

# 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-questions.pdf](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:

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

## 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.