

# HHS OCR Discrimination on the Basis of Disability in Health and Human Service Programs or Activities Comment

This document is submitted by the Massachusetts Health Data Consortium (MHDC) and its Data Governance Collaborative (DGC) in response to the HHS OCR Discrimination on the Basis of Disability in Health and Human Service Programs or Activities NPRM (HHS–OCR–2023–0013) posted in the Federal Register on September 14, 2023 and found here: <https://www.federalregister.gov/public-inspection/2023-19149/discrimination-on-the-basis-of-disability-in-health-and-human-service-programs-or-activities>

## About MHDC

Founded in 1978, MHDC, a not-for-profit corporation, convenes the Massachusetts’s health information community in advancing multi-stakeholder health data collaborations. MHDC’s members include payers, providers, industry associations, state and federal agencies, technology and services companies, and consumers. The Consortium is the oldest organization of its kind in the country.

MHDC provides a variety of services to its members including educational and networking opportunities, analytics services on both the administrative and clinical side (Spotlight), and data governance and standardization efforts for both clinical and administrative data (the Data Governance Collaborative/DGC and the New England Healthcare Exchange Network, respectively).

## About DGC

The DGC is a collaboration between payer and provider organizations convened to discuss, design, and implement data sharing and interoperability among payers, providers, patients/members, and other interested parties who need health data. It is a one stop interoperability resource. The DGC primarily focuses on three areas:

1. Collaboration: Development of common understanding of and specifications for data standards, exchange mechanisms, and what it means to participate in the modern health IT ecosystem
2. Education: helping members understand their regulatory obligations, the data and exchange standards they're expected to use, and modern technology and related processes
3. Innovation: Identification and development of projects and services needed to make modern health data practices and exchange a reality

## Additional Background

In addition to reviewing/discussing portions of this proposed rule, our Data Governance Collaborative spent time in the past considering the barriers to healthcare for disabled patients, what data about accommodations should be collected and exchanged, and some systemic and policy barriers to care at various points in the past both internally and in public discussions we led around SDOH. We previously commented on these areas in response to an AHRQ key question (see below).

We note that our discussions encompass just a subset of the issues patients encounter; we did not make a systematic attempt to cover every issue or type of disability, and that all types of disabilities should be considered throughout any process meant to address access for disabled patients.

## General Comments

This section comments on the general approach taken by OCR in their proposal or comments on items that cross multiple sections of the proposed rule or that do not have questions in the proposal.

## AHRQ Comment on Healthcare Delivery of Preventative Services for People with Disabilities

Earlier this year AHRQ posted a key question requesting comment on barriers to healthcare delivery of preventative services for people with disabilities. MHDC and the DGC provided a lengthy response highlighting three areas:

1. Systemic and policy barriers to care
2. Accommodations data to facilitate care
3. Policies related to captured data

Some of the key points of our comment include:

- Provider policies often exacerbate inequalities and add additional barriers to care for disabled individuals
- Patient data about disability and related accommodations are not captured in any useful way available to clinicians
- Many accessibility decisions around physical space are made with motorized wheelchair access in mind and are not as accessible for patients with mobility issues relying on other types of assistive devices
- Some providers prioritize wheelchair users over other disabled patients
- Many providers have made it harder over time, not easier, for visually impaired individuals or others who need it to get help filling out required forms onsite and now often require use of clinician appointment time to do so
- Automation often inhibits accessibility
- Telehealth including audio-only telehealth should continue unless medically contraindicated
- Portal access can be very problematic for visually impaired patients (and perhaps others)
- Provision of some type of disability advocate or other support personnel that can be assigned to patient encounters the same way language translators are assigned would be extremely helpful

Although only a few of the areas we address are directly discussed in this proposed rule, we believe our entire response to the AHRQ request will be helpful in addressing discrimination against disabled individuals in healthcare and may provide additional areas to consider covering in the final rule or in subsequent rules. Thus, we are appending a full copy of our AHRQ comment to the end of this document.

## References and Links

There are many places, such as the initial mentions of terminology definitions and the specifics of certain requirements where the details of the content being discussed are not found in the location discussing them. In general, non-linked references of the form § NN.MM(J)(K) are used. These references are not linked to the appropriate section and, in general, these exact notations are not searchable. It would be extremely helpful to include a live link when these references are made or, if for some reason that is not possible, at least use the exact textual format of the reference at the start of the relevant content so that basic searches trying to find the relevant content within the full text of the rule do, in fact, locate the relevant referenced content.

## Accessible Communications

While there are one or two general references to the requirement to provide accessible communications throughout the rule, in general this topic is not discussed in detail anywhere or at all in some very relevant places. One glaring example is that in a section of the rule discussing consent there is no discussion about informed consent and what that means in terms of providing the relevant information being consented to and any related consent forms in accessible ways. Accessible communications is one of the biggest barriers for

individuals with certain types of disabilities and it pervades many different aspects of care, sometimes in ways that recipients are not likely to think about until they encounter them. When it is considered, a one size fits all type approach is often taken – we have braille so we're covered for all blind and visually impaired patients, we can make a slightly larger bad photocopy of printed materials and that will work for all visually impaired patients, we have a video explaining the most common aspects of disease Y in ASL so that's good enough for all hearing impaired patients whether or not they have those aspects of the disease (or understand ASL at all), etc

## Ease of Administration of Care Criteria

Throughout most of the proposed rule the mandate to provide non-discriminatory care is stated clearly and strongly. However, under the Provision of Medical Care discussion, OCR includes a clause that indicates that ease of administration of treatment is a valid reason to not provide the same care to a disabled patient as would be provided to a non-disabled patient. Providing care to disabled patients is inherently more difficult to administer or comes with additional administrative or clinical burdens on providers in many or most cases. Without at least a very clear definition that sets a high bar, inclusion of this clause opens the door to permit providers to not treat disabled patients who need any sort of accommodation to receive care.

## Informed Consent

We were surprised to see the section of this proposed rule covering consent does not discuss the need to provide accessible means to provide informed consent. While, in theory, it should be covered under more general accessibility discussion, this is an area that deserves to be called out separately. For many patients with visual disabilities, being faced with lengthy written consent forms and no mechanism to read them is common. Even if a recipient provides someone to read forms containing consent clauses on the spot – which is a big if – that staff member will often try to skim or skip consent language on those forms as something not worth reading that patients should just accept as is. There are likely cases where verbal consent is sought or the thing being consented to is noted verbally before a form is signed or where patients have questions about something in the consent form that cause issues for hearing impaired patients, and the dense, legal language common in these sections may be problematic for individuals with developmental disabilities without someone to further explain what it means.

Two things we think should be considered in this area are:

1. The need to provide materials/information/etc related to potential treatments as well as actual consent forms in accessible formats such as large print, braille, audio recordings, ASL, etc
2. The use of a disability advocate/assistant or other staff to help patients fill out forms, understand written or oral information they can't process the same way as other patients, etc with provenance that such a person was utilized could be an option (see our AHRQ comment)

## Non-discrimination in Prior Authorization

Many payers require some form of step therapy or specific assessment results to qualify for coverage of specific treatments providers would like patients to use. Having an explicit discussion of non-discrimination requirements for prior authorization (or other utilization management processes) would be extremely helpful. We note that prior authorization, in particular, is a difficult area to manage because there is a major push to automate as much of the prior authorization process as possible. As discussed elsewhere in our comments, automation can, at times, be the enemy of accessibility and fairness. If specific prior authorization processes require a particular score on a particular assessment test before services are covered, that requirement is based on the proper score for the general population and does not take any disability or even whether the assessment can be given to the patient in a meaningful way. Similarly, it does not take into consideration any poorer-quality test results stemming from a patient's inability to get into the proper position for a scan or other physical test or any other modifications or exceptions that may be appropriate because of disability.

While an appeal process could be used to attempt to ameliorate any such issues, this puts an increased burden on the patient and provider, delays care, and greatly disadvantages disabled patients. We urge OCR to consider explicitly addressing prior authorization and what is and is not acceptable for disabled patients within

this rule.

Also, on the topic of prior authorization, we note that one solution offered in this rule for meeting accessibility requirements is to send patients to a different location than originally scheduled that has more accessible care available. If the patient required a prior authorization for that care, their authorization may be tied to the specific location where they originally scheduled the care. Requiring a patient to go to another location may invalidate their prior authorization, resulting either in their unknowingly getting care that has not been approved for coverage or a delay while they acquire another prior authorization for the new location. This is not a good solution for those patients.

## **Payer vs Provider Requirements**

The most common question asked during our Data Government Collaborative discussion of this proposed rule was “does that clause/requirement apply just to providers or to payers too?” While we believe the rule is clear that any organization receiving funds is covered by the rule, having some additional discussion around payer applications of specific clauses/requirements might be helpful in assisting payers in meeting their accessibility requirements.

## **Visually impaired individuals Not Relying on Screen Readers**

We note that the majority of the discussion around web, mobile, and kiosk access for visually impaired individuals focuses on use of a screen reader, but many visually impaired individuals rely on browser, app, device, or other adjustments to make content accessible. In particular, user settings for browser and app displays are often used and are not always respected by specific pages/apps. Also, many individuals rely on setting larger global font settings or using a lower screen resolution than the default. Many issues with accessibility for this group of individuals stem from websites or apps that assume that everyone always uses the default settings. Some of the problems that ensue include:

- Screen elements that flow offscreen and are not visible/accessible to the user
- Popups with no way to submit or dismiss (including login screens)
- Screen elements that overlap each other, making it impossible to use them
- Screen elements that display one character or element at a time in single extremely long column of stuff that’s difficult to parse
- Dropdown menus or similar navigation elements that don’t work
- Inability to resize items or otherwise alter them to fit available display space
- Extremely narrow, sometimes hidden scrollbars that make it difficult or impossible to scroll when scrolling is necessary and (technically) available

Kiosks are even more challenging than web or mobile apps because the individual typically has no control over the device settings and thus cannot rely on altered screen resolutions or larger font and other display settings to improve their experience. Further, the individual may not be able to control their distance from or alignment relative to the display, both elements that may greatly affect how well they can see and interact with its content.

## **Voicemail and Required Response Times**

Between the inability to access patient portals and other electronic systems and the need to have discussions about necessary accommodations for an encounter, test, or procedure, disabled patients often need to have a live conversation with an office before they arrive for care. This is typically initiated at the point of scheduling, but many organizations have significantly reduced both their scheduling staff and their other front office customer facing staff. At the same time, many of these organizations offer no option to leave voicemail or, if there is an after hours voicemail option, don’t return messages for weeks if at all. This results in missed or delayed care that is available to patients who can just schedule an appointment via a portal or app with no worries about direct interaction.

For example, a disabled patient who cannot access their patient portal because it’s not accessible recently had

a telehealth call scheduled with a provider who did not show up to the visit. The patient tried to call several times that day to find out why, and followed up with multiple calls the following week and several the week after that. They have spent over 6 hours on hold and, to date, have not yet gotten through to anyone at the office. This appointment, scheduled more than two weeks ago, has not yet been rescheduled let alone held, and the patient has wasted an extensive amount of time trying to arrange for this necessary care that is a prerequisite for other care they need.

We strongly recommend requiring an option to leave voicemail for provider offices for those who do not want to constantly find themselves on indefinite hold and, at least for those calls from patients who are known to be or identify themselves as disabled, a minimum response time to voicemails be required. We suggest no more than 2 business days in general and perhaps 4 business hours for urgent calls. It would also be nice to have some type of estimated wait time indicators while on hold, but given that they are estimates and not always accurate, do not think this rises to the level of requirement.

## Accessibility of Telehealth

We applaud and agree with efforts to make all telehealth more accessible, but in order to ensure equitable access to telehealth for patients with disabilities, continued support for audio-only telehealth should remain a priority. With the end of the official public health emergency, many providers are discontinuing audio-only telehealth even for consultations or other environments where video is not required and its lack does not interfere with proper care. Some are continuing it only for patients who have indicated they have difficulty using video telehealth because of a disability but, because these cases typically require approval of the provider, making such appointments is much more difficult and usually takes longer than making a generic appointment available to any patient.

## Specific Requirements for Kiosks

We urge OCR to reconsider this approach for kiosks:

“In instances where kiosks are closed functionality devices that do not rely on web content or mobile apps, the proposed technical standards in § 84.84 will not apply.”

As noted in other comments, kiosks pose larger issues for disabled patients, not fewer, and without requiring accessible displays and interactive components they will be unusable by many disabled individuals. We understand that manufacturers of devices may need to be the ones who adhere to required standards and that recipients may just be purchasing kiosks as-is, but they are likely also purchasing or renting other items that are covered (apps from vendors, facility spaces, medical equipment, etc) this does not seem like enough of a barrier to exclude kiosks from accessibility requirements. Further, the rule indicates recipients are required to ensure that all of their contracts meet the outlined accessibility rules and there will almost certainly be contracts involved in acquiring kiosks.

That said, it might be reasonable to offer a later enforcement date for kiosks than for web and mobile content as the development lead time and related testing time is likely longer as they are more complex products that integrate the software and hardware together.

Obviously, none of this applies to kiosks that are built around tablets as they will, de facto, use mobile applications for all of their interfaces.

## Accessibility Officer

We suggest that recipients be required to name someone who is ultimately responsible for ensuring accessibility needs are met and for the resolution of complaints made to the organization. It can be very difficult for individuals with disabilities to find someone useful to complain to when they run into issues; while a few larger provider organizations have a specific individual responsible for assisting patients with disabilities who call with issues they're encountering, many do not and only larger hospitals and provider systems even have a specific patient services department more generally. Even when they exist, it has become more and more common to require the initial contact with patient services be via a voicemail (which may or may not be returned and is not helpful for immediate needs). Whether they report to patient services or a DEI officer or someone else, having someone ultimately responsible for ensuring compliance with accessibility, for

addressing issues and concerns about accessibility in real-time when possible or later when not, and for ensuring patients (or members, or whatever individuals are called by the organization) know their rights and how to file complaints with OCR or other relevant organizations.

Note that our AHRQ comment recommends having direct disability liaisons available for patients during encounters (similar to translators); we see this as an entirely different role although perhaps this individual could be in charge of a group of liaisons who help at specific appointments.

## Educational Materials

Related to the last comment, most individuals who run into accessibility issues do not wind up making any sort of real complaint or attempt to get them addressed either because they do not know how or their first attempt was rebuffed. Having some sort of requirements that educate patients and members on their accessibility rights and how to complain if they are not met seems essential, as is educating relevant recipient staff interacting with disabled individuals. It is unclear the exact mechanism this should take as people with different types of disabilities will find varying types of informational outreach inaccessible. We suggest at a minimum printed (in both regular and large print), braille, and recorded versions of standardized content should be available. How it is best disseminated is unclear to us given that it is impossible to know exactly which individuals need the information and which format(s) they need it in.

## Use of CAPTCHA

WCAG 2.1 AA level compliance permits the use of CAPTCHA technology in web forms. Unfortunately, most CAPTCHAs are not accessible, even if they offer alternate audio options. The audio quality of these options are (deliberately) poor and it is nearly impossible for even someone with good hearing to distinguish every letter and number correctly from the background noise included in the file. Individuals who have any issues with their hearing and their vision, even if one or both do not meet the level of actual disability, will likely be unable to complete any CAPTCHA of these forms and all with an issue with either are likely to have difficulty.

There is a newer form of CAPTCHA called reCAPTCHA (developed by Google) which typically is hidden at first then only appears after the first time a form is first submitted (in conjunction with an initial error) that only requires clicking on a checkbox indicating “I’m not a robot” to proceed. These reCAPTCHA elements are typically accessible, working with screen readers, keyboard shortcuts, and respecting user’s font and other browser settings. However, if the related screen movements do not match what Google considers normal human motions or meet other evaluation criteria, the user may be rejected. This may make reCAPTCHA use problematic for some individuals with hand mobility issues. There are a few other alternatives currently in much more limited use and we are certain additional options will be developed over time.

We understand that people want to prevent robots from completing forms, but use of CAPTCHAs is not an accessible way to do so. We urge OCR to ban the use of CAPTCHAs on websites covered by this rule. While not perfectly accessible as noted above, reCAPTCHA or other alternative technologies could be allowed to serve the same purpose. Time limits for response should also be forbidden, but that is likely already covered by the WCAG requirements.

In looking for the name of the alternate CAPTCHA mechanism (reCAPTCHA) we came across this article on the topic of accessibility issues with CAPTCHAs which you might find informative as you develop policies in this area: <https://www.boia.org/blog/how-to-make-captcha-accessible-to-everyone>

## Social Media Posts Prior to Enforcement Date

Many social media platforms do not allow for editing of content once posted. Further, while not universal, much social media content is designed to be ephemeral and is tied to a specific event or action that occurs at a specific time. As time goes on, its utility is lessened. We agree that trying to make this content accessible after the fact is likely both onerous and of limited utility.

However, there are exceptions to this. A company that uses YouTube as its main storage mechanism for videos so they do not need to host them elsewhere is not using YouTube as a social media platform, per se. It is using it as an extension of their own website/a secondary hosting platform. Similarly, the course content of certain free classes may be offered via postings on YouTube or another external platform that may qualify as

social media. These classes should be accessible to all users of the organization's services or, if applicable, to the general public just as if they were presented on the organization's own website.

It is unclear how to set regulatory definitions that clearly and consistently accurately capture this distinction. Perhaps one mechanism that could be employed is if the content is referenced by any current or future services offered by a recipient it must be made accessible even if posted on a social media platform prior to the enforcement date.

This may require capturing the content and reposting it in another form that is accessible – a Twitter chain from 2020 looking at the historical reaction to the May 1 interoperability rules could likely not be recreated in Twitter/X but the content could be captured and presented on an accessible web page or in an accessible PDF file.

## **Adoption of Extra Section 508 Rules for Mobile Apps**

We concur that the extra requirements for mobile apps mentioned in the discussion of Section 508 requirements make sense and should be adopted.

Further, if not covered by WCAG v2.1 AA conformance for websites, we strongly urge that respecting system-wide and browser-specific settings for website be required for web content. Many individuals use these settings to override font settings on specific pages, to set minimum required font sizes for display, and make other necessary adjustments to content display. As time goes on, more and more websites find ways to override these user settings, making it harder and harder for individuals with visual impairments who do not rely on screen readers to access web content.

## **Requirement for CEO or Designee to Sign Off on Exceptions**

Members of our Data Governance Collaborative were concerned about clauses that allowed organizations to forego accessibility if it was an undue financial or administrative burden, but when we realized that OCR would require CEOs or a direct designee to put the specific reason why they believe the exception is valid in writing in a signed document this seemed like a pretty high bar. It means that this individual would likely be directly cited and potentially be held liable in any legislation around accessibility, something that should make them think long and hard before signing off.

We strongly approve of this approach and applaud OCR for determining what seems likely to be a reasonable enforcement mechanism against spurious claims of undue burden.

## **Recorded Audio/Video Content**

The proposed rule has a lengthy discussion of live audio/video content, but most organizations that offer live content provide a mechanism to view or listen to it later as well. For example, most webinars are recorded, as are sessions at virtual or hybrid conferences. It is unclear whether these same rules apply to recorded content.

Perhaps this is why the question about conventional electronic documents asked whether video content should be included, but we feel like it would be better addressed within this section discussing the live versions of the same content.

Our position is that any "recorded live" content should have accessibility requirements, as should any recorded (but never presented live) audio or video content.

## **Live Audio/Video and Telehealth**

It is not 100% clear in the proposed rule if the live audio discussion is meant to cover telehealth systems or just webinars, conferences, meetings, and similar day-to-day organizational activities. The text is written with an eye toward webinars, et al but if taken to the logical extreme should include telehealth. It would be helpful to explicitly discuss accessibility requirements when it comes to telehealth and the use of various telehealth platforms. We'd like to see this discussion from a variety of angles including pre-appointment surveys, use of advertisements that might be problematic, accessibility of the appointment itself, requirements for patients that may be difficult for disabled patients, etc.

We note that if it this section does include telehealth, live captioning via telephone systems is normally provided via other means and provided as a service to those with auditory disabilities and thus likely is not needed directly from the recipient. This is, in fact, one argument we made in favor of continued support for audio-only (phone) telehealth in our AHRQ comment appended to the end of this response.

## Privacy Issues with Accessibility

We would like to see this rule include some type of privacy requirements around a disabled individual's accommodation choices, especially when it comes to settings they employ in third party apps or on websites that may include analytics tools or appointment check-in tools or other external data collectors capable of determining private information about a user's disabilities without their consent. These tools have a history of collecting and using private data for a variety of uses beneficial to the collector without the consent of the individual being observed (the recent FTC Health Data Breach proposed rule is cracking down on the use of health data stemming from these practices, but it would be helpful to see explicit rules for accommodations data – such as non-standard browser settings being used – that could be used to infer disability-related information about the individual).

See <https://themarkup.org/pixelhunt/2022/06/16/facebook-is-receiving-sensitive-medical-information-from-hospital-websites> and <https://www.statnews.com/2023/04/07/medical-data-privacy-phreesia/> for two examples of companies collecting data this way (not specific to accessibility/accommodations data).

## Placing the Onus on the Disabled Individual

While we understand that it reduces the burden on recipients to allow some materials to only be made accessible if a specific individual needing them requires that accessibility, placing the onus on disabled individuals to always request accessible documents, especially documents specifically about their health or for administration of their healthcare or health insurance, is a huge burden on the individual. Further, the pathways for making these requests may be opaque, difficult to access, and lead to significant delays.

While we are focusing on healthcare in our response, we also note that excepting educational materials related to college/university courses from the accessibility rules unless notified that a specific student requires accessible course materials is extremely problematic. Requiring that this notification happen in enough time that someone can prepare accessible materials prior to the first class does not just place a notification burden on the student, but it also requires them to have their classes picked out well in advance and not switch courses or sections at the start of the term – a practice that other students are allowed to engage in.

## Internal vs External Websites and Apps

It is unclear if this rule is meant to apply just to the customers/patients/constituents of recipients or to employees of recipients as well. For example, many companies have extensive intranet sites related to HR practices and services, internal training, policies and procedures, group communications, and more. They might provide apps to manage or enter time off requests or to log how time is spent across different cost centers. Given that employees have disabilities too, are these websites and/or apps also covered by this rule?

## Effective Dates

While some effective dates are clear (2/3 years for web/mobile/kiosk clauses), other effective dates are not as clear and some of the dates around medical equipment seem inconsistent to us. Having more clarity in this area, perhaps by adding a section with all of the effective dates outlined in one place up front, would be helpful.

## Negotiation Requirements

If a recipient is proposing a modification to a disabled individual, do they enter into a negotiation process similar to the way that ADA accommodations are handled in a workplace? If the patient disagrees that a proposed modification will work, what are the obligations of both parties to engage and at what point can they agree that agreement is not possible? Is there an adjudication process available? We would like to see this rule explicitly address expectations in this area.



## Data Standardization, Collection, and Exchange

One of the areas preventing more effective accessible care for patients in healthcare settings is a lack of standardized data about disability and accommodations, its collection, and its exchange. We believe that this an essential part of the process of providing accessible care. We go into some detail about the type of data and data exchange we believe is needed in our response to AHRQ appended to the end of this response.

## Price Transparency Files

Participants in our Data Governance Collaborative wonder if the machine readable files required by hospital and payer price transparency rules must be accessible. While primarily meant to be machine readable, these files are also explicitly designed to be human readable and they are posted – and regularly updated – on a hospital or payer’s website.

## Reporting Requirements

Participants in our Data Governance Collaborative believe recipients should be required to collect data on disability usage, accessibility, modifications requested, modifications made, and other relevant metrics related to accessibility. We agree that defining a set of reasonable metrics to report on, perhaps expanding them over time, makes sense. These reports should all be de-identified and group similar content together or be comprised of counts.

The types of metrics that might make sense are:

- Number of times accessible bed was requested
- Number of times accessible bed was requested but not available
- Number of times help was requested for completing paperwork
- Number of times help was requested for completing paperwork but not available
- Number of times an accessible scale was used
- Number of times a patient was sent to a different location/clinic to use an accessible scale

And so on. We note that collection of this data likely requires the cooperation of each individual provider office/location as the requests are likely made locally within each clinic

## Accessible vs Handicapped Parking

This rule uses the term accessible parking when outlining its requirements. It is unclear whether that is referencing official handicapped parking spots or if it has another definition. We have assumed that they are identical for the purposes of our comments but would appreciate clarification in the final rule.

## Physically Accessible Facilities

It is unclear why this is currently allowed, but there are quite a few medical office locations that are not in physically accessible spaces in the Boston area, particularly in certain near north suburbs. For example, one of our staff members used to get care at a dentist’s office that was in a converted house. The main entrance opened up to a half flight of stairs up and a half flight of stairs down with no elevator or lift available for patients who cannot traverse stairs. This entire building was filled with various medical practitioners. We are aware of other medical offices with similar issues that prevent some or all patients with mobility disabilities from even entering their facilities. This is not an aberration; there are other medical offices with similar issues (mostly in converted residential spaces). We’ve even encountered a physical therapy office in Boston with an outside entrance that opens to a flight of stairs.

We note that this rule does not address the physical accessibility of facilities, perhaps because it is assumed that this is a given for medical office space in this day and age. We urge OCR to require basic physical accessibility of medical facilities as part of this rule.

## Reserving Medical Equipment

The proposed rule suggests:

“the practice could ensure that its services are readily accessible to and usable by people with disabilities by establishing operating procedures such that, when a patient with a mobility disability schedules an appointment, the accessible MDE can be reserved for the patient's visit.”

In theory that sounds like a great idea, but in practice it can be extremely problematic because there is currently no consistent way to determine which patients need specific accessible equipment ahead of time. Recording this data at scheduling time and having a mechanism to pass the data from scheduling systems to clinical systems in an actionable way would be important first steps to implementing such a system in a useful, fair way but that doesn't happen right now. Individuals in wheelchairs are often prioritized, but other patients who may have accessibility needs are ignored even if they have some other visible mobility aid such as a walker or scooter. Patients are often not aware of their specific accessibility needs prior to arriving for an encounter, and even if they are and indicate what they need when an appointment is scheduled the relevant information often never makes it to the clinical staff onsite at the time of the appointment.

We discuss these issues in more detail and provide some suggestions for solving them via standardized data collection and exchange in our AHRQ comment appended to the end of this response.

## Accessible Shuttle Services

Many of the shuttle services offered by or for major hospitals have serious accessibility issues even though they are meant to provide access to the hospitals for patients and staff who may find it difficult to travel between different sections of a large hospital, from one hospital in a system to another, or from nearby subway stations to a hospital. In some cases, public shuttles offered by hospitals are just not accessible – the only vehicle entrances for these shuttles use stairs. In other cases, stops are scheduled in places where the lift cannot be used. In another case, drivers have been trained to only allow wheelchair users to use the lift and will not allow patients with walkers or other mobility issues to use them even if those patients are unable to use the stairs to enter and exit the shuttle. One hospital stopped providing a fixed schedule shuttle and now only operates if the security staff at one of the buildings served by the shuttle calls and requests it, meaning that disabled patients who cannot easily walk between different sections of a large hospital may find themselves waiting for an hour or more for a five-minute shuttle trip, sometimes while having to stand outside so as not to miss the shuttle when it does arrive, causing them to be late or miss the care they were attempting to travel to via the shuttle or physically exhausting themselves in the process of waiting for the shuttle and possibly degrading the ability to get care that might require some level of physical activity.

We believe these services should be accessible and available to all patients if offered to some patients (or all employees if offered to some employees). We also believe they should be offered in a way that does not disadvantage disabled patients or make it harder for them to use than non-disabled individuals. We consider these services qualify as programs offered by the various hospitals either individually or collectively and believe they should be accessible under this rule, but it would be nice to have an explicit mention of shuttle services as, while they are open to all, they are more likely to be needed by disabled patients (if they are able to use them).

## Other Physical Accessibility Issues

Some other physical design issues that may be worth calling out include:

- Blocking hallways, walkways, or turns with unused wheelchairs
- Use of bumps on ramps (sometimes used to make them less slippery when wet) can be interpreted as barriers by visually impaired individuals using a white cane to navigate and make them turn away from the ramp or make them think a sidewalk is blocked when it isn't
- Use of “snake” lines/rope barriers that are not accessible to people with a tight turn radius or that may be difficult for visually impaired individuals to navigate, requiring some disabled individuals to either cut in line or wait off to the side and perhaps never get called up to get service because staff doesn't

recognize they're trying to wait in a line they can't access

- Making "walking space" too narrow and turns too sharp in waiting rooms or similar areas
- Partially blocking exam room doors with chairs so the doors don't open wide enough to allow individuals with walkers or wheelchairs to comfortably enter

## Additional Content Accessibility Suggestions

We suggest making minimum font requirements for public materials and requiring that all paper copies use clean printouts and not photocopies.

We also suggest requiring that slides are available full screen during webinars instead of taking up screen real estate with videos of the speaker without an option to hide them as this de facto decreases the size of the slides as visible to attendees.

## Response to Specific Questions

This section will list specific questions asked in the proposal and provide our responses to them.

### **Value Assessment Methods Question 1: The Department seeks comment on how value assessment tools and methods may provide unequal opportunities to individuals with disabilities**

Many value assessment tests assume that the patient falls within a reasonable distance from the population mean by default and, when evaluating how a patient does on the assessment, they are being graded from that perspective. This may mean that assessments of memory or intelligence or general cognitive function or many other things run into some or all of the following problems (or others):

- Patients who fall outside of a standard deviation (or two) of the norm (in either direction) not only may have their results judged inappropriately, they may be asked to take assessments that do not make sense for their situation
- Patients who naturally fall above the mean may be misjudged because their disability artificially deflates their scores due to an accessibility issue with the format of the test but they are still at or above the population mean
- Patients who naturally fall below the mean, or who do so because of a developmental disability, may be judged inappropriately based on an assessment not designed to test their abilities

Patients who have a visual impairment may face the following issues (among others):

- Inability to follow written instructions as presented
- Assessment tests that require visual acuity they do not have for core assessment tasks
- Assessment tests that use bright lights, flickering or blinking lights, low contrast, poorly photocopied paper content, or other external factors that affect how well the patient can see the required assessment tool (some of these factors may affect some neurodivergent patients too)
- Assessment tests that are timed but do not consider that it takes the visually impaired individual more time to read or that they need breaks between intensive periods of visual concentration or something else that eats up time (this also may be more generally applicable to other types of disabilities, such as developmental disabilities)
- Assessment tests that are done one side or one eye at a time where the patient will always do better on whichever side is performed first because of eye fatigue or the extra strain of trying to process with fewer visual inputs than normal or for some other reason

Patients who have mobility disabilities may face the following issues (among others):

- Not being able to use the default equipment or seating arrangements for a test – for example, an assessment given using a machine that comes with an attached chair with a small gap between the chair and the rest of the machine may be extremely difficult for many people with mobility issues to use
- Not being able to properly achieve the desired position for an assessment, resulting in poor quality results that do not adequately measure what was being assessed
- Not being able to stand/sit/lie down continuously for the desired amount of time, resulting in either interrupted/incomplete assessments or other issues

Patients who have hearing impairments may face the following issues (among others):

- Not being able to adequately follow instructions given verbally
- Not being able to follow auditory cues or other important auditory components of an assessment

Also, it is important to understand that people may have more than one disability or more than one factor requiring some form of mitigation on an exam (some of which are related to disability and some of which are not) and they each need to be addressed either cumulatively or separately. For example, someone who is multiple standard deviations above the mean in intelligence may need some modifications for fair assessment results for some assessments (not under disability rules) lest they be judged against the population mean, but if they are also visually impaired, they need an entirely different set of modifications that fall under the accommodations rubric. The two sets of modifications are both necessary in order for either to be effective and for the patient to get a fair and reliable assessment.

### **Value Assessment Methods Question 2: The Department seeks comment on other types of disability discrimination in value assessment not already specifically addressed within the proposed rulemaking.**

Please see our answer to the previous question. We note that most value assessment is not related to life extension but condition/quality of life assessment and we feel that is an area rife with discrimination (as outlined in our response to the last question above).

### **Web Accessibility Question 1: The Department's definition of "conventional electronic documents" consists of an exhaustive list of specific file types. Should the Department instead craft a more flexible definition that generally describes the types of documents that are covered or otherwise change the proposed definition, such as by including other file types (e.g., images or movies), or removing some of the listed file types?**

We applaud the Department for not trying to specify specific file types (other than PDF files) and rather specify categories of file types given the likelihood that the specific software and file formats used for this content will change over time. We do question whether it makes sense to include database files in the list. We firmly believe that content contained within databases should be accessible, but question whether these files are being made available as files. It is true that, at times in the distant past, people would infrequently post MS Access database files online to distribute certain types of information, but that time is long gone. Content from databases is much more likely to be directly integrated into live webpages and displayed inline as requested via searches, forms, or other contextual clues from the website user. Content of this form should not be considered conventional electronic documents, but an integral part of the website itself.

We believe image files that are not archived should be accessible as should video files, and if you believe the best way to do so is to include them in this designation, we do not object. However, given that there are separate discussions specific to images and video in this rule, we are not certain it's necessary to add them here and do think there is some potential for confusion if the same content is discussed multiple times in different ways. We leave the decision on exactly how to address audio and video files to OCR with the

expectation that making them accessible unless archived will be required.

### **Web Accessibility Question 2: The Department requests comment on whether a definition of “kiosks” is necessary**

We do believe it is necessary to make it clear that fixed mobile devices – that is, tablets that are attached to a desk in some way, such as a reception desk to facilitate check-ins – qualify as kiosks. There are some people who think of kiosks specifically and exclusively as standalone structures with some form of interactive display. Whether that happens via a formal definition or within the text and discussion of the rule does not matter to us.

### **Web Accessibility Question 5: What compliance costs and challenges might small recipients face in conforming with this rule? How accessible are small recipients' current web content and mobile apps? Do small recipients have internal staff to modify their web content and mobile apps, or do they use outside consulting staff to modify and maintain their web content and mobile apps?**

MHDC represents organizations that would qualify as recipients (many participating in our Data Governance Collaborative which helped inform our comments on this proposed rule), but does not anticipate qualifying as a recipient ourselves. However, we are within the “small recipient” size range and, being honest, will note that accessibility is a challenge. At the current time, we do our best to make our website as accessible as possible but we have not undergone a full accessibility review or made a concerted effort to ensure all of our content is fully accessible to a wide range of people with different disabilities (it’s on our list of improvements we’d like to make). We believe strongly that our website (and other content) should be accessible, but urgent issues often overtake the very important issues that do not have specific deadlines. We are able to at least somewhat justify this state of affairs because we do not directly serve the general public or provide essential medical care or related services and because we would swiftly address any specific requests or inquiries related to accessibility.

We believe placing a specific deadline on meeting accessibility goals would likely help other small organizations prioritize it and is likely needed to make it happen in any widespread way. We believe that for organizations that do directly serve the public, engage in medical care, or engage in essential related activities such as providing medical insurance, accessibility is an absolute requirement. This is true whether the organization has 5 employees or 5000.

### **Web Accessibility Question 6: Should the Department adopt a different WCAG version or conformance level for small recipients or a subset of small recipients?**

We strongly agree that specific, consistent accessibility requirements are important for all. It removes complexity in understanding requirements on all fronts, means that vendors have one specific standard to meet across all of their users, and provides consistent expectations for the disabled that allows them to make decisions about their personal settings and assistive technology use that will work across all recipients.

We note that smaller organizations may be more reliant on vendors and outsourcing; those organizations should be compliant.

### **Web Accessibility Question 8: How do recipients use mobile apps to make information and services available to the public? What kinds of barriers do people with disabilities encounter when attempting to access recipients' programs and activities via mobile apps? Are there any accessibility features unique to mobile apps that the Department should be aware of?**

Many visually impaired users find it easier to read on mobile devices than on other devices, but only when the apps they use respect both their device-wide display settings and offer internal settings with larger fonts, line

spacing, and other user-adjustable display features. This may mean supporting views that non-disabled individuals find unwieldy or poorly designed such as screens that only show a few words of text at a time. Applications that do not respect device settings or offer large print and large print friendly layouts/UIs are often unusable to the same population.

Offering options such as easily toggling screen reading on and off, automatic “page turning” with user-settable timing, supporting landscape with a single column of text (not splitting it into two or three columns side by side unless the user explicitly selects this choice), and offering large areas for registering required screen taps (as opposed to requiring them within half an inch of the edge of the screen, for example) are all options that can help people with various disabilities but that may not be appropriate or applicable to all apps.

Many of the specific issues visually impaired individuals encounter with mobile apps are the same or similar to those encountered with websites including:

- Layout elements that overlap each other
- Layouts that display one element per line when not designed to be displayed that way
- Login screens (and other popups) that cannot be submitted
- Cancellation functions that cannot be terminated
- Dropdown menus or other UI elements that don't work
- Text that cannot be enlarged and is too small to read
- Images or video that contains important information not conveyed via other means
- Poor contrast that makes text harder to read
- Jarring color combinations (such as red/yellow combinations) that require some visually impaired users to look away/close the app
- Inability to click on the exact spot where a button or checkbox exists because it's too small for the user to differentiate clearly
- Inability to return to their previous context if they accidentally leave an app (or unexpectedly click on a UI element that moves them to another section of the app)
- Difficulty using the inline keyboard to enter content
- Tasks timeout before they can be completed

### **Web Accessibility Question 11: How will the proposed compliance date affect people with disabilities, particularly in rural areas?**

The biggest issue that this rule will (hopefully) fix is the lack of accessibility of many patient portals, particularly for many visually impaired individuals. While we believe everything else is important too, it is essential portal access be addressed as quickly as possible; lack of access has turned patients without portal access into second-class citizens.

Some of the consequences of patients not being able to access patient portals include:

- They cannot communicate with providers via messaging for routine or normal matters
- They cannot schedule or reschedule appointments directly
- They cannot access or download instructions or other information provided during an encounter that may require further action on their part
- They cannot fill out any paperwork in advance (if made available), exacerbating the paperwork issues many of these patients already experience
- They may not be able to access or use third party health apps that use portal accounts as their authentication mechanism

While there may be other causes and individuals with other disabilities who also have trouble accessing their patient portals, this is a major issue for visually impaired patients who do not use screen readers (we do not have any data either way for users of screen readers). The login and screen display issues noted throughout this response (including in the comment directly above this) abound in patient portals and they seem to be particularly problematic for visually impaired individuals who adjust their screen resolutions.

Please see our AHRQ comment, appended to the end of this response, for a more detailed discussion of portal accessibility.

### **Web Accessibility Question 18: What would the impact of this exception be on people with disabilities?**

We believe this exception is reasonable so long as a recipient must make the content available to a disabled individual upon request. This could take the form of requesting a specific document they know exists but can no longer find on the organization's website (because it's been archived) or the form of "I am looking for content related to X for Y purpose" where Y is a legitimate purpose.

### **Web Accessibility Question 21: Would this "preexisting conventional electronic documents" exception reach content that is not already excepted under the proposed archived web content exception? If so, what kinds of additional content would it reach?**

Initially we were very concerned about this exception; there is a great deal of content that might qualify on the surface - plan documentation that only gets updated annually or less frequently, documentation for a legacy product that's still in use but unlikely to ever be updated again, and a lot of other notices or policies or similar. However, this note in the proposed rule addresses at least some of these concerns:

"a recipient must not only make a new patient form accessible, but it must also make accessible other materials that may be needed to complete the form, understand the process, or otherwise take part in the program."

This means that the use cases we considered – plan documentation that won't be updated again until the rollover period, documentation for software in wide use that may never be updated again, etc – would all fail to meet the exception because they are potentially needed for someone actively trying to sign up for the plan or use the software or do X – any supporting information someone might use, even if not required by all users, must also be accessible.

I think highlighting this more strongly might be warranted, but another possibility is to consider whether any pre-existing conventional electronic documents that meet this exception would actually qualify for archiving. We cannot think of any reason why documents no longer applicable to ongoing or existing programs could not be archived.

### **Web Accessibility Question 22: What would the impact of this exception be on people with disabilities? Are there alternatives to this exception that the Department should consider, or additional limitations that should be placed on this exception? How would foreseeable advances in technology affect the need for this exception?**

If there really is content that does not meet the requirements for archiving and that also falls into this exception, it likely will be fairly exclusionary to disabled individuals who need to access that content. However, as noted in the previous comment, we are not certain there are documents that fall into this narrow space.

### **Web Accessibility Question 23: What types of third-party web content can be found on websites of recipients? How would foreseeable advances in technology affect the need for creating an exception for this content? To what**

## **extent is this content posted by the recipients themselves, as opposed to third parties? To what extent do recipients delegate to third parties to post on their behalf? What degree of control do recipients have over content posted by third parties, and what steps can recipients take to make sure this content is accessible?**

We approve of the idea that recipients should not be responsible for ensuring that content provided by users via message boards, comment threads, or similar have the same accessibility requirements as content provided by recipients themselves. We note that the recipient should be able to provide an accessible system for the general structure and that text-only postings should be easy to make accessible and recommend that this level of accessibility be required. The issues come if attachments of any sort or embedded video/audio/images are allowed.

Regarding oversight of content posted by others, even a basic content moderation system can be onerous and require a level of governance and resources that might be difficult for smaller organizations and even some larger ones.

### **Web Accessibility Question 24: What would the impact of this exception be on people with disabilities?**

In general, user-supplied content should be supplemental. Not having access to it may be annoying and may require additional direct interfacing with the recipient, but in most cases it likely will not rise above an annoyance or inconvenience (which should not be disregarded, but is likely acceptable given how difficult it would be to convert this content). However, this becomes problematic if the recipient relies on the public to provide their customer support. Many organizations use public message boards as their support mechanism, relying on crowdsourcing to meet the needs of posters. In this case, when there is no alternate, direct mechanism for a disabled individual to engage with a customer support function, having this content be inaccessible is extremely problematic.

### **Web Accessibility Question 26: What would the impact of this exception be on people with disabilities, and how would foreseeable advances in technology affect the need for this exception?**

It is reasonable not to expect any organization to be responsible for the accessibility of another's organization unless they have a direct contractual obligation with each other that warrants it. However, should the linked content be important to understanding or providing context to users of the recipient's website, an alternate method of access should be provided. For example, a statement like "please follow this link for relevant context or contact our customer support line if you need help understanding this information" would encourage individuals who need additional information and cannot access it at the supplied link to engage via whatever customer support mechanisms are in place.

### **Web Accessibility Question 27: What types of external mobile apps, if any, do recipients use to provide access to their programs and activities to members of the public, and how accessible are these apps? While the Department has not proposed an exception to the requirements proposed in § 84.84 for recipients' use of external mobile apps, should the Department propose such an exception? If so, should this exception expire after a certain time, and how would this exception impact persons with disabilities?**

We note these apps are typically referred to as third party applications or third party apps in other HHS regulatory documents.

It is our believe that the vast majority of apps being used in the healthcare space, including by both payers and providers, are third party apps. Excluding them from accessibility requirements will almost certainly limit



disabled patient access to some programs offered by recipients. We do not believe they should be exempt, and believe that accessibility requirements in line with this rule should be included with any contract signed between a recipient and a third party app developer.

However, it is very possible that no such contract exists if an application is publicly available and not being directly provided by the recipient. Unfortunately, in this case it is not clear that OCR has the ability to impose accessibility requirements on these apps. It is possible the Department of Justice requirements that have been mentioned elsewhere in this rule will fill the gap, but that is not entirely clear at this point.

### **Web Accessibility Question 49: What would the impact of this exception be on people with disabilities?**

While there have been places in this response where we agreed that disabled individuals could contact a recipient and request alternate access methods for certain content, it is extremely onerous to constantly expect disabled individuals to proactively make such requests. Further, it is one thing if it is unlikely that this content has a direct affect on the individual or that only a small percentage of individuals would want to access a specific type of content, but password protected individual content is almost certainly something that it's important for that specific individual to see.

At a very minimum, it should be required that anyone sending this type of content have a mechanism for making the content accessible in place before any content is sent out and that there be a maximum timeframe for providing it when requested, perhaps 48 hours. Further, any deadlines expressed within the content should be adjusted to account for the delays and reset as of the date the accessible content is provided.

Further, this requirement should be part of any contracts signed with third parties or, if agreeing to a user agreement in lieu of a specific contract, recipients should be required to contact vendors to ensure they can meet these needs. Contracts recipients sign with their vendors should also require that all such documents be available in accessible formats.

For some context, a visually impaired individual we know was prescribed a piece of durable medical equipment for home use several months ago. This equipment was covered by their private insurance and was supposedly being shipped out to the patient by an outside vendor. The provider supposedly arranged for shipment, but the vendor wound up calling the patient to pick it up. The patient explained they were told the item would be shipped and that they have no way to pick it up. Rather than being sent as the patient was told to expect, the vendor asked for the patient's email address and sent them a lengthy document to sign via DocuSign. This document had two portions, neither of which was accessible (the first half was a badly scanned copy of handwritten and typed text on ledger-style paper with vertical lines that made it impossible to see any of the text, the second half was a scanned version of a printed document using a dense, miniscule font that could not be enlarged without losing its clarity). The disabled patient left voicemail with both the provider and the vendor explaining the document was not accessible but neither has engaged nor provided a solution. The patient still has not received the prescribed care.

### **Web Accessibility Question 51: Would allowing conforming alternate versions due to technical or legal limitations result in individuals with disabilities receiving unequal access to a recipient's programs and activities?**

A legal requirement is a legal requirement and there likely isn't much to say about that except it needs to be met. However, the technical requirement has a bit more flexibility. We would question whether the new technology that doesn't have an accessible option is truly necessary to meet the goals of the program. Further, in this day and age, we question whether new technologies should be developed that cannot be made accessible. Allowing loopholes of this sort encourages such development, whereas not providing this type of loophole might make it more pressing for the developer of new technology to make it accessible.

It is possible that there will be new technologies that make new and important programs available that cannot be accomplished with other technology that is accessible, but we believe it would be reasonable to require the CEO or designee level exception signed, written notice to justify use of a new technology that is not accessible.

**Web Accessibility Question 52: What should be considered sufficient evidence to support an allegation of noncompliance with a technical standard for purposes of enforcement action? For example, if a website or mobile app is noncompliant according to one testing methodology, or using one configuration of assistive technology, hardware, and software, is that sufficient?**

If compliance with WCAG 2.1 Level AA is required, then it seems like conformance to the 50 criteria should be judged in some way. Ideally real complaints from disabled users should be considered, but the rule indicates there may be cases where that's okay if WCAG is properly applied. Thus, if there's a complaint and the offending content does not fully comply with WCAG 2.1 Level AA at a minimum some type of corrective action plan should be required. Not all criteria is created equal, though, and the consequences of not being accessible also varies greatly. A strict numerical or percentage-based approach does not seem equitable or aligned with the potential difficulties caused.

Whether a civil monetary penalty should be assessed or what rises to that level is unclear. Impact on disabled individuals should be considered – if one person cannot access one facet of a program that's not okay, but it's probably not worthy of a fine unless the absence of that facet leads to a significant harm to the patient. Conversely, inability to create accounts, log in, or access any content related to a program, an essential website (for example, a provider directory), a patient portal, or an app should be considered a serious non-conformance, as should violations that result in the inability to use that feature in any significantly important way (i.e. can log into a portal but cannot interact with its contents at all).

So, at a minimum, we believe corrective action plans should be created for pretty much every violation. Consequences beyond that, assuming the recipient engages in the correction process, should be dependent on how the violation affects users and not on some arbitrary numerical formula.

We further urge OCR to record and examine accessibility complaints that do not technically fall out of compliance to determine if additional criteria need to be required at a later day.

**Web Accessibility Question 53: In evaluating compliance, do you think a recipient's policies and practices related to web and mobile app accessibility (e.g., accessibility feedback, testing, remediation) should be considered and, if so, how?**

Having a reasonable mechanism should be a requirement but not excuse other compliance issues.

**Web Accessibility Question 55: Should a recipient be considered in compliance with this part if the recipient remediates web and mobile app accessibility errors within a certain period of time after the recipient learns of nonconformance through accessibility testing or feedback? If so, what time frame for remediation is reasonable?**

If a recipient remediates non-compliance, they should be considered in compliance as of the official remediation date. However, the history of having been out of compliance should not be erased. Any public notices of non-compliance should include them, for example (but also note the date that the issues were remediated and they returned to compliance). This seems reasonable to us regardless of the time frame between their notice of non-compliance and the remediation date.

That said, if a recipient can show they had a robust testing process prior to go-live, provide a reasonable mechanism for user notification of issues, and resolve issues within a short timeframe (dependent on severity of issue, maybe 7-14-30 days) then we would be okay if they were not considered out of compliance for purposes of public listings and/or fines.

Robust testing processes might include:

- Some component of usability testing with real disabled users should be performed if possible

- Some combination of manual and automated testing designed to capture issues for multiple different types of disabled users
- Regression testing a randomly selected subset of the whole site should be required after updates/changes

**Web Accessibility Question 56: Should compliance with this rule be assessed differently for web content that existed on the recipient's website on the compliance date than for web content that is added after the compliance date?**

In general, all content that isn't archived should be accessible. Some leeway could be given for complex content such as video, especially recordings of previously held live events.

**Web Accessibility Question 57: In evaluating compliance, do you think a recipient's organizational maturity related to web and mobile app accessibility should be considered and, if so, how? For example, what categories of accessibility should be measured? Would such an approach be useful for recipients?**

It could be considered as a secondary factor but it doesn't really matter if a user cannot access content they need to access. We note that in some ways, serious issues (or multiple/frequent smaller issues) found by users in a production system developed under a so-called mature organization's processes show that the program is not as mature as they think.

**Web Accessibility Question 58: Should the Department consider limiting recipients' compliance obligations if nonconformance with a technical standard does not prevent a person with disabilities from accessing the programs and activities offered on the recipient's website or mobile app?**

No – information is posted on a website because it is believed to be helpful to those interested in reading it. If the content is not applicable or helpful it should be archived. Otherwise it should be compliant. However, as we believe consequences of non-compliance should be dependent on the impact on users, such violations should still be noted and fixed but perhaps not lead to civil monetary penalties or severe consequences for violators.

**Web Accessibility Question 59: When assessing compliance, should all instances of nonconformance be treated equally? Should nonconformance with certain WCAG 2.1 success criteria, or nonconformance in more frequently accessed content or more important core content, be given more weight when determining whether a website or mobile app meets a particular threshold for compliance?**

As noted in comments above, it would be reasonable to have some type of severity lens on issues, although it makes the process more complex. However, an issue that prevents users from logging into a system or from accessing any of its content is inherently more serious than an issue that can be accessed with difficulty is more serious than a technical violation that has minimal effects. Actual impact on users should be a major consideration of the consequences of non-compliance.

**Web Accessibility Question 60: How should the Department address isolated or temporary noncompliance with a technical standard and under what circumstances should noncompliance be considered isolated or temporary? How should the Department address noncompliance that is a result of technical difficulties, maintenance, updates, or repairs?**

Extremely time limited issues that are well understood, not the fault of the recipient, and resolved should not count against them so long as they do not recur with any regularity. Isolated minor issues that are not the fault of the recipient and do not materially affect access should perhaps result in some type of watch list or increased auditing requirements but not formal non-compliance designation unless they repeat. Any issues that significantly disrupt access that are the fault of the recipient should result in non-compliance even if fixed quickly.

**MDE Question 2: The Department seeks public comment on whether different scoping requirements should apply to different types of MDE, and if so, what scoping requirements should apply to what types of MDE.**

We agree that it makes sense to require more accessible equipment in environments designed specifically to treat mobility issues as it's likely a higher percentage of patients will need it.

**MDE Question 3: Because more patients with mobility disabilities may need accessible MDE than need accessible parking, the Department seeks public comment on whether the Department's suggested scoping requirement of 20 percent is sufficient to meet the needs of persons with disabilities.**

We question this requirement as an absolute requirement in general. While some locations, particularly in rural areas, may have their own parking facilities and control over the composition of parking allocation, many medical providers will not. Further, the importance of parking will vary depending on the location and transportation modes common in different areas.

For example, some provider locations in urban areas will not have any dedicated parking at all, but they will prioritize proximity to subway or bus stops for disabled patients using public transportation. In suburban areas, providers might be one tenant in a mixed use building or be located in a shopping mall without any parking specifically designated for their office or even be located in a converted house or other non-traditional space. For example, the last three physical therapy offices one of our staff members used (traveling via public transportation) were located as follows:

- In a suburban strip mall with parking spots along the sidewalk (perpendicular to the sidewalk) and additional parking in other locations not directly adjacent to the sidewalk. The same section of the strip mall also has an urgent care center. There are two handicapped spots directly adjacent to one of the two ramps up to the sidewalk and approximately 15-16 parking spots in total directly abutting the sidewalk. An additional 20 or so spots were directly across from the sidewalk with a driving lane between them. Those 20 spots did not include any handicapped spots as they are not near the entrance to any building or sidewalk. The strip mall is also accessible via a bus with stops across the parking lot and across the street depending on direction.
- On the top floor of a shared office building with some unknown number of parking spots behind the building. The spots are not near the entrance and the walk might be difficult to manage for someone with mobility issues because it is somewhat uphill. The location is also a difficult walk from the local (suburban) subway station or a block away from a bus stop.
- On the ground floor of a condo building in the heart of a major business district in the city. A very limited amount of metered street parking was available within three blocks of the office which was also about three blocks away from a major subway station. Technically there are several public parking options available within 4-5 blocks of the office, but they are all filled with office workers by 7-8am; most people

who drive to the area need to park at least a 20-30 minute walk away. All or nearly all of the patients using this location either walked from a nearby business or took the subway.

The last three dentist offices the same patient used were located as follows:

- A half flight of stairs up from the entrance of a converted house now serving as a shared medical office building (the doorway opens to half flights of stairs up and down; no office space is accessible without stairs) located at the intersection of two bus lines. A very limited amount of street parking is available along one side of the building (the other side is reserved as a bus stop) and there is a very small parking lot across the street and behind another building on hilly ground with broken up pavement – We note this entire location is not accessible; unfortunately, there are quite a few such medical office locations in the Boston suburbs which are, for some reason, allowed to remain in these physically inaccessible spaces.
- In the middle of a suburban town center with no nearby parking. Approximately 8 different bus lines stopped within two blocks of the office
- In a different suburban town center with a town fee for payment lot three blocks away and a bus stop two blocks away in a different direction.

Most medical offices in either the major urban center or the nearby suburbs either do not have any parking available under the direct control of the provider or are major hospitals that build their own parking structures. Nearly everything smaller than a major hospital is not going to have control over their parking situation or have many good options or options that optimize to the requirements outlined in this rule. However, for many of these locations, many if not most patients do not drive to those locations and thus parking is less of an issue. In the suburbs where there will be a mix of driving and public transportation, nearly all non-hospital locations with any parking will have some type of joint parking option that they do not get to control in any way. While OCR could argue that providers or other recipients should only sign leases that meet the parking requirements, this would severely limit the possible office locations and may mean that many existing offices cannot continue to operate in their existing locations or anywhere nearby.

### **MDE Question 5: The Department seeks public comment on whether the proposed approach to dispersion of accessible MDE is sufficient to meet the needs of individuals with disabilities, including the need to receive different types of specialized medical care.**

Without some mechanism for tracking and making both patients and staff aware of which locations have accessible equipment and which do not this is not sufficient. Without some mechanism for allowing other clinics to borrow equipment or send their patients for use in the clinic with the equipment without requiring them to go through a lengthy, confusing process it is not sufficient. Without some way of knowing patient needs and scheduling the accessible equipment accordingly it is not sufficient.

If a disabled patient arrives at a clinic without an accessible scale and needs to be weighed before they can be seen, either the clinic or the patient needs to know where they can go to get weighed. There needs to be time built into the schedule to allow the patient to travel to the other clinic, get their weight taken, and get back without them losing time with their provider. When they arrive at the other clinic, that clinic needs to know that they may be receiving patients who just need to be weighed and do not have an appointment in that clinic and have a mechanism in place for a staff member to take them back to the accessible scale, take their weight, and give it to them to report to the clinical staff where they actually have an appointment. Right now, this mechanism usually does not exist and the staff at the second clinic doesn't know how to process a patient who just needs their weight taken or who to task with the job. The original clinic isn't prepared for the delay of 20-30 minutes or even more and may cut short the patient's visit. In some cases they may instead tell the patient to get weighed in after the appointment and report back, but if the weight is an important detail for the clinical to know – for example, if the patient has fluid in their legs and knowing how much weight they've gained in the past week is important in judging how to treat it – the provider will not be able to make that determination until after their designated appointment time.

This type of distribution is also problematic for equipment that needs to be scheduled, such as an accessible bed that can be raised and lowered. There often isn't any mechanism for reserving this bed. Patients who need it may arrive and find a non-disabled patient is already using the room with that bed and be turned away, or they may find that someone in a wheelchair is expected to arrive an hour later but the room has already been reserved for them just in case and the staff will not allow anyone else to use it in the intervening hour. The crux of this problem is that there are no standardized mechanisms for collecting and exchanging data around accessibility and accommodation requirements. We discuss this particular use case and the issue of data collection and exchange in detail in our response to AHRQ, appended in full to the end of this response.

**MDE Question 6: The Department seeks public comment on whether additional requirements should be added to ensure dispersion (e.g., requiring at least one accessible exam table and scale in each department, clinic, or specialty; requiring each department, clinic and specialty to have a certain percentage of accessible MDE).**

Not having at least one accessible item in each physical location treating patients is a major hardship for patients. Sometimes even one is not sufficient if in use or the clinic does not check for accessibility needs in advance or does not get the related information given at the time of scheduling (see our immediately preceding response and our AHRQ comment for more on this and on some of the issues that might occur when each clinic does not have its own accessible scale).

There have been times when patients had to stand for the entirety of their time in both the waiting room and treatment room at clinics because they did not have a single chair the patients could use. This is not tenable, and may require appointments to be cut short if the patient can only stand for a certain length of time at once. It also might mean that the patient periodically uses the restroom facilities as a chair for portions of their visit when they need to take a break from standing which can cause problems if there are insufficient facilities for the clinic as a whole.

**MDE Question 7: The Department seeks information regarding:**

- **The extent to which accessible MDE can be moved or otherwise shared between clinics or departments.**
- **The burdens that the rule's proposed approach to dispersion or additional dispersion requirements may impose on recipients.**
- **The burdens that the rule's proposed approach to dispersion may impose on people with disabilities (e.g., increased wait times if accessible MDE needs to be located and moved, embarrassment, frustration, or impairment of treatment that may result if a patient must go to a different part of a hospital or clinic to use accessible MDE).**

We have already covered much of this in previous comments above, but the movement of equipment is obviously variable. Some beds can be moved, some cannot. Some chairs can be moved, some cannot. Scales, radiology equipment, eye examination equipment, and other larger equipment is obviously harder to move.

One comment worth repeating if equipment is shared across different clinics is having some mechanism for accepting patients from the clinic without the equipment quickly and processing them as fast as possible is needed so as not to cause a 30-40-60 minute disruption to their care and the schedule of the original clinic/clinicians.

Requiring some training (or additional training if any happens now) on where to send people for certain equipment or how to respond if someone shows up just to use certain equipment without an appointment seems warranted.

As far as burdens on patients go, we already mentioned a few issues but will repeat them and add a few more here:

- Having care denied because the one accessible bed is being reserved for someone in a wheelchair but another patient needs it too
- Having care abbreviated because it took so long to go get weighed at another clinic
- Extra physical exhaustion/pain/mobility issues because the patient had to do extra walking/standing/waiting around to go to another clinic
- Having to be the one to explain to staff in another clinic that no, you don't have an appointment, you're just there to be weighed and waiting for them to figure out how to do that/who should be pulled out of an appointment to do it
- Having to stand for an extended period of time because no accessible chair is available in the clinic
- Getting a substandard scan or test result that's deemed good enough because they did not provide an accessible manner to take the test and the patient was unable to use the standard equipment well enough to get a better result – but then clinical staff relies on the poor quality results to make care decisions

**MDE Question 8: The Department seeks public comment on the potential impact of the requirement of paragraph (c) on people with disabilities and recipients, including the impact on the availability of accessible MDE for purchase and lease.**

Referrals to other clinics may be a significant hardship for some patients with disabilities. Transportation may be difficult, expensive, or both and alternate locations that make sense for patients that drive may not be the same ones that make sense for people relying on public transportation. Prior authorizations acquired for the first location may not be valid for the new location and may need to be reissued for the new provider and location.

**MDE Question 14: If this rule were to apply to medical equipment that is not used for diagnostic purposes,**

- **“Should the technical standards set forth in the Standards for Accessible Medical Diagnostic Equipment be applied to non-diagnostic medical equipment, and if so, in what situations should those technical standards apply to non-diagnostic medical equipment?”**
- **Are there particular types of non-diagnostic medical equipment that should or should not be covered?**

We believe these clauses should apply to all medical equipment and note that a lot of the equipment already called out in this rule is not diagnostic, or not solely diagnostic. Beds, chairs, scales, and even radiology equipment can all be used as part of treatment as well as diagnosis.

## **AHRQ Healthcare Delivery of Preventive Services for People with Disabilities Comment**

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This document is submitted by the Massachusetts Health Data Consortium (MHDC) and its Data Governance Collaborative (DGC) in response to the AHRQ Key Question - Healthcare Delivery of Preventive Services for People with Disabilities request for comment found here: [https://effectivehealthcare.ahrq.gov/sites/default/files/related\\_files/healthcare-delivery-preventive-services-key-](https://effectivehealthcare.ahrq.gov/sites/default/files/related_files/healthcare-delivery-preventive-services-key-)

[questions.pdf](#)

## About MHDC

Founded in 1978, MHDC, a not-for-profit corporation, convenes the Massachusetts's health information community in advancing multi-stakeholder health data collaborations. MHDC's members include payers, providers, industry associations, state and federal agencies, technology and services companies, and consumers. The Consortium is the oldest organization of its kind in the country.

MHDC provides a variety of services to its members including educational and networking opportunities, analytics services on both the administrative and clinical side (Spotlight), and data governance and standardization efforts for both clinical and administrative data (the Data Governance Collaborative and the New England Healthcare Exchange Network, respectively).

## About DGC

The DGC is a collaboration between payer and provider organizations convened to discuss, design, and implement data sharing and interoperability among payers, providers, patients/members, and other interested parties who need health data. It is a one stop interoperability resource. The DGC primarily focuses on three areas:

- Collaboration: Development of common understanding of and specifications for data standards, exchange mechanisms, and what it means to participate in the modern health IT ecosystem
- Education: helping members understand their regulatory obligations, the data and exchange standards they're expected to use, and modern technology and related processes
- Innovation: Identification and development of projects and services needed to make modern health data practices and exchange a reality

## General Comments

Our Data Governance Collaborative spent time considering the barriers to healthcare for disabled patients (draft key question #1), what data about accommodations should be collected and exchanged, and some systemic and policy barriers to care. This response reflects some of those conversations and will cover three areas:

1. Systemic and policy barriers to care
2. Accommodations data to facilitate care
3. Policies related to captured data

We note this is just a subset of the issues patients encounter, that we have not made a systematic attempt to cover every issue or type of disability, and that all types of disabilities should be considered throughout any process meant to address access for disabled patients.

## Systemic and Policy Barriers to Care

This section will discuss systemic and policy barriers to care identified by the DGC both among its regular participants and also during public discussions it convened around SDOH (including disability).

### Assuming Motorized Wheelchairs as the Default

Many of the accessible spaces in buildings are designed for motorized wheelchairs. Patients using motorized wheelchairs often have a much tighter turn radius than patients using other wheelchairs, patients using walkers, and some other patients with mobility disabilities. This has several consequences for patients with mobility disabilities not using motorized wheelchairs:



- Many of these patients cannot reach automatic door open buttons or, worse, cannot reach them and then get out of the way of a door opening into them
- Many waiting rooms do not leave enough room for these patients to turn around or to turn to move to the next row of seats
- Many of these patients cannot use designated lines, particularly if they use rope/cable barriers that snake around
- Many of these patients cannot maneuver into spaces designed for triage, registration, checkin, checkout, and other specialty spaces often jammed into corners, sometimes blocked by chairs, performed in small cubicles, filled with many different pieces of equipment, or otherwise not designed for ease of access.
- Many patient rooms and even some waiting rooms/outer office spaces do not have enough clearance at the doorway for these patients to get into the room around chairs, desks, or other items placed along the wall near the doorway

### Prioritizing Patients in Wheelchairs over Other Disabled Patients

Some facilities have policies or practices that favor patients in wheelchairs over other patients with mobility-related disabilities without consideration for the actual capabilities of either type of patient or the specific needs of the care they're scheduled to get during that visit (in some cases they may not collect the relevant data for other patients, see below). For example, clinics may only have one or two rooms with adjustable beds and may automatically assign them to wheelchair patients whether or not their planned care requires using the bed (and perhaps reserve the room for significant time before their appointment to ensure availability) but other patients who cannot step up onto a normal bed but could use an adjustable bed are not vetted ahead of time and are often assigned to rooms with standard, non-adjustable beds they cannot use. This often happens even if the patient indicates they need such a bed (see further comments in the data section below). When the patient arrives needing an adjustable bed it may already be reserved for a patient in a wheelchair or (perhaps) in use by another patient who could use a non-adjustable bed but won't be moved because their visit is already underway. In these cases, the patient who needs the adjustable bed may be turned away without getting the scheduled care.

### Available Chairs or Seating

Some patients with physical disabilities have limitations in the type of chairs they can use. For instance, some people have to be able to put a leg off to the side (meaning they need a chair without arms) or need a chair with a straight back or they cannot tolerate sitting.

As time has gone on, more and more waiting rooms have changed to fancier chairs and do not have any place for some patients to sit by default. In most (but not all) offices the actual patient rooms do have a viable chair for both of these groups (although perhaps not for all cases where patients need specific types of seating) but in some cases, entire offices do not have an available chair and patients have to either spend their entire visit from arrival to departure standing or leave without getting their scheduled care.

Some staff are resistant to the idea that some patients cannot sit anywhere and balk at the idea of asking someone to bring a useable chair into the waiting room even when one is available within the office. Sometimes staff end up going off to another nearby clinic with a known acceptable chair, delaying the care and disrupting their schedule. The staff bringing a patient from one section of a facility to another may not be capable of carrying the chair themselves for any number of reasons, so finding someone to move the chair around can also be problematic.

In many cases, a simple \$10-20 metal folding chair would be fine for these patients. Keeping one or more of these on hand at clinics and other care centers would not solve this problem but it would help. Also, having advanced knowledge of the seating needs of patients would likely help (see data section below).

### Provider Arrival Window Policies

Many provider organizations have policies not to see patients who arrive more than 10 or 15 minutes late. In

some extreme cases, we have encountered policies with zero tolerance for any lateness at all. While we believe this policy is problematic for all patients, it is particularly problematic for patients relying on public transportation and for patients with disabilities (who often are also patients relying on public transportation; see below).

Many patients with disabilities have no choice but to rely on public transportation or paratransit (or both) and these services are not designed to ensure timely travel. No matter how early or how much extra time patients leave for their travel there is no guarantee they will arrive before their appointment time. This is exacerbated for patients who may only be able to take certain trains or buses (not all cars/cabins are accessible, a ramp is broken, the only wheelchair securement area is already in use, etc), who may miss transfers other patients have no trouble making because they move more slowly, who may be taken on a circuitous route that picks up and drops off multiple other riders before they're taken to their destination, or who may encounter any number of other difficulties that would not cause issues for most non-disabled patients.

Further, some disabled patients have a higher frequency of care than many other patients. Any patient trying to also work may have a limited ability to leave three hours early for an appointment in hopes of arriving on time, but this is greatly exacerbated when the patient needs to get care frequently. Further, there is a compounded effect that does not just affect the care they get frequently but all of their care, something the less frequently visited providers may fail to take into account. For example, some clinics performing standard preventative care like mammograms or specialized diagnostic testing or other care that patients may use once a year or less frequently will often incorporate the idea that it's a special appointment and the patient can adjust for that into their thinking, but if the patient has to deal with eight or ten or twelve or more other appointments that month they often cannot.

Leniency in this type of policy (when at all possible) would go a long way toward improving care for disabled patients who (sometimes frequently) spend half a day getting to an appointment only to be told they were five minutes too late to be seen. This trip may have exhausted them, caused them pain, meant they can't physically handle doing other things they should be doing for a few days, or otherwise have used up some portion of their available energy/movement/stamina for nothing as they did not get the care they needed and will have to try again hoping for a better result in the future.

### Automation and Unattended Check-In

While this happened pre-pandemic at times, it is extremely common now to have automated/unattended check-in processes at provider offices. This may work for the average patient but can pose problems for the disabled in several ways including:

- Patients who are blind or visually impaired may not be able to follow signs telling them what to do
- Patients who are blind or visually impaired may not be able to see UI elements on a tablet being used to check in
- Patients with hand mobility issues may not be able to fill out information on tablets directly
- Affixed tablets may not be physically accessible to patients with mobility disabilities

In addition to the inability to check in, patients who need additional assistance or information to know how to proceed have no way to gather that information or convey their needs to the people on the ground. Given the lack of information capture about these needs ahead of time (see the data section below), there is no consistent mechanism to even inform personnel the automation may be insufficient for one of the expected patients, let alone to bypass it.

For example, one patient arrival area at a local hospital has had patients enter via an unattended waiting room for years. When you walk in, a locked door is a few feet ahead of you with a sign indicating to use a phone sitting on a somewhat shielded from view shelf to the left of the door to let staff know you've arrived. Blind patients have walked in, found the locked door, and stood there knocking on it then, after some time, started yelling for help until eventually someone comes out for some other reason. The blind patients weren't warned or given any special instructions and no one inside was told a blind patient would be arriving or may need additional help with the check in process. While there were other patients in the waiting area, they were

wearing headphones or otherwise not paying attention or unwilling to interject.

Another example that isn't tied to the physical characteristics of a specific space is a patient who has a timed medication regime needed to be able to physically handle certain types of exams, tests, and procedures (for example, muscle relaxants and pain killers to improve mobility or allow a patient to tolerate a specific position needed to complete the care). The timing for this regime may be strict and needs to be coordinated with the staff to ensure the ability to successfully complete the needed care. The timing of the medication can't be based on the scheduled appointment times, but rather must use the times when certain portions of the care will actually take place. Not being able to coordinate the timing until called back for care will only delay that care and may, if the provider is on a tight schedule, prevent it from happening.

## Paperwork and Its Consequences

Some patients are unable to complete paperwork required at intake (or infrequently other times) because of visual impairment, mobility issues with their hands, or from other limitations caused by disability. In the past, patients were often assisted in these types of activities at providers by reception staff upon request, but many provider organizations stopped doing this some time ago without having an alternative in place.

In some cases, the nurse, tech, or doctor is left to use the time normally reserved for actual care to gather this information, perhaps over the course of multiple appointments for complex patients. This either delays care or causes care to commence without the standard information available for other patients before treatment (which could lead to less than ideal or even inappropriate treatment choices that might be contraindicated by information the doctor has not yet collected). It also forces the patient to pay for the intake process – which is classified as an encounter - rather than have it be outside of the financial elements of the relationship.

Online availability of paperwork can be helpful in some cases, but currently it is most often available only via patient portals which themselves can be difficult or impossible for the same cohort of disabled patients to access (see portal entry below).

Having clean, printed out copies using dark black ink on white paper with a reasonable font size and font face (sans serif is usually better) can also make paperwork more directly accessible to some individuals with visual impairments. Photocopies are common, but they degrade the quality of text and often reduce contrast, both things that can make text harder to read for the visually impaired with some vision. We also note that the standards for normal font sizes have slowly decreased; in the 1980 and 1990s 12-14pt was considered standard print size, now 10 or 11pt print is quite common (we note AHRQ requires 11pt print for its grant submissions) and some current "large print" materials use 14pt despite a traditional standard of needing to be at least 18pt to qualify. Not following these trends as sizes get smaller would be helpful for some patients with visual impairments.

In addition, offering a large print option for informational paperwork the patient is expected to read (as opposed to paperwork to be filled out) would be helpful, as would supporting some mechanism for an audio recording (even if that just consists of someone at the facility reading them into a recording device and sending the resulting file to the patient via the means of their choice).

The suggestions above are measures that will only help around the edges. Members of our Data Governance Collaborative suggest that providers be required to support personnel specifically hired to support disabled patients through their care journey by filling out paperwork or otherwise assisting in required tasks that they cannot perform without assistance (we are noting this suggestion here as it explicitly arose from our discussion of paperwork issues and, most likely, this is the area where they will be of the most direct assistance). These individuals could also be experts that advise the providers on issues related to accessibility that come up during an encounter, test, procedure, etc. We recommend that such individuals be available by request the same way patients who do not speak English well can request a translator.

## Double Appointments or Other Scheduling Requirements

Disabled patients sometimes need extra time or extra assistance for certain types of care. In these days of short booking, this may mean booking them for two consecutive appointments for certain types of services. In addition, some providers may decide they will only serve disabled patients during their peak staffing times to

ensure they get the attention they need. While well meaning and at times necessary, both of these can severely restrict when disabled patients can be scheduled for these services or delay care while staff checks with clinicians to okay the non-standard scheduling. It also may lead to the need for these patients to take time off for certain services that others may not be required to do.

For example, a particular radiology clinic may routinely schedule 15 minutes for a mammogram and schedule these services from 8am to 8pm on weekdays. However, disabled patients may be required to book two consecutive appointments sometime on Monday through Thursday between 10am and 3pm. Not only are they not allowed to book an appointment after normal working hours, they have to book at times that are likely to require them to maximize the amount of time off they need to take if working a 9-5 job. If they are unable to book the following year's appointment onsite after an existing appointment, convincing a scheduler later on that they are restricted to the specified hours or that they need a double appointment may be difficult because these needs are not usually captured in a way that the scheduler can see them (see data section below).

### Telehealth Including Audio Only

While many providers do still support some telehealth, many clinics have long since ceased, reduced, or modified their telehealth service as the pandemic went on and started winding down and many others have been considering doing so as the public health emergency officially ends. There is need to have certain services onsite, but there are many others that work perfectly well via telehealth. Many of these services work well via audio-only telehealth. In particular, consultative services often do not require physical examinations, nor do most behavioral health services and several other types of care. Other services may require periodic onsite care that can reasonably be augmented via telehealth. Being able to have those services that can be provided in a reasonable way via telehealth some or all of the time use that model of care is a huge boon for the disabled. Instead of hours of travel time waiting for public transportation or paratransit, care only requires a short break from work or whatever else the patient is doing that day. In addition to the time savings, not having to travel to medical care as frequently means less physical stress on bodies with physical limitations or the ability to conserve energy if they tend to get tired easily or spend their limited number of available functional cycles on other activities.

Video telehealth may be a good option for some, but it is not always as accessible. Patients with mobility issues in their hands may find operating the software difficult. Patients with visual impairments may find video software doesn't work with their necessary computer settings or cannot be seen well enough to use on mobile devices. Patients with auditory impairments may have assistive captioning technology set up for use with their phone service and find it easier to use than an application not directly designed for the hearing impaired that may have inadequate captioning. And so on.

Telehealth has been a godsend for disabled patients; audio telehealth is often easier for them to use than video options. Both should continue to be supported in cases where they have been found effective on an ongoing basis to better serve disabled (and other) patients.

### Portal Access

Many people assume that any digital interface is automatically accessible to all, but this is not the case. Patient portals, in particular, can be very problematic for some visually impaired (and perhaps other disabled) patients to access. There can be several reasons for this, one of which is an assumption of a minimum screen resolution that low vision patients often cannot meet and still function. When accessed on a machine not meeting the minimum resolution assumed by the portal developers, the apps have issues ranging from failure to open to displaying with UI elements superimposed on each other to having critical UI elements offscreen and inaccessible to the user so their only option is to quit. In some cases, patients may be able to create an account but not use it; in other cases even creating an account or logging in is not possible.

Lack of access to patient portals impacts these patients in multiple ways:

- They cannot communicate with providers via messaging for routine or normal matters
- They cannot easily send accessibility questions, concerns, or information to new providers or about new exams, tests, procedures, etc to make it more likely they'll be able to access their care

- They cannot schedule or reschedule appointments directly
- They cannot access or download instructions or other information provided during an encounter that may require further action on their part
- They cannot fill out any paperwork in advance (if made available), exacerbating the paperwork issues many of these patients already experience
- They cannot answer SDOH, equity, or other questionnaires being sent to patients via portals to help determine whether patients have needs in these areas despite being patients likely to benefit from SDOH interventions of various sorts that may be available based on these survey results. We know of several pilot projects in this area only available to patients via their portals so some disabled patients are excluded without the chance for assessment.
- They may not be able to access or use third party health apps that use portal accounts as their authentication mechanism

## Accommodations Data to Facilitate Care

Patients with disabilities who need specific accommodations to facilitate their care often spend a lot of time explaining what they need over and over again. In this world of electronic data capture and increased interoperability there should be no need for patients to do this unless they are unsure of the specific requirements of a new type of exam, test, or treatment.

This section will discuss some of the accommodations data identified by DGC participants and some of our thoughts around capturing and exchanging it.

### Basic Accommodations Required All the Time

For many disabled patients, having to go over the same accommodation needs over and over again is a major issue, particularly for fairly standard issues that apply all of the time. There should be a mechanism for capturing this data once and sharing it – with consent – to all relevant parties in the healthcare system.

USCDI v3 added a Disability Status data element under the Health Status Assessments data class, but it is designed only to report the existence of a disability. Further, it is defined to rely on patient assessment of their condition rather than any quantitative or qualitative clinical assessment of function (ex: a patient used to seeing 20/20 who suddenly only sees 20/40 may consider themselves significantly impaired and say so, but they are not considered disabled by any medical or legal definition). Regardless, indication of a disability (whether determined by personal assessment, clinical guidelines, or legal standards) is generally not sufficient to indicate any assistance or accommodations needed to ensure the disabled patient receives the care they need.

Development of standard mechanisms and locations for storing general accommodation needs – preferably attached to the patient information so it's seen whenever patient data is accessed – is important. Having this data linked, referenced, or imported into relevant encounter, procedure, or other resources so it can be acted on in the right places at the right times is also essential.

Some of the data we identified as important to capture in this general “basic accommodations” category include:

- Whether the patient can read text
  - Fill out forms with/without limitations (minimum font size, clean copy, color of paper, etc)
  - Understand/refer to instructions they're sent home with
  - Read signs on doors/find their own way to various locations in a facility
  - Follow a clinician explanation when they reference posters or information on their computer
- Whether the patient can tolerate bright lights
  - Whether the patient needs dimmed lights in an exam room

- Whether the patient can keep their eyes open if bright lights are shone in them
- Whether the patient can handle changes in ambient light conditions/lights being brightened/lights being turned on without warning
- Whether the results of any additional visual tests will degrade after a bright light is used
- Whether the patient can see 15 feet away (or some other similar distance) with clarity
- Whether the patient is deaf or hard of hearing
  - Needs a sign language interpreter
  - Needs text or visual demonstration of information normally imparted verbally
  - Needs to be greeted/called back using a non-verbal cue/request
- Whether the patient has any limitations for the distance they can walk
  - Needs to be transported from one location to another via wheelchair or other means
  - Needs to have an alternate version of a test requiring walking or running
  - Needs to be seen at a facility close to a bus stop or train station or have alternate transportation provided
- Whether the patient has any limitations on the time they can stand
  - Needs a chair in between actions requiring standing (chest x-rays, mammograms, etc)
  - Needs a wall to lean against while standing for any length of time
- Whether the patient has any limitations on the time they can sit
  - Needs to be able to move between standing and sitting while in a waiting area
  - Needs modifications to procedures/tests/exams that require extensive sitting
- Whether the patient has any limitations regarding their body positioning or how they change position
  - Needs to return to a neutral position to move rather than shifting in place
  - Needs extra time for exams that require repositioning or moving
  - Needs help getting up from a prone or seated position
  - Cannot be moved/pushed/positioned by others via dragging/pulling/etc
  - Cannot have adjustable beds (or similar) moved while in use
  - Cannot achieve certain positions without medical issues or medical intervention (ex: cannot tolerate lying down at all, cannot breathe naturally while lying on their back, etc)
  - Cannot sit with their legs straight in front of them or pushed together in any orientation
- Whether the patient has any limitations regarding the type of chair they can sit in
  - Needs to ensure that the clinic or facility has a chair they can sit in during their visit
  - Needs someone to move an acceptable chair with them if one is not available in all spaces used
  - Cannot use a wheelchair for transport when that's the normal mechanism
- Whether the patient has any limitations on their turn radius or how much room they need to make a 90 degree turn
  - Can the patient reach all of the places they need to go
  - Are items blocking hallways that will impede their progress or ability to turn
- Whether the patient can navigate any stairs or step upward or downward

- Can they step onto a standard scale or do they need an accessible scale
- Can they step onto test areas for various radiology exams
- Can they step onto a normal exam bed or do they need a bed that can be lowered
- Do they need help getting down from a bed or exam area
- Whether the patient can tolerate ambient noise
  - Do they need special arrangement instead of using a standard waiting room
- Whether the patient has any time sensitive requirements
  - Do they need to take a timed medication regime to tolerate the exam, test, or procedure?
  - Do they have a limit to how long they can do something that's part of the care?

We are certain there are many other common issues that could be captured once and addressed everywhere.

### Data Specific to a Particular Encounter, Test, or Procedure

While there are many barriers to care that are general, there may also be barriers that are specific to a particular encounter, test, or procedure.

For tests and procedures the disabled patient hasn't had before, they may need to discuss the exact process and expectations with an expert in order to access if they need accommodations beyond their standard accommodations to complete the test or procedure.

This typically involves a lengthy conversation with a clinician or technician who should be taking notes. Some specific things that may be needed and should be captured (these are just a sampling) include:

- Whether more time is needed to accomplish the tasks being performed
- Whether the patient can normally meet any physical requirements of the test (positioning, length of time without moving, etc)
- Whether assistance from additional personnel is required to complete the test or procedure (a technician holding the patient's eyes open, needing someone on each side of a bed to help a patient stand up after being prone, etc.)
- Whether any modifications to materials used during the test or procedure are needed (larger print, higher contrast, adjusted colors, printed rather than verbal prompts, help holding something, etc)
- Whether the way the results are interpreted need to be adjusted because of a visual or auditory impairment, developmental disability, or other disability

The patient should also review their standard accommodation needs with this person to make sure they understand what's needed and can make the necessary adjustments.

In addition to data needed for a specific encounter at the time of the encounter, there may also be accommodations needed for future appointments, some or all of which may need to be scheduled in the future. We outlined an example in the policy section where a radiology department requires certain disabled patients to schedule two consecutive appointments within a specific portion of their normal operating hours. Similar requirements may exist for gynecology appointments or other preventative (or other) services. These requirements should be documented in a way that allow a future scheduler to act on them without delays confirming those requirements. We recommend at a minimum having some mechanism to note (in a mechanism visible to both scheduling and clinical staff):

- Whether the patient needs multiple consecutive appointments to be seen
- Whether the patient needs a "long" appointment for circumstances beyond those other patients use them in (for example, primary care offices may have a long appointment designed for full physicals and a short appointment for other visits but disabled patients may require a long appointment for all visits)

- Whether there are any time window constraints for when the patient needs to be scheduled (ex: during peak staffing times so multiple people can assist with the appointment, just before lunch or at the end of the day so an extra few minutes can be used, in the morning so they have more mobility, etc)
- Whether the patient needs to be scheduled into a specific room or location (adjustable bed, etc)
- Whether there are any requirements for additional staff to be present (ex: need two techs to perform a mammogram instead of one, need an extra person present at the end of the appointment to assist with helping the patient stand up, etc)

See the section on capturing data from pre-appointment discussions below for further thoughts around the actual collection and use of this data.

### Data Captured During Encounters, Tests, and Procedures

Having data available ahead of time and accessible to staff is ideal, but no matter how much data is available ahead of time, there may be additional barriers or issues that arise during a medical visit. Documenting these in a consistent way that is available beyond the single encounter is important.

These items should be added to the basic accommodations needed all the time as appropriate, or noted in some way that they will be seen in the appropriate context if specific to a particular physical space or type of care.

If observed by others, the name of the observer and their comments should also be captured.

### Policies Related to Captured Data

This section brings the two previous sections of this comment together by outlining some of the policy issues affecting access to data about accommodations needed by disabled patients.

#### Capturing Information from Pre-Appointment Discussions

Currently some disabled patients spend a considerable amount of time discussing tests, exams, procedures, and other care events with clinicians or technicians providing those services to determine whether they're accessible and, if not, what accommodations might be needed to make them so. For more routine care, they may provide a reminder of ongoing needs when scheduling a service.

Some of this lift could be assisted by collecting the data in the section above and making it available to clinicians ahead of time so they can follow up if they have questions, but there will always be some need to discuss specific items ahead of time.

These discussions are often not well documented, or not documented in a way that usefully captures the specific accommodations or requirements of the patient in a way that the staff can access, absorb, and use on the day of services.

In some cases, this data is captured in a scheduling note that is visible to others using the scheduling system but is not transferred or accessible in any way within EHRs or other clinical data systems available at the time of an appointment.

In some cases, this data may be added as an encounter note ahead of time. This type of note is more traditionally generated during encounters and may not be viewed ahead of time.

In both of these cases, the information captured may be tied to a specific appointment and may disappear if the patient reschedules the appointment, if it gets postponed or cancelled by the staff, or is altered in some other way. Sometimes there are manual mechanisms for transferring these notes during rescheduling, but the scheduler may not be aware of them.

This process is onerous for both the disabled patient and the clinical staff. Making them do it more than once or having them arrive without the adequate accommodations available because the information they spent time reviewing ahead of time was either removed from the system or not shown to the appropriate staff frustrates everyone, can prevent care from happening, and adds to the burden of both the patient and the staff.



## Ensuring All Relevant Staff Sees Information

As noted in the previous section, relevant information about a patient's disability and accommodation needs can be stored in scheduling notes not traditionally viewed by clinical staff or in encounter notes not expected to be present prior to the appointment time.

Ensuring that all staff have access to relevant information and having alerts or other notifications informing clinical staff that they have an upcoming patient with a disability and accommodations they should review ahead of time should be part of the process. This may entail having direct interoperability between scheduling and clinical systems or giving clinical staff access to portions of scheduling software and the impetus to review relevant information stored there.

In addition to access to previously supplied information, patients may have tests or procedures where the staff they encounter beforehand is different from the staff they interact with afterward prior to release. For example, patients getting a colonoscopy may be held in one area with staff preparing them for the procedure and a different area for recovery after the test is complete prior to their release. The patient may impart important accessibility information to the first set of staff that also needs to be acted upon by the post-procedure staff but this information is not always a priority for either set of staff and may not be communicated properly. Having a representative from both sides of the house discuss accessibility with the patient would be ideal, but at a minimum having some mechanism for documenting the necessary accommodations before the procedure and ensuring they're seen by the staff caring for the patient afterwards is necessary to ensure appropriate care.

## Final Thoughts

The use of a disability advocate as outlined in the policy section of this comment would help immensely with many of the issues and suggestions outlined in this response, but even without one being aware of how general hospital policies affect disabled patients, having standard policies around awareness of upcoming patients with disabilities and ways to adjust standard policies and practices (such as automated check in) as needed to accommodate them, collection of standard accommodations data ahead of time in a way/place accessible to all relevant staff, using alerts or notifications to prompt information review in advance, policies to share data provided during an encounter to everyone working on that encounter, and standard locations and format of disability and accommodations data would go a long way toward making it easier and more effective for disabled patients to access preventative (and other) healthcare.