What Some Physicians Say About Caring for Patients with Disability: Responses to Open-Ended Question to Nationwide Physician Survey

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Disability and Health Journal

What Some Physicians Say About Caring for Patients with Disability:

Responses to Open-Ended Question to Nationwide Physician Survey

Brief Report

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Keywords: disability, physicians, access, reasonable accommodations, barriers, structural ableism

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1	What Some Physicians Say About Caring for Patients with Disability:
2	Responses to Open-Ended Question to Nationwide Physician Survey
3	Brief Report
4	Abstract
5	Background. For over 50 years, federal disability civil rights laws have mandated that patients
6	with disability receive equitable health care. However, disabled patients continue to experience
7	health care disparities.
8	Objective. To explore physicians' views, in their own words, about caring for patients with
9	disability.
10	Methods. Review of responses to open-ended question at the end of a nationally
11	representative survey of 714 outpatient physicians about their experiences caring for adult
12	disabled patients. The open-ended question asked for additional comments participants
13	wanted to share. Only 108 (15.1%) survey participants provided responses suitable for analysis
14	(e.g., legible, complete thought). All issues reported here reflect comments from \geq 5
15	participants.
16	Results. Common concerns involved high costs, too little time, insufficient space, inadequate
17	training, and lack of adequate mental health services to care for disabled patients. Many
18	physicians appeared frustrated by legal requirements that they cover accommodation costs.
19	Multiple physicians described as "unfair" having to pay for sign language interpreters, especially
20	since interpreter costs generally exceed reimbursements for patients' visits. Physicians also
21	commented on high costs and space demands of accessible exam tables, especially for small
22	practices, and on challenges accommodating patients with severe obesity, including concerns

- 23 that patients with severe obesity could damage their exam tables. Some participants suggested
- that disabled patients require advocates to get good quality care.
- 25 **Conclusions.** Albeit limited by the small number of responses, these open-ended comments
- 26 from our nationwide survey of physicians suggest some doctors view certain accessibility
- 27 requirements as unfair to them or infeasible in their practice environments.
- 28 Word count: 250 words (up to 250)
- 29 Keywords: disability, physicians, access, reasonable accommodations, barriers, structural
- 30 ableism

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Introduction

32 For more than 50 years, federal disability civil rights laws have mandated that patients with disability receive equitable health care.¹ Nevertheless, these laws have not eliminated 33 health care disparities for disabled people. In 2000 federal public health officials recognized this 34 inequity,² and in 2023 the National Institutes of Health finally designated people with disability 35 as a population experiencing health disparities.³ 36 For more than 25 years, researchers have documented health and health care 37 disparities among persons with diverse disabilities and across health care needs.^{4,5} Most 38 research has used data gathered directly from people with disabilities, either through surveys 39 or individual or focus group interviews. Therefore, perceptions of disabled people about the 40 41 barriers impeding their care are well understood and include many obstacles disability civil rights laws explicitly address, such as ineffective communication, inaccessible care settings, and 42 failures to accommodate disability-related needs.^{1,4} Other problems are less amenable to legal 43 remedies, including ableist attitudes among physicians, their inadequate knowledge about 44 caring for people with disabilities, and financial concerns. For most barriers, physicians play 45 central roles in perpetuating these impediments. 46

Several years ago, we conducted the first nationwide survey of doctors about their experiences with and perceptions of caring for people with disability.⁶⁻¹¹ Our survey was limited by focusing exclusively on adults and outpatient care within seven medical specialties. To bolster response rates, we kept our survey short and asked few follow-up questions (e.g., about why participants answered as they did). However, as do many surveys,¹² we included an openended question at the end of the survey, inviting participants to provide additional comments

about caring for patients with disability. We anticipated that these open-ended responses
would explain participants' answers to survey questions or raise new issues our short survey did
not address.

This brief report summarizes major themes from the open-ended comments at the end 56 of our physician survey. Although many surveys include open-ended questions, ultimately these 57 comments are not analyzed because of "their uncomfortable status ... [as] strictly neither 58 qualitative nor quantitative data."¹² However, given persisting health care disparities for people 59 with disability – and physicians' roles in access barriers – even unstructured responses in 60 physicians' own words could yield clues about mitigating this inequity. Below, the Methods 61 62 section briefly reviews survey development and administration (details are available elsewhere⁶⁻¹¹) and then describes the open-ended question and analysis of responses. To 63 provide context, the Results section briefly presents the nationally representative survey results 64 (i.e., findings from the close-ended survey questions), most of which are already published,⁶⁻¹¹ 65 followed by related themes arising from the open-ended comments. Appendix A contains the 66 survey. 67

68 Given differing preferences about disability language, this paper alternates between 69 person-first ("person with disability") and identity-first ("disabled person") language.

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72	Methods
73	The Massachusetts General Hospital/Partners Healthcare and University of
74	Massachusetts-Boston Institutional Review Boards approved the survey study.
75	Developing and Conducting Survey
76	Details about developing and conducting this survey are available elsewhere. ⁶⁻¹¹ Briefly,
77	we developed a survey for physicians caring for adult outpatients in seven specialties: family
78	medicine, general internal medicine, neurology, obstetrics-gynecology, ophthalmology,
79	orthopedic surgery, and rheumatology. The University of Massachusetts-Boston Center for
80	Survey Research (CSR) conducted 8 cognitive interviews of the draft survey; CSR then pilot
81	tested the revised survey. We aimed for the survey to take 10-15 minutes to complete, and
82	most questions had Likert scale-type response categories. The final survey contained 75
83	questions grouped into 8 modules: chronic mobility limitations, vision limitations, hearing
84	limitations, serious mental illness, intellectual disability, the Americans with Disabilities Act
85	(ADA), participant demographics, and practice characteristics (Appendix).
86	To create our sampling frame, we purchased commercially available information about
87	all physicians nationwide in the seven specialties and deleted physicians meeting exclusion
88	criteria (e.g., trainee, no longer practicing, incomplete contact information). ⁶⁻¹¹ From remaining
89	physicians, we randomly selected 350 in each of the two primary care disciplines and 140 in
90	each of the five specialties (n = 1,400). We mailed paper surveys, including a link to answer
91	online, with a \$50 cash payment in late 2019; CSR followed up twice with nonrespondents and
92	closed the survey in June 2020.

93	We received 714 responses, 84.2% on paper and 15.8% online. According to the
94	American Association for Public Opinion Research Response Rate #3 (which applies to mailed
95	surveys), ¹³ the weighted response rate was 61.0%. Using sampling weights from CSR, our survey
96	analyses calculated nationally representative estimates.

97 Open-Ended Question

At the bottom of the final page of the 6-page paper survey, we had a small empty space (roughly 1") and inserted an open-ended question: "In the space below please provide any comments or insights regarding caring for patients with disability that you feel is important for us to know about." For both paper and online responses, CSR staff copied verbatim participants' open-ended comments into an Excel spreadsheet; CSR did not include information about the participant (e.g., gender, specialty). When handwriting was illegible, staff inserted "(can't read)."

We received 135 comments overall (18.9% of the 714 survey participants). Comments were brief and sometimes ended abruptly (e.g., "The interpreters we provide for the hearing im," "The insurance companies should make," "As an ophthalmologi"). Comments were often misspelled, agrammatical, and unclear. Of the 135 open-ended responses, 13 could not be analyzed (ended mid-word or mid-sentence, were illegible); 5 criticized aspects of the survey; and 9 thanked us or complimented the survey. The analysis included 108 open-ended comments (15.1% of the 714 survey participants).

Using the principles of conventional content analysis,^{14,15} we did not attempt to infer what those writing open-ended responses meant or overinterpret their comments, instead taking their words at face value. The principal investigator and a research assistant separately

reviewed the open-ended responses, grouping them into themes and reaching consensus 115 116 through discussion. Because publishing the quantitative survey findings took priority, several years elapsed, during which we revisited the open-ended responses analysis multiple times. 117 Below, we present themes mentioned by \geq 5 open-ended responses. Single comments 118 119 addressed wide-ranging concerns (e.g., excessive paperwork from group homes, inadequate nursing home medical records). All tables reproduce in totality selected open-ended comments 120 121 that exemplify each theme, including the punctuation and lower- and upper-case lettering in 122 the original comment, with one exception: capitalizing the first letter of the first word. Although some open-ended responses fell into multiple themes, the tables display each comment only 123 once, to maximize the number of comments shown. 124

126	Results
127	This Results section first reports findings from the nationally representative survey,
128	followed by related open-ended responses.
129	Significant Hearing Limitation Accommodations
130	Accommodating communication with patients with significant hearing limitations
131	generated the most open-ended comments.
132	In the nationally representative survey results, 49.8% of participants reported never
133	using an in-person sign language interpreter hired by the practice; 63.2% never used video
134	remote interpreting. ¹⁰ In contrast, 30.7% always and 29.8% usually spoke louder and slower to
135	these patients, while 8.4% always and 24.9% usually communicated by writing notes. ¹⁰ The
136	ADA requires practices to pay accommodation costs, as correctly reported by 79.5% of survey
137	participants. ⁹
138	Table 1 shows selected open-ended comments about this topic, generally illustrating
139	resentment about being required to pay for in-person sign language interpreters. Participants
140	viewed this as unfair, especially when they are reimbursed less for the visit than sign language
141	interpreter fees. Even when patients do not show up for the visit, one physician wrote, doctors
142	must compensate the sign language interpreter – "frustrating." Some physicians believed that

143 insurers or patients should cover interpreter costs. One physician, with a "private practice,

small town," expressed frustration that a deaf patient refused to communicate through notes
instead insisting on an in-person sign language interpreter covered by the practice: "I couldn't
do that very often."

147	Two additional comments evoked other concerns about patients with significant hearing
148	limitations (Table 1). One physician described settling a lawsuit for several thousand dollars
149	filed by a patient complaining about malfunctioning closed captioning in the practice's waiting
150	room television. Another physician acknowledged feeling "very fatigued and tired" after
151	"almost [having] to yell" to communicate with a "hearing loss pt."
152	Significant Mobility Limitation Accommodations
153	Accommodating patients with significant mobility limitations generated the next most
154	common open-ended responses.
155	In the nationally representative survey results, only 22.6% of participants reported
156	always or usually using accessible weight scales for patients with significant mobility
157	limitations. ⁷ Furthermore, only 34.6% and 47.3% of primary care and specialist physicians,
158	respectively, always or usually used an accessible exam table or lift device to transfer patients
159	who cannot transfer independently. ⁷
160	Table 2 presents selected open-ended comments about accommodating significant
161	mobility limitations. No comments addressed weight scales. Some physicians described efforts
162	to improve access at their practices, such as having "a new state of the art completely
163	accessible building." In contrast, multiple open-ended responses focused on patients' weight.
164	One physician described a patient weighing more than 600 pounds, writing "our ADA tables
165	only lift up to 400." The physician described the patient sitting in a wheelchair in the exam
166	room, commenting that the practice could not "risk replacing 5000K [\$5,000] table."
167	Other open-ended comments addressed resources required to improve access, ranging
168	from equipment to a valet parking service. One physician described being unable "to

169	accommodate heavy special equipment" in a "small private practice," adding that the practice
170	only has two patients who use wheelchairs. Another physician commented that "the lack of
171	funds to purchase special equipment does not necessarily equate to poor care" – provided
172	there is an "intelligent, thoughtful, motivated, and creative" approach – albeit recognizing "it is
173	certainly less than ideal."
174	Other Topics Addressed by Open-ended Responses
175	Table 3 shows selected open-ended comments from other themes supported by \ge 5
176	participants.
177	Mental Health
178	In the nationally representative survey findings, when asked about being prepared to
179	care for patients with serious mental illness, 22.4% reported being "very prepared" and 58.1%
180	"somewhat prepared"; 35.7% indicated that people with serious mental illness get "much
181	worse" care than patients without this condition (unpublished data).
182	The open-ended responses raised various concerns about mental health care, including
183	inadequate time, problems finding mental health clinicians, and difficulties with insurance.
184	Role of Family Members, Caretakers
185	With few exceptions, the survey did not ask about roles of family members or
186	caretakers (Appendix). For example, in the module about patients with significant intellectual
187	disability, 85.0% and 69.7% of specialists and primary care physicians, respectively, reported
188	always or usually communicating with someone other than the patient. ¹¹
189	Several open-ended comments underscored the critical assistance, advocacy, and
190	information that family members or caretakers sometimes provide. "Most of my patients with

191	intellectual or mental disability are accompanied by family or caregiver," wrote one physician.
192	"I try to communicate directly with patient and family/caregiver will give information if patient
193	is unable" One physician commented that disabled patients risk receiving substandard care
194	without an advocate.
195	Training
196	In the nationally representative survey results, 7.5% and 27.5% of participants reported
197	that lack of formal education and training was a large or moderate barrier, respectively, to
198	caring for patients with disability.9
199	The open-ended responses raised concerns about inadequate training, calling for
200	increased training in medical schools and residencies. One comment urged that curricula be
201	evaluated for disability content, and another advocated for training about the ADA.
202	General Health Policy Issues
203	As noted above, the nationally representative survey found that most participants
204	recognized that the ADA requires practices to cover accommodation costs. ⁹ Participants in
205	small (1-3 physicians) practices were much more likely (81.5%) to report having at least some
206	risk of an ADA lawsuit because of problems providing reasonable accommodations compared to
207	those in large (12+ physicians) practices (66.4%). ⁹
208	The open-ended responses focused largely on increasing payments for seeing disabled
209	patients, including accommodation costs, as well as implications of practice size. Larger health
210	systems are more likely to provide accommodations, wrote one participant. "It is not very
211	practical if the volume is small," wrote another.
212	Overarching and Miscellaneous Comments

- The nationally representative survey found that 16.6% of participants viewed lack of 213
- time as a large barrier to caring for disabled patients; 27.5% saw it as a moderate barrier.⁹ 214
- Some open-ended responses made broad points about the need for but also 215
- challenges to providing good quality care to disabled patients. Time limitations appeared 216
- prominently in these comments, as elsewhere in Tables 1-3. 217

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Discussion

219 Eliminating health and health care disparities for persons with disabilities will require 220 active and informed commitment from physicians. However, the 108 open-ended responses analyzed here, 15.1% of participants in a nationwide physician survey, suggest that some 221 222 physicians view caring for people with disability as, in the words of one physician, a "tough issue." Common concerns raised in the open-ended responses involved high costs, too little 223 time, insufficient space, inadequate training, and lack of adequate mental health services to 224 225 care for disabled patients. Depending on whether health care facilities are public, state or local 226 entities (covered under ADA Title II) or private organizations serving the public (ADA Title III), physicians play prominent or leading roles,^{9, 16, 17} respectively, in determining reasonable 227 228 accommodations for disabled patients. The open-ended comments reported here suggest that some physicians are frustrated by legal requirements that they pay accommodation costs. 229 230 The nationwide survey findings indicated that about half of physicians had never hired sign language interpreters for an office visit,¹⁰ and the open-ended responses suggest one 231 potential reason. Multiple open-ended comments described as "unfair" having to pay for sign 232 language interpreters, especially since interpreter costs generally exceed reimbursements for 233 patients' visits. Notably, failure to ensure effective accommodations accounts for "a high 234 percentage of ADA cases against healthcare providers."17 235 236 Similarly, in their open-ended responses, several physicians commented on high costs 237 and space demands of accessible exam tables, perhaps offering one reason why less than half of physicians usually use them.⁷ The open-ended comments found frequent mentions of severe 238

obesity and challenges to accommodating these patients, although no comments addressed

Two recent developments indicate renewed U.S. federal efforts to improve health care access for people with disability. On September 14, 2023, the Office for Civil Rights in the U.S. Department of Health and Human Services issued proposed rules to update and strengthen provisions under the Rehabilitation Act of 1973, Section 504, which governs disability civil rights

at entities receiving federal funding.²¹ In coordination with this proposed rule, on January 12, 262 2024, the Civil Rights Division, U.S. Department of Justice, issued another proposed rule under 263 ADA Title II, specifically to provide accessible medical diagnostic equipment^{19,20} in health care 264 facilities funded by state or local governments.²² These rules are not yet final. However, the 265 open-ended responses reported here suggest that engaging physicians to understand, endorse, 266 and implement these initiatives may require targeted education and efforts to recognize 267 ournal prevence 268 physicians' concerns.

270	Conclusions
271	Physicians play key roles in ensuring accessible health care for disabled patients.
272	Although only 15.1% of participants in a nationwide physician survey provided open-ended
273	comments at the end of the survey that were amenable to analysis, these open-ended
274	responses suggest that some doctors view certain accessibility requirements as unfair to them
275	or infeasible in their practice environments. Mitigating health care disparities for people with
276	disability may require better understanding and possibly addressing some of these physician
277	concerns.
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Table 1

Open-Ended Responses about Communication Accommodations^a

Cost of and paying for accommodations

"Physician have to pay for translators for patients. I strongly feel this is unfair, that any physician has to pay to see and care for patient for personal issue for that patient. This should be covered by insurance or patients."

"I don't believe it is right to pass the cost of interpreter to the physician caring for the patient when Medicare and Medicaid reimbursements aren't enough to cover the cost of delivering the care to them and absorb the interpreter's billing"

"Payors and insurers should be responsible for the additional cost of caring for disabled patient. The insurers do not pay for a sign language interpreter and they push it on the practice which is totally unfair in my opinion."

"I lose revenue seeing patients with hearing or sight or even translator needs – we must pay those costs and cannot bill the patients – our minimum fee is \$110 – even if patients do not show we cannot bill them. Frustrating"

"As a private practice, small town, I was frustrated when a deaf patient insisted I pay for and provide an interpreter instead of writing back and forth during her exam. it cost me to see her. I couldn't do that very often."

"Very happy to see patients who need sign language interprets 30 min care = payment of \$88, I pay \$150 to interpret"

"The cost for an interpreter per hour... It is nice to be futuristic but to the point and financial burden..."

Other comments

"We have had one lawsuit – by a patient who sued because our closed captioning was not working in writing room. Settled for several thousand dollars..."

"I feel very fatigued and tired after completing an encounter with hearing loss pt when you almost have to yell..."

"Physicians should be able to add a modifier to get reimbursed for the extra time it takes to care for patients with disabilities (for example, consenting a deaf person for surgery takes longer than someone with normal hearing)."

"Lack of social resources. If I would afford a social worker or a deaf interpreter and if social resources existed then I would welcome – the extra time would be ok."

a Center for Survey Research staff transcribed these open-ended responses exactly as they appeared on the completed survey.

Table 2

Open-Ended Responses about Accommodating Patients with Mobility Disability^a

Accommodating disabled patients for physical exam

"We have recently moved into a new construction building fully ADA complied which has made navigating the clinic much easier for patients with disability."

"We are fortunate to have a new state of the art completely accessible building and Physical Therapists who have provided an in service to our staff regarding safe transfers."

"As a practice, we make every effort to accommodate patients with disabilities. We have wheelchair access examination rooms so that patients don't have to be transferred to the examina"

"I make home visits to those where in office exams etc. a serious challenge. Easier for all concerned."

"My office is on first floor with parking within 15 feet of the entrance. Biggest concern is weight of pt and exam table."

"I am including extreme obesity"

"Adult patients with Morbid obesity often refuse to be weighted"

"By our mobility challenged patient weighs well over 600 pounds and our ADA tables only lift up to 400. She brings a wheelchair to sit in the exam room. We are not able to risk replacing 5000K table"

"In orthopedics we can care for patients who can not get out of wheelchair by exam in wheelchair if needed. We order X-ray that can be done at (can't read). While not ideal it can be common to treat patients this way (for example - can't read)"

Resource considerations

"The lack of funds to purchase special equipment does not necessarily equate to poor care. An intelligent, thoughtful, motivated and creative can still find ways to provide good care, although it is certainly less than ideal."

"Small private practice not able to accommodate heavy special equipment. Very small number of patient has wheel chair with (2). I do ask height and/ with by patient"

"When Medicare and Medicaid won't support the necessary mobility devices or weight reduction options, may as well not see them... Waste of time."

"It is sometimes difficult to get patients with mobility disabilities into the building from the parking lot. Valet parking with assistance would be very valuable."

"They do take more time, more money, more space, more flu, more reflecting to be taken care of"

a Center for Survey Research staff transcribed these open-ended responses exactly as they appeared on the completed survey. When staff could not read the handwriting on a paper response, they inserted (can't read).

Table 3

Other Comments^a

Mental health

"Mental illness remains my primary concern regarding adults with disabilities. Our medical system continues to provide woefully inadequate care for this portion of my practice"

"We underestimate the time it takes to see and adequately care for patients with disability, particularly mental health"

"The mentally ill need case managers not just for their mental health but for their overall health and should accompany to all medical visits"

"I believe the biggest obstacle is providing my patient mental health care in my community. It is difficult for patient and PCP to find psychologist and psychiatrist who take then insurance"

"Drop by any homeless shelter in America – you will see that nobody wants to deal with the country's mentally ill population. its indictment of us as Americans."

Role of family members, caretakers

"They need time and attention. Prefer that they accompany family member."

"The care takers are very helpful in the patients general health. they help us as physicians care for the patient"

"Most of my patients with intellectual or mental disability are accompanied by family or caregiver. I try to communicate directly with patient and family/caregiver will give information if patient is unable to do so are don't ever need interpreter"

"People with disability is always at risk of sub par care unless they or a family member or a friend act as an advocate for them"

"More family/community/church support is beneficial to patient's health and wellbeing. So sad to see the elderly who can have multiple disabilities come in to office alone particularly when facing surgery such as hip or knee replacement"

Training

"More training in medical school and in residency is needed to adequately care for people with disabilities."

"Assuring medical students and residents understanding how to care for disabled patient is also important. Review curriculum regarding this"

"Health care professionals have the capacity to care for patients with disability but need more resources, time and training"

"Generally not enough time. Inadequate training."

"Training and infrastructure our primary limitations to taking care of patients with disability."

"1) more public service announcements encouraging people to be kind to people with

disabilities would be good 2) doctors and medical students need training about the ADA"

Health policy issues

"Try to increase funding to physicians."

"I have seen decreasing reimbursements have a strong role in the care of these subset of patients."

"The larger the health care system one practices for, the more likely accommodations will be provided to patients' need"

"Caring for the disabled would be better if practices were not responsible for the costs of accommodations. It is not very practical if the volume is small"

"Patients with disability should be treated with care and gentleness and physicians should be compensated better and also there should be a quota of such patients"

Overarching observations

"TOUGH ISSUE!"

"While it is not always possible to have the identical care for every patient with disability, it is our responsibility to provide the best quality care we can to every patient we care for."

"We do the best we can to be the best option for primary care for all the patients. It is not realistic to expect a disabled person to receive the same level of care but we strive to do the best we can to do right for the patient."

"Some patients are disability are delayed getting to an M.D. until treatment is absolutely needed and their outcome are effected because they are ignored initially"

"In the current practice model no additional time is provided when scheduling appointments for patients with disabilities."

"The limitations for caring patient's at any disability or medical complexity is the lack of time and the amount of proper^b work. FMLA forms, disability forms, parking card, physical therapy, plna authentation ,etc."

"Having nurses and staff willing to do the extra care is important caring for patients with disabilities is challenging but rewarding"

"As a person with a disability myself, I make every effort to insure all my patients get quality care"

- a Center for Survey Research staff transcribed these open-ended responses exactly as they appeared on the completed survey.
- b Respondent may have meant paperwork, given subsequent comments.