

“Defining Disability” TED Talk Instructor’s Guide

Erica Seidel, MD

The goal of the activity is to discuss patient-doctor communication when caring for people with disabilities.

Estimated Time: 45 minutes

Recommended Group Size: <12 medical students

Outcome Objectives:

1. Students will recognize that disability can be thought of as a form of diversity as opposed to a medical diagnosis.
2. Students will be able to identify the importance of using neutral and accurate language when counseling someone with a disability.
3. Students will be able to identify consequences that can occur when providers and patients have different views of what it means to have a disability.

Potential Integration Points

Course Topics: Disability, Diversity, Communication skills, Professionalism, Rehabilitation Medicine, Cultural Competency

Physician Competencies Reference Set (PCRS) Domains: Interpersonal and Communication Skills, Professionalism, Systems-Based Practice

Physician Competencies Reference Set (PCRS) Competencies:

4.1 Communicate effectively with patients, families, and the public, as appropriate, across a broad range of socioeconomic and cultural backgrounds

5.5 Demonstrate sensitivity and responsiveness to a diverse patient population, including but not limited to diversity in gender, age, culture, race, religion, disabilities, and sexual orientation.

6.4 Advocate for quality patient care and optimal patient care systems.

Background

Health care providers are typically taught to focus on the medical/biological aspect of disability while they are in training. This mindset overlooks the fact that disability can be thought of as a form of diversity, just like gender, age, or sexual orientation.

Too often, health care provider's negative assumptions about disability are conveyed in how they speak to their patients. This may impact patient satisfaction, health care disparities in areas

ranging from Pap Smears to smoking cessation to depression screening, and ethical considerations.^{1,2}

It is within the physicians scope of practice to convey prognostic information, but the way this information is discussed can be influenced by the underlying assumptions physicians have about disability. Prognostic information should always be conveyed in a way that is neutral, and free from inaccurate assumptions about what life is like living with a disability. In fact, studies have shown that health care providers consistently underestimate the quality of life of people with disabilities.³

Student Preparation:

Note: Before meeting for this discussion, students should complete the following items.

- 1) Write a short definition of how they would define disability
- 2) Watch the 22 minute TED Talk, "The Opportunity of Adversity" by Aimee Mullins. This video discusses her own experiences interacting with health care providers as a woman living with a congenital disability.

http://www.ted.com/talks/lang/en/aimee_mullins_the_opportunity_of_adversity.html

Activity Outline

1. Complete discussion prompts.
2. Ask students to reflect on the definition of disability they wrote as preparatory work, and how they might change it after watching the video.

Discussion Prompts

Section 1:

"There's common, there's typical, there's no normal... if we can change this paradigm from one of achieving normalcy to one of possibility or potency... we can release the power of so many more children and invite them to engage their rare and valuable abilities with their communities." [clip is from 13:15-13:56]

"There's an important difference and distinction between the objective medical fact of my being an amputee and the subjective societal opinion of whether or not I'm disabled. Truthfully, the only real and consistent disability I've had to confront is the world ever thinking that I could be described by those definitions." [clip is from 9:29-9:51]

1. Do you agree with her claim that there is no normal? Why or why not?
2. Do you agree that there is a difference between the medical fact of having a certain condition and the opinion of society as to whether that condition makes a person disabled?

3. To what extent do you think doctor's opinions affect society's opinions regarding what is normal/abnormal? How are the medical fact of impairment and the value judgment that society makes to categorize something as abnormal intertwined?

Section 2:

"In our desire to protect those we care about by giving them the cold hard truth about their medical prognosis... we have to make sure that we are not putting the first brick in a wall that will actually disable someone. Perhaps the existing model of only looking at what is broken in you and how can we fix it serves to be more disabling to the individual than the pathology itself. By not treating the wholeness of a person, by not acknowledging their potency we are creating another ill on top of whatever natural struggle they might have. We are effectively grading someone's worth to our community. So we need to see through the pathology and into the range of human capabilities." [clip is from 9:50-10:55]

1. Do you agree with her assertion that by labeling someone as having a disability you are limiting them? How do we balance this with the need for medical diagnoses?
2. Can there be benefits to making a medical diagnosis that categorizes someone into a group that society views as abnormal? If yes, what are they?
3. What steps can physicians take to make sure that they see the whole person, not just the disability? What steps can they take to adjust their attitudes so that they don't see people with disabilities as "broken"?

Section 3:

Note: Have students break into smaller groups of 2-4 students to discuss the following questions.

Aimee Mullins describes encounters with two different physicians in her video. For the first doctor, she speaks about how he helped her to shape her own view of herself as strong, powerful, and athletic. The other she describes as wrongly giving her parents a grim prognosis that anticipated she would never be independent.

Later, she talks about the "X Factor" in her video, which she describes as understanding "there is a difference between the medical condition and what someone might do with it."

1. What role do doctors play in their patient's perception of their capabilities?
2. How can you best balance this unpredictable "X Factor" piece of what someone might be capable of with patients/parents who want information when they receive a new diagnosis?
3. How would you counsel a person with a recent spinal cord injury? A couple who just received a prenatal diagnosis of Down Syndrome?

4. What are some possible consequences if patients and doctors disagree on the definition of normal?
5. What was the definition of disability that you wrote down prior to this class? How do you think Aimee Mullins would respond to that definition? Is there anything about your definition that you would change after this discussion?

Note: If time permits, have a representative from each group summarize their group's discussion of the above questions.

Section 4: Wrap Up (whole group)

1. What is one thing that you have taken away from the discussion today that you can apply when you are seeing patients?

References

1. Testimony by Lisa Iezzoni to the Senate Health, Education, Labor, and Pensions Committee. January 27, 2009.
2. Reis, Judy Panko; Breslin, Mary Lou; Iezzoni, Lisa I & Kirschner, Kristi. It Takes More Than Ramps to Solve the Health Care Crisis for People with Disabilities. 2004.
3. Albrecht, G.L. & Devlieger, P.J. (1991) The disability paradox: high quality of life against all odds. Social Science & Medicine., 48, 877-88.