A Community-Centered Disability Curriculum for Medical Students

BY JULIE M.G. ROGERS, PHD, AND RACHEL D.A. HAVYER, MD

Although disabilities are prevalent, many medical professionals lack knowledge about them. Many haven’t been trained to care for patients who have them and have negative attitudes about disabilities and those who have them. Their attitudes can affect health care and patient outcomes. Despite recommendations by U.S. surgeons general to include disability curricula in medical education, only a small minority of medical schools have done so. In 2011, Mayo Medical School developed a new disability curriculum for its first-year students. The aim was that they might gain insight into their potential biases and understand how those biases could affect the care they provide to persons with disabilities. Here we describe Mayo Medical School’s experience with its disability-awareness curriculum.

More than half a million Minnesotans live with a disability, and this number is expected to rise because of the aging of the population and the prevalence of chronic conditions. Although people with disabilities often interact with the health care system, they may not receive high-quality health care. In fact, there are substantial disparities in the quality of care and outcomes between those with and without disabilities. People with disabilities report that physicians’ lack of knowledge about disability and negative biases are substantial contributors to those disparities. Narratives about their negative experiences with the health care system are common.

Studies have found physicians and medical students do indeed have negative attitudes toward disability. For example, one study found that only 18% of emergency department workers said they would want to live if they had a spinal cord injury; that compares with 92% of those who actually have a spinal cord injury. Furthermore, 41% of these health care workers believed that resuscitation is too aggressive for patients with acute spinal cord injuries. Another study of physicians, psychologists, social workers and special education teachers found that physicians had significantly lower expectations of and more negative attitudes toward people with intellectual disabilities than those in the other professions.

The negative attitudes of health care professionals have an effect on patient outcomes. Compared with their non-disabled peers, people with disabilities are less likely to receive preventive care, including counseling about contraception, smoking cessation and weight loss. They also are less likely to receive treatment for an acute condition or a terminal illness and to receive desired end-of-life care. Aware of such disparities, U.S. surgeons general have urged that the health needs of persons with disabilities be addressed. One of their suggestions: train health professionals on the needs of this population.

Incorporating Disability Education into Mayo Medical School’s Curriculum

Education about disabilities has been shown to positively affect health professionals’ views of people who live with disabilities. Yet such training is rarely provided in medical school. In fact, fewer than one in five medical schools currently address disability anywhere in their curriculum. Often, the only way medical students learn about disability is by observing the way people with disabilities are treated by preceptors, mentors or others within their institution.

Mayo Medical School recognized the need to better train medical students to care for patients with disabilities after hearing concerns from students who had previous experience with the disability community. Those students believed the curriculum then espoused the view that the role of medicine was to “fix” the individual with the disability and failed to include information about the experiences and perceptions of persons who have disabilities. The faculty agreed, and in 2011 they began working with the students and members of the local disability community to develop and implement a new curriculum for first-year medical students (Table).

Now students begin to learn about disability during their genetics course, which
includes four two-hour sessions on disability. During these sessions, students hear from speakers who have a disability and participate in small-group discussions facilitated by a person with a disability. The public health course includes a didactic session in which students learn about disability definitions, history, ethics and health disparities between people with and without disabilities. Students discuss their personal experiences with disability and medicine’s role in caring for people with disabilities, including the difference between the medical model (that the person with a disability should be “fixed”) and the social model of disability (that society should be “fixed” to include those with disabilities). The session concludes with a panel of individuals who have disabilities fielding questions from the medical students.

The Most Influential Teachers
There is a large experiential gap between those who do and do not have disabilities. In fact, scholars contend that it is difficult for outsiders to understand what they call the “disability culture.” Hearing from people with disabilities can help bridge that gap.

In the sessions in which people with disabilities teach the medical students, the students gain insight into what it’s like for a person with a disability to navigate the health care system. For example, when one man whose daughter has an intellectual disability was asked whether he was happy with his medical care, here’s how he responded:

Yes and no. We have to be vigilant because not every doctor knows how to work with someone with a disability. We have to be plugged in to the community to know which doctor to take Amelia* to and also who might not treat her well. People talk. If we stay with the doctors who have experience with disability and have a good reputation, her health care is great. If she needs care from other providers, however, it can be scary.

* Not her real name

<table>
<thead>
<tr>
<th>Mayo Medical School Integrated Disability Curriculum</th>
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<tr>
<td><strong>GENETICS COURSE</strong></td>
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<tr>
<td>Occurs during weeks 4 through 8 of the first year of medical school</td>
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<td>Four sessions on disability experience (two hours each/eight hours total)</td>
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<td>• Speakers with disabilities present, (eg individuals with Down syndrome, William’s syndrome, achondroplasia)</td>
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<tr>
<td>• Small-group discussions facilitated by community members with disabilities</td>
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<td>Organized with community input (ARC Southeastern Minnesota, Down Syndrome Association of Minnesota, William’s Syndrome Association)</td>
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One time Amelia was admitted to the hospital by a doctor who told us she wasn’t able to eat or drink anything, and she needed an IV and antibiotics. But another doctor came in shortly after saying she didn’t need the medication anymore and could go home. When I asked why the change in recommendation, the new doctor could not give me a reason except for “It wouldn’t help Amelia.” When I explained that we wanted her treated, the doctor conceded. Amelia was in the hospital for several days, until she could drink on her own, and is now doing very well. According to the doctor who saw her in the clinic, she did need to stay in the hospital. I think everyone is well-intended, but I shudder to think that some doctors might not value Amelia’s life.

After hearing this man’s story, the students easily understood why he might be wary of medical professionals. In these sessions, students also have an opportunity to ask questions they may not be able to ask in a clinical setting such as: How does disability contribute to your personal identity? What do you think the term “disability” refers to? How does your impairment affect your life?

On surveys, the students have rated the sessions in which they interacted with people with disabilities above average in terms of their relevance to future clinical practice. When asked to comment on what they liked most about the genetics course as a whole, two-thirds said they thought the discussions with community members with disabilities were the most helpful part.

Our hope is that medical students will be more likely to understand why, for example, a woman with a spinal cord injury might be glad she was resuscitated after her injury and why she might benefit from counseling about smoking cessation and contraception. We also hope that as understanding grows, attitudes will change and we will begin to address the health disparities between those with and without disabilities.

Conclusion
At Mayo Medical School, we have learned that it is feasible to integrate a disability curriculum into medical training. We also have learned that it is essential to involve community members who have disabilities in teaching, as that enables students to learn about their very diverse lived experiences, allowing them to gain valuable insight into the disability culture. By hearing their stories, students begin to understand the depth of discrimination experienced by people with disabilities and the factors causing the disparities in health care and outcomes between those with and without disabilities.
disabilities. We believe that through our disability curriculum, students’ assumptions and biases are being challenged and that attitudes toward this population will improve. MM

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The authors would like to thank Dr. Keith Swetz of Mayo Clinic Rochester for his thoughtful review of the manuscript.

REFERENCES


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