

Equitable Care for Patients with Disabilities Starts with Documentation in the EHR



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08/31/2022

Ten years ago, I had the opportunity to meet Pam, a woman in her late 40s who had [Primary Lateral Sclerosis](#) (PLS), a motor neuron disease that affects muscle movement. Pam, who was married with several teenage children, was fiercely independent; she used a walker to get around and still drove. However, her condition significantly affected her ability to speak and she used a smartphone-like device to communicate.

I asked Pam about her experience interacting with her medical team. She attended her medical appointments alone and developed a 1-page paper document that included a short description of her PLS, her abilities, and strategies to facilitate communication with her – such as not interrupting or changing topics when she was spelling out a message on her device. The document worked well except for one problem: she would hand it to the receptionist, who used the information to better communicate with her but then it wouldn't be shared with other members of her healthcare team. Pam was stumped. How could she get the information on that paper to her entire health care team?

One of the promises and advantages of electronic health records (EHRs) is the ability to share information amongst a patient's healthcare team members.

In Pam's case, she would greatly benefit from information about her disability and needed accommodations being prominently displayed in her chart – similar to how a patient's primary language is displayed when they do not speak English.

Since meeting Pam, I have learned many patients with disabilities desire information about their disability and need accommodations to be prominently displayed within their charts.

Federal Requirements for Providing Accessible Care

Multiple federal laws, including the [Rehabilitation Act of 1973](#), the [Americans with Disabilities Act of 1990](#), and the [Affordable Care Act of 2011](#), require health care organizations to provide patients with disabilities equitable health care through the provision of accommodations. Example accommodations include:

- Height-adjustable examination tables that allow patients with mobility disabilities to easily transfer to the table
- Materials such as consent forms in large print or braille for patients with visual disabilities

The most common [ADA lawsuit](#) in the healthcare setting is the lack of provision of [accessible and effective communication](#).

The US Department of Justice (DOJ) states that in order to provide communication accommodations, healthcare organizations need to collect and record patient disability status. This is logical. *But, how can you provide accommodations if you do not know who has a disability and needs accommodations?*

Building Evidence for Documenting Patients' Disability Status

Inspired by Pam's story, along with other stories and experiences of individuals with disabilities, I embarked on a series of studies to build evidence for how best to collect and document patients' disability status in the EHR.

Almost all hospitals and clinics do not consistently and systematically collect and record patients' disability status. So, we started at the beginning.

- **Can we obtain patients' disability status from existing information in the EHR?** Unfortunately, [there is no reliable method](#) for obtaining patients' disability status from existing information, such as clinical diagnoses in the EHR. For example, if a patient has had a stroke, they could have a range of types of disabilities, including mobility, communication, visual, or cognitive disabilities. The [diagnosis code for a stroke](#) does not reveal what type of disability the person has and what accommodations the person needs. This necessitates the collection and recording of patients' disability status in the EHR.
- **What do patients think about healthcare organizations collecting their disability status?** We conducted a survey of patients with and without disabilities, which was published in the [Journal of Healthcare Quality](#), and found that they overwhelmingly endorsed the collection of disability status by healthcare organizations. Like Pam, patients who require specific accommodations want their healthcare team to know about their needed accommodations.
- **What questions should healthcare organizations use?** We engaged patients with diverse disabilities, caregivers, healthcare providers, researchers, policymakers, and other experts to narrow down the set of questions to inquire about disability status, yet be concise and implementable in a fast-paced healthcare setting. We identified 6 "required" questions and 3 "recommended questions" and published our findings in the [Joint Commission Journal on Quality and Patient Safety](#).
- **How can disability questions be implemented in the health care setting?** We conducted another study, also published in the [Joint Commission Journal on Quality and Patient Safety](#), in which we trained registration staff in 52 primary care clinics in Colorado to collect patients' disability status during new patient registration. With the training, we increased documentation of disability status in patients' EHR by 500% during the study period.

Supporting Healthcare Systems

After publishing several of the aforementioned studies, I began receiving calls from individuals who worked within healthcare systems. These individuals led disability accessibility initiatives and activities at their own organizations and were charged with implementing the documentation of patients' disability status in the EHR. During the calls, the individuals expressed frustration and felt overwhelmed in their roles. There is little guidance on how to provide equitable healthcare to patients with disabilities. Consequently, these individuals felt isolated and unsure of how to succeed in their roles.

We began what is now known as the [Disability Equity Collaborative \(DEC\) Leaders Workgroup](#) to address these unmet needs. Initially starting with 5-10 individuals, the group now includes representatives from over 50 health care hospitals and systems across the country. The group meets

virtually twice a month and is an opportunity for participants to ask questions, share advice and celebrate successes in their efforts to provide accessible health care to patients with disabilities.

A frequent challenge discussed in the DEC Leader's meetings is how to implement the collection and recording of patients' disability status in the EHR.

To address this, in 2021, we developed a national working group of health care systems, advocates, policymakers, EHR vendors, and others interested and invested in documenting disability status in the EHR. The group is collaboratively identifying standards and recommendations for documentation of patients' disability status in the EHR and is advocating for policy changes.

New Policies are on the Horizon

Our DEC members have consistently stated a need for policy requirements and standards for documenting disability status in the EHR. Fortunately, we recently saw a major development.

In July 2022, the Office for the National Coordinator for Health Information Technology (ONC), which oversees federal standards for EHRs, released the [newest version of their Core Data for Interoperability standards](#), which included disability status.

In developing these standards, several researchers and advocates were invited to present to ONC on the topic. I was fortunate to be able to represent the DEC Leaders and Documenting Disability Status workgroups and present their experiences and needs to the committee.

Future Directions

Much work is still needed to ensure that patients with disabilities receive equitable healthcare. Through collaboration, research, and advocacy, we anticipate the following will soon become the norm:

1. Patients are consistently asked about their disability and disability accommodation needs.
2. The information is stored in the EHR and shared with the healthcare team.
3. The healthcare team uses the information to provide disability accommodations that facilitate patients' engagement in their healthcare.

All patients have the right to effectively communicate and participate in their care. For patients with disabilities, documenting their disability status is the first step in that journey.

About the Author

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Dr. Megan Morris is the Founder and Director of the Disability Equity Collaborative. She is an Associate Professor in the Division of General Internal Medicine and a faculty member within the Adult and Child Consortium for Health Outcomes Research and Delivery Science (ACCORDS) and the Center for Bioethics and Humanities at the University of Colorado Anschutz Medical Campus. Her research focuses on understanding, identifying, and addressing disparities in care delivered to patients with disabilities. Dr. Morris's passion for equitable care for persons with disabilities stems from her personal experience as a family member of a person with multiple disabilities. She is also a licensed speech-language pathologist with almost a decade of clinical experience.