

I am very pleased to share some of my story today in the hope that elements of it will strike a chord for legislators poised to advocate for change in the experience of people with disabilities as they seek medical care which is as thorough as that of their non-disabled colleagues. While there are numerous issues worthy of consideration when designing a model for healthcare which is respectful of and inclusive to those with disabilities, I will focus primarily on the provision of accessible medical diagnostic equipment. Furthermore, I will propose a means by which the use of such equipment can be facilitated.

I will not be citing statistics about numbers of people affected by disability or about numbers who are not receiving the care that they deserve. Instead, I bring to the discussion my own lived experience as a person with a disability, including observations made in two different careers. I practiced diagnostic radiology in 2 academic medical centers over a period of 27 years, during which time I honed my ability to teach medical students and residents. In the course of an appointment with my own internist about 10 years ago, he asked if I would be interested in teaching with him in a session for second year medical students who were about to go onto the wards where they would be interacting with patients for the first time. This was to be the only formal education they would receive about caring for patients with disabilities. I was enthusiastic about this opportunity as I knew I had a story to tell, and I thought I would be able to convey my experiences in a way that was entertaining, yet instructive. I must admit, though, that I was not sure that the students would necessarily be interested or even present as attendance in class was not mandatory. In its first iteration, the session consisted of my internist and I sitting in the front of an auditorium completely filled with attentive students. My internist posed questions to me, which I answered with illustrative vignettes. When given the opportunity to ask their own questions, it was clear that the students' minds had been awakened to issues which they had not previously considered. It was also clear that a single didactic session on disability would not be adequate to answer all of the questions which had arisen. Although I retired from medical practice 6 years ago, I have continued to participate in this introduction to "dealing with" patients with disability and chronic illness. After retirement, I pursued a Master's in Social Work with a concentration in advocacy about issues related to social justice. Certainly the inability of a substantial portion of our population to receive a complete medical exam falls squarely into this "wheelhouse."

And now, I will share part of my own medical story in order to illustrate some realities of the current situation where adequate care is not being provided to all.

Just over 65 years ago, the delivering obstetrician described me as being a floppy baby - a term given to infants who lack muscle tone. As is often the case, it was determined quickly what diagnoses I did not have; it took nearly 4 decades to figure out the all encompassing diagnosis. This only occurred after new symptoms - seizures - prompted imaging of my brain with surprising findings that prompted input from numerous radiologists and neurologists in the U.S. before consultation with a group in Paris provided the diagnosis of congenital muscular dystrophy with merosin deficiency - also known as LAMA 2 congenital muscular dystrophy. Unfortunately, with a confirmed

diagnosis came the knowledge that I would experience significant progression of weakness, rendering me nonambulatory and in need of mobility equipment.

When I was a medical student, I might have read that description and thought to myself, "Wow, that's an interesting case." And very quickly, my mentors would have encouraged us to think, "But, she is not a case; she is a human being." I am not sure that there would have been any discussion of the modifications which would be necessary in order to perform a routine physical exam. In all but a few medical schools currently, there is little to no attention to addressing the modifications which would be necessary to facilitate a complete exam for a disabled person.

So what sorts of omissions am I making reference to?

I can't forget my visits to my internist. Twenty years ago, I would arrive in his clinic in a motorized scooter. A nursing assistant would first ask me to step onto the scale. I know I lost my temper when I explained that I wouldn't be using the scooter if I were able to rise unassisted and stand on the scale. I was asked if I knew what I weighed. I did not. Some years ago, I became aware that I had lost a significant amount of weight, based on how my clothes fit. That year when I was asked what I weighed, I replied that I did not know, but that I thought we needed to figure out a way to obtain an accurate weight. As there were only a few large scales in the entire clinic building, it was necessary to go to another floor where a simple chair had been placed on a scale and weighed. And then I was transferred to the chair, after which my weight was obtained by a simple subtraction. My weight that day was 76 lbs (!), down from 93. Clearly, it was dangerous not to have been able to get an accurate weight, the message being that my weight would need to be recorded at least annually.

All patients experience the same frustration about the short time they are given for routine appointments. For those with disabilities and the inability to move with ease to an examining table, this often translates to their having an incomplete exam - particularly as physicians attempt to examine them while they remain in their wheelchairs. There are 2 possible ways in which this can be improved upon; height adjustable tables - which would require that the patient be able to transfer independently, and Hoyer lifts for which staff knowledgeable in their operation must be available. Another solution which could complement accessible equipment would be a "care extender," similar in some respects to a doula who assists a woman during pregnancy.

As I close, I want to share some words which I read on the website of Hyde Park, the home of Franklin D. Roosevelt who spent much time during his presidency in a wheelchair. Hyde Park has intentionally given attention to FDR's disability. On its website are the following words. Disability is not only a state of health; it is also a social construct - an interaction between the features of a person's body and the social or environmental barriers he encounters. It is imperative that the barriers to obtaining a complete physical exam be broken down for those with disabilities.

