I’ll start with a personal story—what could be more enlightening to the listener or empowering to the teller? It is the way a good clinician begins the medical encounter.

Early in my recovery as an amputee, before I was fitted with my prosthesis, I was wheelchair bound. Confident in my abilities to overcome any obstacle, I wheeled up to the door of a public rest room only to find that I was unable to open the door. From the angle of my seated position, the heavy wooden door wouldn’t budge. Each time I managed to haul it open a crack, unable to maneuver the chair one-handed to back up, the door would slam closed again. I started to sweat. A nice lady saw my predicament and opened it for me. A bit embarrassed but still un-daunted, I casually wheeled back to the handicap stall at the end of the row, swung open the door easily and wheeled in—immediately coming in contact with the toilet. Unable to turn, I reached back to close the door and found that I couldn’t do it without twisting the chair slightly to the side, standing up on my one good leg, turning, and kneeling in the chair facing backwards. I won’t even tell you about the sink and towel dispenser. Who in the world thought this was a handicapped-accessible bathroom? Who indeed?

Becoming physically disabled for me was an experience of great loss and profound lessons. Here are some of the things that I learned, both from reading and experiential learning.

**We Are a Big and Ever-growing Group**

According to Census 2000, there are 49.7 million people in the United States (almost 20% of the population) living with disabilities. Not surprisingly, the greatest burden falls on vulnerable groups like those of minority race such as American Indians and Alaska Natives (of whom 21.2% are disabled by a variety of chronic conditions, compared to only 12.2% of non-Hispanic whites) and the elderly (of whom 44.0% are disabled).

**There Are Many Barriers to Health Care for Disabled Persons**

Highlighted in the paper by Morrison et al in this month’s issue of *Family Medicine*, barriers encountered by persons with disabilities include lack of provider knowledge about the disabling conditions, lack of community resources, physical barriers to access, and communication difficulties such as clinicians focusing on the disability almost to the exclusion of the chief complaint. In a focus group study similar to that of Morrison’s, individuals who were blind or had low vision reported the same barriers, and also a lack of respect from the health care system, exemplified by physicians thinking that they (the patients) could not participate fully in their own care, and receiving written materials in inaccessible formats.

There is also ample evidence that individuals with disabilities receive poorer care, making them another community for focus in our efforts to reduce health disparities. In a national survey to study the effects of disability on a broad range of objective health care quality indicators, investigators found that disability status was a significant independent factor in quality-of-care measures for six important medical conditions (acute myocardial infarction, breast cancer, chronic obstructive pulmonary disease, diabetes, angina, and pneumonia). This difference in care for disabled individuals has also been highlighted in studies of early-stage breast cancer (women with mental disorders and neurological conditions had significantly lower adjusted rates of breast-conserving surgery and radiation therapy) and stage I non-small-cell lung cancer (persons with disabilities were less likely to receive surgery and had significantly higher cancer-specific mortality rates).
We Need to Embrace a New Model of Understanding Disability

Having a disability is a personal matter, and the effect and meaning of disability varies by individual and setting. As noted by the Environmental Task Force of the World Health Organization, recognition of the central role of environmental factors has changed the locus of the problem of disability from a feature of individuals to an interaction of the individuals with the environment around them. As discussed in a recent editorial, this new paradigm replaces the earlier medical model (disability as a problem of the person with management aimed at cure or adjustment/behavior change) and social model (disability as a socially created problem requiring fuller accommodation and integration of individuals into society) into one of a person’s experience of disability considering environmental barriers and facilitators. The International Classification of Functioning, Disability and Health (ICF), unanimously approved this model, recognizing the role of external forces (physical, social, and attitudinal) in precipitating or mitigating disability, thereby shifting the emphasis from prevention, cure, or maximal adaptation to maximizing functioning and well-being.

There Are Many Solutions

Having endorsed the idea of the personal medical home, we as health providers must take a hard look at the “homes” we provide in our practices. Fortunately, there are many resources for improvement, including an excellent book titled More Than Ramps: A Guide to Improving Health Care Quality and Access for People With Disabilities by Dr Lisa Iezzoni and a recent article (in fact an entire issue) in the Journal of the American Medical Association on structural impairments limiting access to care for patients with disabilities. Asking patients what they need, creating a true collaboration between patients and clinicians, may be one of our most powerful and still often neglected strategies.

Training for health care providers was mentioned by many of the participants in Morrison’s study, and training is what many of us as members of the Society of Teachers of Family Medicine believe we do best. Yet there is a paucity of literature describing optimal training. Our writing is still summative and reflective without clear guidance based on evaluated curricula. Indeed, I found only 34 articles on PubMed using the MeSH terms “teaching,” “disabled persons,” and “curriculum” and limiting to family medicine and the major education journals. Of these, only six described curricula—two in pediatrics and the others describing only portions of curricula such as a workshop, an objective structured clinical examination station, and using elderly patients to teach about disabilities. The most comprehensive paper was 32 years old!

Even searching the Family Medicine Digital Resource Library, I found only three references to two programs, only one of which described their curriculum in detail. The curriculum presented by Drs Zwygart and Woodard falls within a 16-week primary care experience for medical students. It includes a group experience with high school students who have intellectual disability, clinic-like experiences with four-six model patients with physical disabilities, a panel discussion with patients with varying abilities and their advocates, paired student home visits, and a service learning project.

It is time to step up and write up our evaluated curricula and innovative practices that truly begin to meet the needs of the disabled in our practices and our communities. Many of us already fall into the disabled category and as you age, most of the rest of you will be joining the ranks—if you are lucky. Provider attitudes, described by Morrison, of lack of interest, fear of burnout, or disability exceeding the usual scope of primary care must be challenged. It is the responsibility of all of us to include this vulnerable population that we serve in the best tradition of family medicine.

Correspondence: Address correspondence to Dr Smith, Michigan State University, PMB 281, 4155 Deep Lake Boundary Road, Colville, WA 99114. 517-231-2458. Fax: 250-368-8004. smithm69@msu.edu.

References

6. Iezzoni LI, Ngo LH, Li D. Early stage breast cancer treatments for younger Medicare beneficiaries with different disabilities. Health Serv Res 2008;May 12 [ePub ahead of print].


