

SC 31301 Sociology of Disability and Chronic Illness
Spring 2008
M 3-5:20 McGuinn 526

Instructor: Dana Červenáková Ahern
Office: McGuinn 410D, Department of Sociology
Office Hrs: M 11:00a -1pm in O'Neill 200, Connors Family Learning Center; and by appointment.

E-mail: cervenak@bc.edu
Phone: 617-256-6192

“The sociological imagination enables us to grasp history and biography and the relations between the two within society. That is its task and its promise. To recognize this task and this promise is the mark of the classic social analyst.” C.W. Mills The Sociological Imagination, 1959

“The tragic aspect of blindness does not inhere in the condition nor can it do so. In nature it is absent. It is an entirely civilized idea. The world in which a man [sic] finds himself creates the tragedy for him and in him.”
Chevigny, *My Eyes Have a Cold Nose*.
Preface, xi.

Course objectives

This course will provide an introduction to the major themes of sociology of disability and chronic illness. Until the advent of the disability rights movement, disability was predominantly seen as a matter of individual medical diagnosis. People with disability were seen as in need of repair; those who could not be repaired often became objects of pity and fear.

The cumulative effect of the disability rights movement activities has shifted the understanding of the concept of disability from the personal/medical to the social – it introduced disability as a social construction. In other words, the physical or intellectual impairment -- of hearing, sight, movement, intellectual ability, etc. -- is real, but the meaning that society assigns to the impairment is flexible, changes over time and from culture to culture.

Thus, throughout this course we will explore the contrast between the traditional view of disabled people as medically “broken” with the emerging view of what has become known as ‘disability theory’. This view has argued that people with accredited or perceived impairments are disabled by society’s blatant failure to accommodate their needs. We will not ignore or deny the significance of any particular impairment in people’s lives. We will simply concentrate on noticing and analyzing those social barriers which are constructed ‘on top of’ impairments. We will also examine the ways in which:

- a) the definitions meanings and experiences of having a disability and/or chronic illness are shaped by cultural, political, economic and historical factors;
- b) the institutions shape the definitions, meanings and treatments of disability;
- c) people resist or accept dominant definitions and treatments of disability.

Representative readings and films will provide the basis for in-class discussions, exercises, assignments, and exams.

Course requirements

- 1) **Class attendance** – students are expected to attend all classes.
- 2) **Class participation** – students are expected to actively participate in class by asking questions, offering comments and exchanging their ideas regarding the material with class mates and the instructor.
- 3) **Assigned readings and exercises** – students are expected to complete all readings and take-home exercises before the class of the date for which they are assigned.
This class is reading intensive. Without knowledge of the readings you will not be able to fully participate.
- 4) **Response paper** (5-8 pages) – respond to a specific problem or issue we will be grappling with during the course. During this reflective paper, I encourage you to first summarize what the central issues are, then elaborate on how your own experiences and critical readings respond to these issues. You are expected to demonstrate your understanding of the issues discussed and use the conceptual tools offered in class to critically analyze the social realities that frame the lives of persons with disabilities. More detailed guidelines will be discussed in class and posted on WebCT.
- 5) **Class presentations** – Pairs of students will be expected to make a presentation on any one's class assigned readings (concentrating on one or more articles, or chapters) and to generate discussion for part of the class. This assignment gives you some autonomy to lead discussion on issues you deem important to the course. On the day of your presentation you are expected to provide an outline and/or handout of your presentation. Presentations are expected to be well organized and students should be ready to address comments from class members and the instructor. You can always see me for assistance. Additional materials or notes contributing to the discussion are welcome.
- 6) **Interview/Review**
You will be asked to provide a written report of an interview with a person with disability (or a parent of a child with a disability) and relate the issues discussed in the interview to the theoretical framework and conceptual tools we will learn in this class.
OR
You can choose to review one of the additional books regarding disability, the list of which will be posted on WebCT and handed out in class. Review paper (2 pages-4) should include a summary, your reflection on what you find most interesting in the reading as well as an analysis of how this book relates to the topics and issues discussed in our class.
- 7) **The Final Paper**
A final paper is due on May 1st on a topic of your choice. This should be a formal, sociological research paper. Detailed guidelines and notes on this assignment will be discussed in class and posted on WebCT.

Grading

Final grades will be determined as follows:

- Class Participation and Presentation 20%
- Response Paper 20%
- Interview/Book Review 20%
- Final Paper 40%

Academic Honesty

You are responsible for adhering to the statement of academic honesty in your Student Handbook.

Disability Statement

If you have a disability you would like me to know about so that I can make appropriate accommodations for you, please, let me know at the beginning of the semester.

Required Readings

- Barnes, C., Mercer, G., Shakespeare, T. **EXPLORING DISABILITY: A Sociological Introduction.** Polity Press, 1999.
- Dunsford, Clare. **SPELLING LOVE WITH AN X: A mother, a son and the gene that binds them.** Beacon Press, 2007.
- Mairs, N. **WAIST-HIGH IN THE WORLD : A Life Among the Nondisabled.** Beacon Press, 1997.
- Simon, R. **RIDING THE BUS WITH MY SISTER : A True Life Journey.** Plume, 2003.
- Zola, Irving. **MISSING PIECES: A chronicle of Living with a Disability.** Pub: Temple University Press, 2003.
- **Electronic Readings on WebCT.**
- Class handouts.

Documentaries and films.

NOTES

*****SCHEDULE*****

14th January **INTRODUCTIONS AND DEFINING DISABILITY**

- Course overview, objectives, assignments.
- Introduction to the main themes and topics in the sociology of disability and chronic illness.
- In class activity.

21st January **Martin Luther King day – NO CLASS**

28th January **UNDERSTANDING DISABILITY**
HISTORICAL OVERVIEW

- Setting the context for the study of disability and chronic illness: Disability and the “sociological imagination”. What is the interplay between the individual’s everyday life and the wider society?
- Historical context of disability in the West: evolution of ideas regarding disability across time, theories of normalcy and deviance/difference, stigma, poverty, mechanisms of social control, emergence of institutions.

Readings:

- Barnes, Mercer, Shakespeare. 1999. Chapter 2. “Understanding Disability”, pp. 10-38.

WebCT:

- Braddock, T., Parish, S. “An Institutional History of Disability”, pp. 11-54. From *Handbook of Disability Studies*, eds. Albrecht, Seelman, Bury. Sage: 2001.

4th February **SOCIOLOGY OF DEVIANCE AND ACCEPTANCE**
CONSTRUCTION OF “NORMALITY”
STIGMA AND SOCIAL IDENTITY

- Social theories about disability and human difference. Social and cultural construction of normalcy and deviance: What is the sociology of deviance? How is deviance socially constructed? What is normal and abnormal? How do these ideas affect our social identity?

Readings:

WebCT:

- Bogdan, R., Biklen, T. 1977. “Handicappism.” *Social Policy* 7: 14-19.
- Becker, H. 1964. “Introduction”, pp. 1-6. *The Other Side: Perspectives on Deviance*. Glencoe, IL: The Free Press. (CONTINUED ON NEXT PAGE)

- Dexter, L. 1967. "On the Politics and Sociology of Stupidity in Our Society." Pp. 37-49 in *The Other Side: Perspectives on Deviance*. Glencoe, IL: The Free Press.
- Goffman, I. "Stigma and Social Identity", pp. 1-40, in *Stigma* by Goffman, I. Simon&Schuster, 1963.
- Bogdan, R. Taylor. S. 1976. "The Judged, Not the Judges?". *American Psychologist* 31:47-52.

11th February

SOCIOLOGICAL APPROACHES TO DISABILITY AND CHRONIC ILLNESS
THEORIZING DISABILITY

- Different models of disability: traditional models, biomedical model, disability Rights Movement -- reframing disability - the social model of disability.

Readings:

- Barnes, Mercer, Shakespeare. 1999. Chapter 3 & 4. "Sociological Approaches to Chronic Illness and Disability" + "Enter Disability Theory", pp. 39-96.

WebCT:

- Williams, G. "Theorizing Disability", pp. 123-144. From *Handbook of Disability Studies*, eds. Albrecht, Seelman, Bury. Sage: 2001.

18th February

DISABLING SOCIAL BARRIERS: FAMILY, EDUCATION, EMPLOYMENT, BUILT ENVIRONMENT

- From theoretical debates to empirical examples of the diverse structural barriers to disabled people's meaningful participation in mainstream society.

Readings:

- Barnes, Mercer, Shakespeare. 1999. Chapter 5 "Disabling Barriers", pp. 96-123.
- Mairs, Nancy. 1996. *Waist-High in the World*. Beacon Press.

25th February

WHAT IT MEANS TO BE DISABLED
NARRATIVES OF DISABILITY/LIVED EXPERIENCE
MOBILITY IMPAIRMENT/ PHYSICAL DISABILITY

- Narratives of disability and chronic illness have greatly contributed to the sociological study of disability. In the second half of this semester we are going to look at a number of personal narratives of people with various disabilities and examine them in the context of their wider social contexts. We will start by discussing and learning about mobility impairment.

Reading:

- Zola, I. 2003. *Missing Pieces*. Temple University Press.

3rd March SPRING BREAK -- NO CLASS

10th March LOSS OF HEARING/DEAFNESS/*/**RESPONSE PAPER DUE*******

- What is the experience of auditory impairment? What is its social context?

WebCT:

- Davey, M. "As Town for Deaf Takes Shape, Debate on Isolation Emerges." *The New York Times*, March 21, 2005.
- Reagan, Timothy. "A sociocultural understanding of deafness: American Sign Language and the Culture of Deaf People" *Int. J. Intercultural Rel.*, Vol. 19, No. 2, pp. 239-251, 1995.
- Dolnick, E. (1993). Deafness as culture. *The Atlantic*, 272(3), 37-53.

17th March LOSS OF SIGHT/BLINDNESS

- What is the experience of visual impairment? What is its social context?

WebCT:

- Sacks, O. "The Mind's Eye: What the Blind see." *The New Yorker*, March 28, 2003.
- Who is blind Guidebook. National Federation for the Blind.
- To be assigned

24th March Easter Monday – NO CLASS

**31st March INTELLECTUAL DISABILITIES INTRODUCTION
LEARNING DISABILITIES, AUTISM**

*****INTERVIEW/REVIEW DUE*****

- What are intellectual and developmental disabilities? How do lives of people with intellectual disabilities fundamentally differ from other disabilities? What is the social context informing intellectual disabilities?

WebCT:

- Grandin, T. 1996. *Thinking in Pictures*. Vintage Press. Selected chapter.
- Haddon, M. 2003. *The Curious Incident of the Dog in the Night-time*. Vintage Books. Selected excerpt.
- Parmenter, T. "Intellectual Disabilities: Quo Vadis?", p. 267. From *Handbook of Disability Studies*, eds. Albrecht, Seelman, Bury. Sage: 2001.
- Reading on learning disabilities to be assigned.

7th April DEVELOPMENTAL DISABILITIES

- Sibling's account of developmental disability

Readings:

- Simon, R. 2003. *Riding the Bus with My Sister : A True Life Journey*. Plume.

WebCT:

- Larson, E. "Reframing the Meaning of Disability to Families: The Embrace of Paradox." *Social Science and Medicine*, Vol. 47, No. 7, pp. 865-875, 1998.

**14th April DEVELOPMENTAL DISABILITIES/ MOTHERHOOD
FRAGILE X SYNDROME, DOWN SYNDROME
BROADER ETHICAL DILEMMAS/EUGENICS**

- Another look at a developmental disability. What are the ethical dilemmas that arise in the context of disabilities and most of all in the context of prenatal testing? *To be or not to be?*

Readings:

- Dunsford, Clare. 2007. *Spelling Love with an X: A mother, a son and the gene that binds them*. Beacon Press.

WebCT

- Colson, Charles, Pearcey, Nancy. Why Max deserves a life. *Christianity Today*, June 16, 1997, v41 n7 p80(1).
- McDonald, Victoria. "Mothers pressed to abort Down's babies." *The Human Life Review*, Wntr 1996, v.22, n1, pp.119-121.
- Landsman, G. "Reconstructing Motherhood in the Age of Perfect Babies". *Signs*, Autum 1998, pp. 69-96.

21st April Patriot's Day – NO CLASSES

**28th of April RESISTING DISABLING REPRESENTATIONS
REFLECTING ON THE COURSE AND SEMESTER**

*****Final Paper Due*****

- Who has the right to speak for whom? What is the place of the non-disabled narrator in disability studies? What different positions did we take during the semester? Did we miss something? What was our lens, our position informing our analysis and our point of view? What can we learn from it?

Reading:

- Barnes, Mercer, Shakespeare. 1999. Chap 9. "Advancing the Sociology of Disability." Pp. 211-227.
- To be assigned