

## **Disability, Medicine, and Representation**

Consortium for Culture and Medicine  
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This course aims to bring disability and medicine into cross-disciplinary dialogue by examining representations of disability and medicine in film, literature, and medical texts on disability. These texts and conventions are considered in light of critical discussions of representation and disability. The "medicalization" of disability is examined, with students invited to explore disability and ability as cultural representations, wherein bodily abilities and limitations are conditioned by subjective perceptions of "normalcy." A principal question is how to incorporate a "social model" of disability into medical/clinical education and practice. Disability studies scholars and clinicians working on disability will be guest speakers.

### Rationale for the course

People with disability are disproportionately patients in the medical system, yet medical school curricula offer little by way of instruction about disability. At the same time, disability studies programs offer little by way of instruction about medicine and medical culture. This course begins to position its students as translators of different discourses and cultural understandings of disability. Students in this class will represent different disciplinary approaches—such as medicine, the humanities, and the social sciences—and together have a unique opportunity for peer learning on a subject that is represented often dramatically differently by different disciplines. By providing students with the opportunity to examine disability comparatively, this course will help them to understand how different systems of representation produce different understandings of disability.

### Course objectives: At the end of the course students will have learned

- a basic range of stereotypes of disability and difference and to consider how those stereotypes are naturalized within the logic of dominant discourses;
- to articulate working models of disability such as the medical and social models and to explore the strengths and limits of those models;
- to identify how disability functions metaphorically in film, literature, and popular culture;
- to analyze the different perspectives of medicine and disability studies in order to translate meanings and goals effectively, working toward collaboration;
- to analyze representations in culture in relation to questions of power and marginalization and in terms of the question of identity and self-representation; and
- to compare high art, popular, and medical discourses and discuss how they mutually inform each other and compete for dominance.

Class 1

Introduction: Translation and Representation

Class 2

Exploring discourses of disability: the social and the medical models

Lisa I. Iezzoni and Vicki A. Friedman, "Turning the Disability Tide: The Importance of Definitions," *JAMA*

Joan Aleshire, "Midway: State Fair" and "The X-Rays" from *Staring Back* (short stories)

Amanda Baggs, "In My Own Language," YouTube video

Clips from Gretchen Berland, *Rolling*

Class 3

Disability and medicine: foundational issues

Nancy Mairs, *Waist-High in the World* (essays)

Lucy Grealy, *Autobiography of a Face* (memoir)

AM Rosland, "A Piece of My Mind: Assuming the Worst," *JAMA*

Darshak M. Sanghavi, "Wanting Babies Like Themselves, Some Parents Choose Genetic Defects," *New York Times*

Class 4

History, disability, and ethnicity: from freak shows to grand rounds

Rosemarie Garland-Thomson, "The Cultural Work of American Freak Shows, 1835-1940" (25 pp.)

Selections from Suzan-Lori Park, *Venus* (play)

Clips from David Lynch, *The Elephant Man*

Class 5

Staring back: Representations of medicine

Leonard Kriegel, "Falling into Life" from *Staring Back* (12 pp.) (essay)

Jim Ferris, *The Hospital Poems*

Selections from Kenny Fries, *Body, Remember* (memoir)

Class 6

Disability and representation

W. J. T. Mitchell, "Representation" (11 pp.) (essay)

Rosemarie Garland-Thompson, "Disability and Representation" (5 pp.) (essay)

recommended: David T. Mitchell and Sharon L. Snyder, "Disability Studies and the Double Bind of Representation" (33 pp.) (essay)

Class 7

Representations of others

Screening: Selections from Rob Epstein and Jeffrey Friedman, *The Celluloid Closet* and Marlon Riggs, *Color Adjustment*

Paul Darke, "Understanding Cinematic Representations of Disability" (16 pp.)

Kathleen LeBesco, "Framing Fatness: Popular Representations of Obesity as Disability" (10 pp.)

Class 8

Midterm paper due

Class 9

"No Pity": sympathy, empathy, and points of view

Harriet McBryde Johnson, "Alas for Tiny Tim, He Became a Christmas Cliché," *New York Times*

Evan Kemp, Jr., "Aiding The Disabled: No Pity, Please," *New York Times*

Rebecca Garden, "Expanding Clinical Empathy: An Activist Perspective," *Journal of General Internal Medicine*

"Telethons and Pity," Growing Up with a Disability (blog)

Felicia Nimue Ackerman, "We Gather Together" (4 pp.) (short story)

Classes 10 & 11

Fat/obesity, disability and medicine

Judy Freespirit, "On Ward G," from *The Strange History of Suzanne Lafleshe* (7 pp.) (short story)

Betty Rose Dudley, "Fat Kills," from *Fat!So?: Because You Don't Have to Apologize for your Size!* (short story)

Emily Merrill & Jane Grassley, "Women's stories of their experiences as overweight patients," *Journal of Advanced Nursing* (5 pp.)

Linda Bacon, MA, PhD, "End the War on Obesity: Make Peace With Your Patients" MedScape webcast, Posted 11/27/2006

Lisa Roney, "Hunger and Plenty," from *Sweet Invisible Body: Reflections on a Life with Diabetes* (memoir)

Yale University, Weight Bias in Clinical Settings: Improving Health Care Delivery for Obese Patients, online course for medical professionals

"First, Do No Harm: Real Stories of Fat Prejudice in Health Care" (blog)

Class 12

Final paper due, wrap up & course evaluation

## Course Texts

- Baggs, Amanda, "In My Own Language," [www.youtube.com/watch?v=JnylM1hI2jc](http://www.youtube.com/watch?v=JnylM1hI2jc)
- Berland, Gretchen, dir., Galen Buckwalter, Vicki Elman, Ernie Wallengren, assoc. dirs., *Rolling*, Fourwheeldrive Productions, 2004
- Darke, Paul, "Understanding Cinematic Representations of Disability," in *The Disability Reader: Social Science Perspectives* (London: Continuum, 1998), pp. 181-197
- Dayton, Kim, "Procedures," *The Arduous Touch: Women's Voices in Health Care* (West Lafayette, IN: NotaBell/Purdue University Press, 1999)
- Dudley, Betty Rose, "Fat Kills," from Marily Wann, *Fat!So?: Because You Don't Have to Apologize for your Size!* (Ten Speed Press, 1998), pp. 42-43.
- Epstein, Rob and Jeffrey Friedman *The Celluloid Closet* (1995) (film)
- First, Do No Harm: Real Stories of Fat Prejudice in Health Care*. Weblog.  
<http://fathealth.wordpress.com/>
- Fries, Kenny, *Body, Remember: A Memoir*, Living Out: Gay and Lesbian Autobiographies (Madison: University of Wisconsin Press, 2003)
- Garden, Rebecca, "Expanding Clinical Empathy: An Activist Perspective," *Journal of General Internal Medicine* 24(1), January 2009:122-5
- Garland-Thomson, Rosemarie "The Cultural Work of American Freak Shows, 1835-1940," *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (NY: Columbia University Press, 1997), 55-80.
- , "Disability and Representation," *PMLA* March 2005, 120(2): 522-527.
- Iezzoni, Lisa I. and Vicki A. Friedman, "Turning the Disability Tide: The Importance of Definitions," *JAMA* 2008; 299(3): 332-334
- Kemp, Jr., Evan, "Aiding The Disabled: No Pity, Please," *New York Times*, September 3, 1981, <http://query.nytimes.com/gst/fullpage.html?sec=health&res=9902E5D8133BF930A3575AC0A967948260&scp=5&sq=evan%20j%20kemp&st=cse>
- LeBesco, Kathleen, "Framing Fatness: Popular Representations of Obesity as Disability," in *Revolting Bodies?: The Struggle to Redefine Fat Identity* (Boston: University of Massachusetts Press, 2004), pp. 74-84
- Lynch, David, *The Elephant Man*, Paramount Pictures, 1980
- Mairs, Nancy *Waist-High in the World: A Life Among the Nondisabled* (Boston: Beacon Press, 1996)
- McBryde Johnson, Harriet, "Alas for Tiny Tim, He Became a Christmas Cliché," *New York Times* Op-Ed, December 25, 2006, <http://www.nytimes.com/2006/12/25/opinion/25johnson.html?pagewanted=print>
- Merrill, Emily & Jane Grassley, "Women's stories of their experiences as overweight patients," *Journal of Advanced Nursing* 64(2):139-146.
- Mitchell, David T. and Sharon L. Snyder, "Disability Studies and the Double Bind of Representation," *The Body and Physical Difference: Discourses of Disability*, ed. David T. Mitchell and Sharon L. Snyder (Ann Arbor, MI: University of Michigan Press, 1997), 1-34.
- Mitchell, W. J. T., "Representation," in *Critical Terms for Literary Study*, 2<sup>nd</sup> ed., Frank Lentricchia and Thomas McLaughlin, eds. (Chicago: Chicago University Press, 1995), 11-22.

Nimue Ackerman, Felicia, "We Gather Together," from *Ragged Edge* Online magazine:  
<http://www.raggededgemagazine.com/departments/fiction/002894.html>

Parks, Suzan-Lori, *Venus* (New York: Theatre Communications Group, 1997)

Roney, Lisa, "Hunger and Plenty," from *Sweet Invisible Body: Reflections on a Life with Diabetes* (NY: Henry Holt, 1999): 111-139.

Rosland, Ann-Marie, A piece of my mind: assuming the worst, *JAMA*, Jan. 9, 2008, 299(2): 144-145

Sacks, Oliver, *The Man Who Mistook His Wife for a Hat and Other Clinical Tales* (NY: Touchstone, 1998)

Sanghavi, Darshak M., "Wanting Babies Like Themselves, Some Parents Choose Genetic Defects," *New York Times*, December 5, 2006,  
<http://www.nytimes.com/2006/12/05/health/05essa.html>

*Staring Back: The Disability Experience from the Inside Out*, ed. Kenny Fries (NY: Plume, 1997)

*The Strange History of Suzanne Lafleshe and Other Stories of Women and Fatness*, ed. Susan Koppelman (NY: Feminist Press, 2003)

"Telethons and Pity," Growing Up with a Disability blog, August 31, 2008,  
<http://growingupwithadisability.blogspot.com/2008/08/telethons-and-pity-repost.html>

Trueman, Terry, *Stuck in Neutral* (NY: Harper, 2001)

Yale University, "Weight Bias in Clinical Settings: Improving Health Care Delivery for Obese Patients," online course for medical professionals,  
<http://learn.med.yale.edu/rudd/weightbias/login.asp?ec=50017>