilities.<sup>5</sup> Despite these legal stipulations, the identification of disabilities and the provision of necessary accommodations for PWD in health care settings, including primary care, remain poor.<sup>2–4,6–12</sup>

Disability-related accessibility barriers to health care can compromise each of the six domains of health care quality, particularly patient-centeredness, effectiveness, and eq-

uity.<sup>13</sup> For example, deaf patients who require the use of an American Sign Language (ASL) interpreter must be provided access to an interpreter for effective communication to occur between patients and providers<sup>14</sup>; patients with cognitive, intellectual, and developmental disabilities should be provided person-centered care and dignity in care, including involvement of caregivers to the extent needed by the patient<sup>15</sup>; and patients who use wheelchairs should receive appropriate screenings, including a physical examination on an accessible exam table.<sup>16</sup> Without these accommodations, PWD are at risk of missed or delayed diagnosis of health conditions and poorer management of their health.<sup>17</sup>

The importance of disability-related accommodations, for regulatory compliance and higher-quality care, is juxtaposed to the relatively poor guidance provided by health systems to care staff responsible for implementing accommodations.<sup>18</sup> Understanding a clinical service's engagement with PWD and their accommodation needs allows for tailored methods to improve the quality of care for this priority population. This remains a challenge due to an absence of systematic collection of disability-related information in health care settings. Limited and prior efforts have included the American Community Survey (ACS) six-item

disability questions to help identify patients with a disability.<sup>19</sup> These efforts failed to capture accommodations that patients with disabilities may require for their primary care appointments. In addition, there is scarce literature documenting the proportion of patients with disability-related accommodation needs in primary care settings.

Therefore, the purpose of this study was to identify the overall prevalence of disability, the most common types of disabilities present, and accommodations requested at a primary care health center. This was intended to be descriptive and informative for our primary care team and to assist in streamlining the provision of accommodations.

## METHODS

A clinical informatics intervention (Disability and Accommodation Questionnaire) was implemented to identify the presence of a disability, including the type, and to better capture accommodation needs among patients with disabilities.<sup>20</sup> As part of the implementation of this intervention, a paper-based disability questionnaire (Appendix 1, available in online article) was developed for use in ambulatory care settings.

Our questionnaire differs from the more commonly used Washington Group questions and the ACS six-item disability questions.<sup>21</sup> This was done on purpose as those questions have implementation issues at a clinical level. For example, the ACS questions measure only functional or activity limitations (for example, difficulty seeing and difficulty concentrating). For instance, one question on the ACS asks, "Because of a physical, mental, or emotional problem, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?" This question combines multiple functionally and qualitatively different disability categories that have different indicated accommodation needs. As a result, we opted to be specific with respect to the type of disability a patient presents. In addition, there were concerns from our Council for Disability Concerns that the language implies that only those with severe types of disabilities (for example, deaf or having serious difficulty hearing) should respond in the affirmative even though milder forms may still benefit from an accommodation. Although no validation studies were conducted, the development of the questionnaire was done with patient and community feedback, and the questionnaire was derived from our Disability and Accommodations Questionnaire on our Epic-based electronic health record system.

The Disability and Accommodations Questionnaire and its subsequent paper format, along with disability types and affiliated disability options, were developed by subject matter experts at Michigan Medicine and the University of Michigan Council for Disability Concerns.<sup>22</sup> This included patients, community members, staff and faculty members with disabilities, disability advocacy groups, service centers, and clinicians who work routinely with patients with

disabilities. The development of the questionnaire was led by the Accessibility Task Force through the University of Michigan's Center for Disability Health and Wellness.<sup>23</sup> The questionnaire underwent multiple rounds of reviews and revisions with council members before its use in clinical settings.

The questionnaire was administered to all new and established patients presenting for wellness-based visits (for example, health maintenance exams) at an academic health system primary care clinic in southeast Michigan between March 2022 and August 2022. Patients presenting for other types of health care visits, such as acute visits, were not targeted and did not receive the questionnaire. This was due to time constraints and shorter appointment times for non-wellness visit types. Patients received the questionnaire at appointment check-in and were asked to complete the survey prior to being seen. Patients were also informed that assistance completing the form was available. A paper questionnaire with larger font was also available for those with low vision. All questionnaires had an attached patient-specific label that included the patient's name, medical record number, date of birth, and date of service to ensure that information was properly collected and entered into the right patient's chart. On completion, surveys were collected by medical assistants and subsequently entered into the patient's medical record. Hard copies of the questionnaires were also made available to the research team for data entry purposes and analysis. Patient-related information on these hard copies permitted linkages to the patient's health record for further data abstraction, including gender, sex, race, and ethnicity.

The primary outcomes of this study were whether a patient reported having a disability and, if so, the type(s) of disability, and whether they needed accommodations and, if applicable, the types of accommodation(s) requested. The presence of a disability and the need for accommodations were categorized via "yes" or "no" responses. The disability and accommodation types could be selected from a list<sup>20</sup> or entered as free text. Descriptive analysis was conducted using SAS 9.4 statistical software (SAS Institute Inc., Cary, North Carolina). The study was approved by the [blinded] Institutional Review Board (IRBMED).

## RESULTS

A total of 541 completed surveys were included in the analysis. The mean age of the sample was 46.7 years (range: 7 to 89 years). The majority of respondents were female (56.2%), white (93.0%), non-Hispanic (93.9%), and English-speaking (96.9%) (Table 1). Approximately 13% of respondents self-reported having a disability, and the most common disabilities indicated were mental health and hearing-related disabilities, with 4.8% and 4.6% of patients, respectively. In addition, 5.7% of respondents re-

**Table 1. Patient Characteristics**

Characteristic	Responders (N = 541) n (%)
<b>Age (in years)</b>	46.7 (SD 20.4)
<b>Gender*</b>	
Female	304 (56.2)
Male	237 (43.8)
<b>Sex*</b>	
Female	305 (56.4)
Male	236 (43.6)
<b>Race*</b>	
American Indian or Alaska Native	2 (0.4)
Asian	13 (2.4)
Black	7 (1.3)
Native Hawaiian and Other Pacific Islander	1 (0.2)
White	503 (93.0)
Other	7 (1.3)
Patient Refused	4 (0.7)
Unknown	4 (0.7)
<b>Ethnicity*</b>	
Hispanic or Latino	11 (2.0)
Non-Hispanic or Latino	508 (93.9)
Patient Refused	13 (2.4)
Unknown	9 (1.7)
<b>Preferred Language</b>	
English	524 (96.9)
Farsi; Persian	1 (0.2)
Russian	1 (0.2)
Sign Language	15 (2.8)

\* Gender, sex, race, and ethnicity were abstracted from the patients' charts.  
SD, standard deviation.

**Table 2. Self-Reported Patient Disability and Type**

Characteristic	Responders (N = 541) n (%)
<b>Disability</b>	
No	469 (86.7)
Yes	72 (13.3)
<b>Blind/Low Vision</b>	
No	533 (98.5)
Yes	8 (1.5)
<b>Cognitive, Intellectual, or Developmental Disability</b>	
No	522 (96.5)
Yes	19 (3.5)
<b>Deaf, Hard of Hearing, or Deaf-Blind</b>	
No	516 (95.4)
Yes	25 (4.6)
<b>Mental Health Disability</b>	
No	515 (95.2)
Yes	26 (4.8)
<b>Mobility disability and/or use a wheelchair</b>	
No	524 (96.9)
Yes	17 (3.1)
<b>Respiratory disability</b>	
No	537 (99.3)
Yes	4 (0.7)
<b>Speech/Communication Disability</b>	
No	527 (97.4)
Yes	14 (2.6)
<b>Other Sensory Disability</b>	
No	530 (98.0)
Yes	11 (2.0)
<b>Upper Body and Fine Motor Skill Impairment</b>	
No	533 (98.5)
Yes	8 (1.5)
<b>Dual Disability</b>	
No	510 (94.3)
Yes	31 (5.7)

ported having more than one disability (dual disability) (Table 2).

Approximately 8% of all respondents indicated that they needed accommodations, but not all of these patients reported a disability. Among those who reported a disability, 54.2% indicated that they needed accommodations. The most frequently requested accommodations were communication- or language-based (for example, presence of an ASL interpreter, assistive listening devices) cognitive-based (for example, inclusion of a support person with care decisions), and mobility-based (for example, assistance with transfers) (Table 3). For those self-reporting low vision, large print was most often chosen. For those with mental health-based, speech/communication-based, and upper body/fine motor skill-based disabilities, the top requested accommodations were assistance and modifications to how care was delivered. Listed accommodations requested ranged from assistance with managing emotions and completing patient intake forms to providing additional time for facilitated patient-provider communication and comprehension.

## DISCUSSION

This is the first known study that incorporated a questionnaire that captured patients' disability status, disability types, and accommodation need in a primary care setting. This critical step provided an opportunity to start the process of ensuring accessible health care for patients with disabilities. Overall, 13.3% of respondents reported a disability. Although this is lower than the national prevalence of disabilities (27.2%),<sup>24</sup> it still represents a significant volume of patients at a large primary care-based health center. The documentation of patient's disability-related information, including specific accommodations required by the patient, differs from prior efforts (for example, based on ACS six-item disability questions) and can be useful for health care providers and staff in preparing for upcoming health care appointments and patient-based accommodations.

Table 3. Accommodations Requested Grouped by Disability Type	Accommodations Requested (N = 43)*, n (%)†
<b>Accommodations, Grouped by Disability Type</b>	
<b>Blind/Low Vision Accommodation‡</b>	<b>6 (14.0)</b>
Documents provided in large print	6 (100.0)
Screen readers	2 (33.0)
<b>Cognitive, Intellectual, or Developmental Accommodation‡</b>	<b>13 (30.2)</b>
Assistance with completing surveys/patient intake	4 (30.8)
Checks for understanding	4 (30.8)
Closed captioning during video visits	2 (15.4)
Do you want to give people information in advance before going to the clinic?	1 (7.7)
Support person who needs to receive aftercare documents	7 (53.8)
Support person who needs to be involved in medical discussions	9 (69.2)
Do you need directions/follow-up in writing?	7 (53.8)
Visuals or pictures to explain concepts	1 (7.7)
Modifications to the COVID-19 mask policy	2 (15.4)
Modifications to the COVID-19 visitor policy	1 (7.7)
Reduced sensory	1 (7.7)
<b>Deaf, Hard of Hearing, or Deaf-Blind Accommodation‡</b>	<b>17 (39.5)</b>
Assistive listening devices	4 (23.5)
ASL interpreter	11 (64.7)
Closed captioning during video visits	2 (11.8)
Providers and staff wear a clear mask	4 (23.5)
Deaf, directions/follow-up in writing	2 (11.8)
Quiet space for communication	1 (5.9)
Real-time captioning	2 (11.8)
Written communication/information	3 (17.6)
Modifications to the COVID-19 visitor policy	1 (5.9)
<b>Mental Health Accommodation‡</b>	<b>7 (16.3)</b>
Additional structure and assistance regulating emotions	3 (42.9)
Clear protocols to help you prepare for care	4 (57.1)
Reduced sensory input	1 (14.3)
Directions/follow-up in writing	3 (42.9)
Modifications to the COVID-19 mask policy	1 (14.3)
Modifications to the COVID-19 visitor policy	1 (14.3)
<b>Mobility Accommodation‡</b>	<b>8 (18.6)</b>
Adjustable tables	3 (37.5)
Assistance with transfers and walking	6 (75.0)
Availability of transfer equipment (for example, a lift, a transfer board)	1 (12.5)
Human assistance with transfers	2 (25.0)
Larger exam rooms	4 (50.0)
Wheelchair scales	3 (37.5)
Modifications to the COVID-19 mask policy	1 (12.5)
Modifications to the COVID-19 visitor policy	1 (12.5)
Other accommodations	2 (25.0)
<b>Respiratory Accommodation‡</b>	<b>1 (2.3)</b>
Modifications to the COVID-19 mask policy	1 (100.0)
Plug outlet for an oxygen concentrator	1 (100.0)
<b>Speech/Communication Accommodation‡</b>	<b>12 (27.9)</b>
Closed captioning during video visits	4 (33.3)
Providers to confirm your understanding	7 (58.3)
Additional time to speak	9 (75.0)
Understanding prompts from the provider	2 (16.7)
Whiteboards for communication	1 (8.3)
Other accommodations	1 (8.3)
<b>Other Sensory Accommodation‡</b>	<b>6 (14.0)</b>
Fragrance-free environment	4 (66.7)
Limited touch	1 (16.7)
Placement in a room early	2 (33.3)
Other accommodations	1 (16.7)

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**Table 3. (continued)**

Accommodations, Grouped by Disability Type	Accommodations Requested (N = 43)*, n (%) <sup>†</sup>
<b>Upper Body and Fine Motor Skill Impairment Accommodation<sup>‡</sup></b>	<b>6 (14.0)</b>
Assistance with clothing management	3 (50.0)
Assistance with completing surveys/patient intake	4 (66.7)
Modifications to the COVID-19 mask policy	1 (16.7)
Modifications to the COVID-19 visitor policy	1 (16.7)
Other accommodations	1 (16.7)

\* Four patients requested accommodations but did not identify as having a disability or answer "Yes" to the "Do you need accommodations?" question.

<sup>†</sup> Note: The percentage of patients requesting specific accommodations (for example, "Screen readers," n = 2) was calculated within the corresponding disability type groupings (for example, "Blind/Low Vision Accommodation," n = 6). Some respondents requested more than one specific accommodation, so percentages for specific accommodations may total more than 100% within the disability type groups.

<sup>‡</sup> Percentage is based on total number of patients requesting an accommodation (n = 43).  
ASL, American Sign Language.

Among individuals who indicated that they had at least one disability, there was a nearly equal split between those who requested accommodations and those who did not. Furthermore, there was significant variability in the types of accommodations requested, even among those who reported having the same type of disability. This finding highlights a crucial need for health care providers and staff to avoid making assumptions when it comes to providing accommodations and to allow patient preferences to guide which accommodations should be provided. We recommend that other primary care clinics conduct similar surveys of their patients to identify which accommodations are required.

The Disability and Accommodations Questionnaire, with its data entry into the electronic health record's Disability and Accommodations Tab, provides an opportunity to make disability-related information available to the entire health care team, not just the assigned primary care provider. This addresses the need to standardize disability-related patient information to identify those with a disability and also to initiate steps to proactively arrange for any requested accommodations. The ACA's Section 4302 requires health care systems to collect this information.<sup>5,25</sup> The Joint Commission further recommends collection of patients' disability information to provide better patient-centered care.<sup>26</sup>

The disability-related information helps to inform health care teams about the backgrounds and needs of their patients, potentially reducing awkward interactions and ineffective visits.<sup>11,20,27</sup>

Most requested accommodations did not require significant workflow modifications or expenses. For example, large print was a commonly requested accommodation among those with low vision or blind. The large print feature is already available for free in certain electronic health

records, including Epic Systems. Other requested accommodations typically did not require additional expenses but centered on how care was delivered at the clinic. This required flexibility on care protocols (for example, assistance with transfers, filling out forms) and communication approaches (for example, inclusion of support persons, additional communication time between patients-providers) by the primary care team.

Accommodations requiring additional expenses or equipment (for example, ASL interpreter or adjustable exam tables) are still required by legal mandates in the ADA and Section 1557 of the ACA. Clinics may collect similar information to advocate for procurement of additional accessible equipment for their setting (for example, purchasing a wheelchair-accessible scale).

Although more research is needed to explore how to best integrate patient disability-related information into scheduling processes to ensure the timely provision of accommodations at upcoming appointments, there are several promising clinical approaches to proactively arrange requested accommodations at upcoming patient visits. Schedulers can include questions about the presence of a disability<sup>19</sup> and subsequently inquire if there are specific needs or accommodations to make the upcoming appointment more accessible. Disability-related questions were found to not be intrusive to patients. A past study found that no patients objected to being asked about the presence of a disability<sup>19</sup> while demonstrating the feasibility of implementing these questions in a primary care setting.

Certain accommodations do require some up-front time and effort to set up. This may include scheduling sign language interpreters in advance or securing assistive technologies to be available for the patient at their next appointment (for example, Hoyer lift). Patient questionnaires, including the Disability and Accommodations Question-

naire, can and have been distributed through the use of patient portals and e-check-ins, yielding another avenue to gather these important data in advance of an upcoming appointment.

The use of daily or weekly health care team huddles can help ensure the setup of requested accommodations and remind primary care providers and their staff of any patient care needs.<sup>28</sup> Due to a lack of awareness and training by primary care providers and their staff, health care systems would greatly benefit from the inclusion of ADA compliance officers, disability advocates, and navigators to comply with the ADA and the ACA's Section 1557, Section 4203, and Section 5307.<sup>17</sup> Iezzoni et al. found that 71.2% of US physicians provided incorrect answers on who makes decisions about reasonable accommodations for PWD, and 68.4% believed they were at litigation risk due to accommodation provision failure.<sup>4</sup> These disability resources can help address these concerns while improving the accessibility and quality of care received by patients with disabilities.<sup>29</sup> An example of these patient-based disability resources can be found at the UPMC [University of Pittsburgh Medical Center] Disabilities Resource Center.<sup>30</sup>

### Limitations

This study had several limitations. All data were self-reported, and given the social stigma attached to disability, we expected underreporting of disability in our sample. In addition, all data were collected from a single primary care clinic whose patient population is low in racial and ethnic diversity and relatively high with respect to patients who use ASL. As such, this study's estimates of disability prevalence are not generalizable. Because the questionnaire was distributed by clinical staff, not by the research team, data on response rate, how often assistance was requested by patients, and if there is sampling bias among nonresponders are unavailable. Last, the Disability and Accommodations Questionnaire, although developed with extensive input from subject matter experts, has not been validated. Further validation work is needed. Nevertheless, our study is novel, providing the first ever results on patients' disability status, disability types, and accommodation need in a primary care setting.

### CONCLUSION

The inclusion of the Disability and Accommodations Questionnaire demonstrates the benefit for health care centers to capture disability-related information to help characterize the needs of their patient population to ensure accessible primary care. The collection of these disability-related data is critical to meet the legal mandates and address longstanding health inequities among patients with disabilities in primary care settings. Further implementation studies are needed to determine best approaches to arrange requested accommodations.

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### SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.jcjq.2023.10.012](https://doi.org/10.1016/j.jcjq.2023.10.012).

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