

McMaster University

Department of Health, Aging & Society

HLTH AGE 3D03: Chronic Illness, Disability, and Aging
Winter 2016

Instructor: Dr. Mat Savelli
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Office: Kenneth Taylor Hall Rm 233
Office Hours: Mon 12-4

Course Description: This course examines the concepts of chronic illness and disability from both theoretical and lived experience perspectives. It considers how the meanings and understandings of these terms have evolved across time and place. Drawing upon the insights of a diverse range of disciplinary traditions (including history, geography, sociology, and anthropology), it encourages students to critically analyze social and personal interpretations of the experience of chronic illness and disability. Throughout the course, special emphasis is placed on studying these concepts later in the life course.

Course Objectives: By the conclusion of the course, students should be able to explain varied theories of disability, ranging from the medical model to the social constructionist approach. Moreover, they should demonstrate an understanding of the wide range of actors and methods involved in the construction of ideas about disability and chronic illness. It is hoped that the course will help students develop a broader, more sensitive, and nuanced approach to these concepts.

Grading Breakdown:

Final Exam: 30%

Discussion/Alternative Assignment: 15%

Essay: 25%

Project: 30%

Required Texts: all required readings can be found on Avenue to Learn.

Jan 5th and Jan 7th - Introduction to Studying Disability and Chronic Illness

Jan 12th - Historical Perspectives I

Jan 14th - Group A Discussion

Reading: A. Phelps, "Diseased, Maimed, Mutilated" *Journal of Social History*, Fall 2010, pp.23-37; D. Baynton, "Disability and the Justification of Inequality in American History" excerpt from *The New Disability History: American Perspectives*, ed. by Paul K. Longmore and Lauri Umansky (New York: New York University Press, 2001), pp. 33-53.

Jan 19th - Historical Perspectives II

Jan 21st – Group B Discussion

Reading: G. Reaume, “Accounts of Abuse of Patients at the Toronto Hospital for the Insane, 1883-1937” *Canadian Bulletin of Medical History* 14 1997, pp. 65-106; L.J. Davis, “Constructing Normalcy,” in: L.J. Davis (Ed.) *The Disability Studies Reader*. New York: Routledge, 1997, pp. 3-16.

Jan 26th – Theories of Disability

Jan 28th – Group C Discussion

Reading: T. Koch, “The Ideology of Normalcy: The Ethics of Difference,” *Journal of Disability Policy Studies* 16(2) 2005, pp. 123-129; P. Singer, “Ethics and Disability; A Response to Koch,” *Journal of Disability Policy Studies* 16(2) 2005, pp. 130-133; J. Swain & S. French, “Towards an Affirmation Model of Disability” *Disability & Society* 15(4) 2000, pp. 569-582; S. Gabel & S. Peters, “Presage of a Paradigm Shift? Beyond the Social Model of Disability towards Resistance Theories of Disability,” *Disability & Society* 19(6) 2004, pp. 585-600.

Feb 2nd - Popular Representations

Feb 4th – Group D Discussion

Reading: G. Goggin and C. Newell, “Crippling Paralympics: Media, Disability, and Olympism,” *Media International Australia, Incorporating Culture & Policy* 2000, 97, 71-83; T. Titchkosky, “Disability in the News: A Reconsideration Reading” *Disability & Society* 20(6) 2005, pp. 655-668; R. Olstead, “Contesting the Text,” *Sociology of Health & Illness*, 24(5) 2002, pp. 621-643.

Feb 9th – Personal Narratives

Feb 11th – Group A Discussion

Reading: A. Sexton, “Caring for Aunt Alice,” *Journal of Disability Policy Studies* 16(1) 2005, pp. 61-67; T. Siebers, “Disability as Masquerade” *Literature and Medicine* 23(1) 2004, pp. 1-22; M. Bury, “Chronic Illness as Biographical Disruption” *Sociology of Health & Illness* 4(2) 1982, pp. 167-182.

Feb 16th and 18th – no classes (Reading Week)

Feb 23rd - Social Movements, Chronic Illness, and Disability [essay due]

Feb 25th – Group B Discussion

Reading: B. Hughes, “Disability Activisms: Social Model Stalwarts and Biological Citizens,” *Disability & Society*, 24(6) 2009, pp. 677-688; H. Jonson & A. Taghizadeh Larsson, “The Exclusion of Older People in Disability Activism and Policies” *Journal of Aging Studies* 23 2009, pp. 69-77; J. Dumit, “Illnesses You Have to Fight to Get,” *Social Science & Medicine* 62 2006, pp. 577-590.

Mar 1st - Disability and the Spatial Environment

Mar 3rd – Group C Discussion

Reading: N. Hansen & C. Philo, “The normality of doing things differently: bodies, spaces and disability geography” *Tijdschrift voor economische en sociale geografie*, 98(4), 2007 pp. 493-506; P. Anderson, R. Kitchen, “Disability, Space, and Sexuality: Access to Family Planning Services” *Social Science & Medicine* 51 2000, pp. 1163-1173; P. Moss, Negotiating Spaces in Home Environments: Older Women Living with Arthritis,” *Social Science & Medicine* 45(1), pp. 23-33.

Mar 8th - Dementia

Mar 10th – Group D Discussion

Reading: G. Sanders, “My Dementia: Telling Who I Am before I Forget,” *Slate* 2014, http://www.slate.com/articles/health_and_science/family/2014/03/dementia_and_aging_diary_of_a_sufferer_of_microvascular_disease.html ; E. Peel, “The Living Death of Alzheimer’s” *Sociology of Health & Illness* 36(6) 2014, pp. 885-901; G. Boyle, “Recognizing the Agency of People with Dementia,” *Disability & Society* 29(7) 2014, pp. 1130-1144;

Mar 15th – Bio- and Neuro- Diversity

Mar 17th – Group A Discussion

Reading: E.T. Savarese & R.J. Savarese, “‘The Superior Half of Speaking’: An Introduction,” *Disability Studies Quarterly* 30(1) 2010; K. Runswick-Cole, “‘Us vs Them’: The Limits and Possibilities of a ‘Politics of Neurodiversity’ in Neoliberal Times” *Disability & Society* 29(7), 2014, pp. 1117-1129; M. Orsini, “Autism, Neurodiversity, and the Welfare State,” *Canadian Journal of Political Science* 45(5) 2012, pp. 805-827.

Mar 22nd - Deaf and Blind Cultures

Mar 24th – Group B Discussion

Reading: E. Dolnick, “Deafness as Culture” *The Atlantic*, Sept 1993, pp. 37-53; J. Savelescu, “Deaf Lesbians, ‘Designer Disability,’ and the Future of Medicine,” *BMJ* 325 2002, pp771-773; J. Levy, “Deafness, Culture, and Choice,” *Journal of Medical Ethics* 28 2002, pp. 284-285; R. Sparrow, “Implants and Ethnocide: Learning from the Cochlear Implant Controversy,” *Disability & Society*, 25(4) 2010, pp. 455-466.

Mar 29th – Institutions [creative project due]

Mar 31st – Group C Discussion

Reading: K. Rossiter & A. Clarkson, “Opening Ontario’s Saddest Chapter: A Social History of Huronia Regional Centre” *Canadian Journal of Disability Studies* 2(3) 2013; C. Malacrida, “Bodily Practices as Vehicles for Dehumanization in an Institution for Mental Defectives,” *Societies* 2 2012, 286-301.

Apr 5th - “Solving” Disability [alternate assignment due]

Apr 7th - Group D Discussion

Reading: Tom Shakespeare, “Choices and Rights” *Disability & Society* 13(5) 1998, pp. 665-681; K. Beauchamp-Pryor, “Impairment, Cure, and Identity” *Disability & Society* 26(1) 2011, pp. 5-17; E. Barnes, “Valuing Disability, Causing Disability,” *Ethics* 125(1) 2014, pp. 88-113.

Discussion Participation:

Except for those completing the alternative assignment, students are required to sign up for one of the four discussion groups. Each group will meet three times per term to discuss the assigned reading for the week. Students will be graded on the quality of their participation. Sign up will begin after class on Jan 7th - instructions on how to sign up for a discussion group can be found on Avenue to Learn.

OR

Alternative Assignment:

Students who opt out of the discussion component of the course may complete the alternative assignment. In this case, they are required to choose a disability or chronic illness advocacy organization and write a five page essay answering the following question: “to what extent does this advocacy organization reflect popular (medical) understandings of disability and chronic illness?” It is necessary to consult (and cite) a minimum of FIVE peer-reviewed sources. Students should be sure to include a bibliography. Essays should be double spaced, using a 12 point font and APA style margins.

Essay:

Students are required to complete an 8 page essay on one of the following topics. It is necessary to consult (and cite) a minimum of EIGHT peer-reviewed sources. Students should be sure to include a bibliography. Topics not listed here are possible but they **MUST** be cleared by the instructor at least three weeks prior to the essay deadline. Essays should be double spaced, using a 12 point font and APA style margins.

- 1) Why have tropes relating to heroism dominated popular narratives of disability?
- 2) How can we best explain the proliferation of organizations dedicated to chronic illness advocacy?
- 3) Why did so many prominent politicians and scientists support the eugenics movement?
- 4) How has the mad movement impacted the situation of people diagnosed with mental illness?

- 5) How can the sharp increase in rates of autism over the last three decades be explained?
- 6) “Genetic counselling is the new eugenics” – to what extent is this statement accurate?
- 7) “People first language is the most appropriate way to discuss disability” – to what extent is this true?
- 8) How can we account for the dominance of the medical model’s approach to disability?
- 9) Should older adults be required to undergo screening for dementia?
- 10) “Chronic illness and disability are fundamentally the same things” – to what extent is this true?

Project:

For this project, students are encouraged to take a creative approach to the issues of disability and chronic illness. Students should complete one of the following projects, drawing upon the major themes discussed throughout the course. Alternative projects may be proposed but they **MUST** be cleared by the instructor at least three weeks prior to the project deadline.

- 1) Create a piece of art (drawing, sculpture, painting, etc.) with an accompanying three page explanation of how this piece of art reflects popular understandings of chronic illness and disability.
- 2) Develop a 13-16 minute podcast discussing popular understandings of chronic illness and disability. This could take many forms, incorporating interviews, music snippets, or other auditory aids.
- 3) Write a short screenplay or story (minimum 10 pages) analyzing popular understandings of disability and chronic illness.
- 4) Complete a photo-voice project examining depictions of disability and ableism. Students should take at least 10 photos and include a half-page discussion of each.
- 5) Write a short musical (seriously) critiquing popular discourses about disability and chronic illness.
- 6) Collect and create a “song book” by compiling the lyrics from ten songs related to disability and chronic illness. Include a half-page commentary for each song you’ve included.

Other Crucial Course Notes

- 1) Do not email the course instructor or TAs via Avenue to Learn. Direct all communication to our McMaster email addresses.
- 2) Students making use of MSAFs will have to complete all assignments at a later date. In other words, there is no chance that the grade for missed assignments or tests will be tacked onto the final exam.
- 3) Late assignments will be penalized 5% per day.

- 4) There will be absolutely no leniency on plagiarism. Don't copy and paste anything directly into your essay...even if you cite it!

If you require this information in an alternate/accessible format, please contact the Department of Health, Aging & Society at 905.525.9140 ext. 27227 or hasdept@mcmaster.ca.

Students should be aware that, when they access the electronic components of this course, private information such as first and last names, user names for the McMaster e-mail accounts, and program affiliation may become apparent to all other students in the same course. The available information is dependent on the technology used. Continuation in this course will be deemed consent to this disclosure. If you have any questions or concerns about such disclosure please discuss this with the course instructor.

Academic Accommodation of Students with Disabilities: Students who require academic accommodations must contact Student Accessibility Services (SAS) to make arrangements with a Program Coordinator. Academic accommodations must be arranged for each term of study. Student Accessibility Services can be contacted by phone at 905-525-9140 ext. 28652, or by email at sas@mcmaster.ca. For further information, consult McMaster University's Policy for Academic Accommodation for Students with Disabilities: <http://www.mcmaster.ca/policy/Students-AcademicStudies/AcademicAccommodation-StudentsWithDisabilities.pdf>

Grades will be based on the McMaster University grading scale:

MARK	GRADE
90-100	A+
85-90	A
80-84	A-
77-79	B+
73-76	B
70-72	B-
67-69	C+
63-66	C
60-62	C-
57-59	D+
53-56	D
50-52	D-
0-49	F

Avenue to Learn: Course material will be posted on Avenue to Learn. Please check the site often to keep informed of important course information or announcements.

Faculty of Social Sciences E-mail Communication Policy: Effective September 1, 2010, it is the policy of the Faculty of Social Sciences that all e-mail communication sent from students to instructors (including TAs), and from students to staff, must originate from the student's own McMaster University e-mail account. This policy protects confidentiality and confirms the identity of the student. It is the student's responsibility to ensure that communication is sent to the university from a McMaster account. If an instructor becomes aware that a communication has come from an alternate address, the instructor may not reply at his or her discretion.

Email Forwarding in MUGSI: <http://www.mcmaster.ca/uts/support/email/emailforward.html>

*Forwarding will take effect 24-hours after students complete the process at the above link

Academic Integrity

You are expected to exhibit honesty and use ethical behaviour in all aspects of the learning process. Academic credentials you earn are rooted in principles of honesty and academic integrity.

Academic dishonesty is to knowingly act or fail to act in a way that results or could result in unearned academic credit or advantage. This behaviour can result in serious consequences, e.g. the grade of zero on an assignment, loss of credit with a notation on the transcript (notation reads: "Grade of F assigned for academic dishonesty"), and/or suspension or expulsion from the university.

It is your responsibility to understand what constitutes academic dishonesty. For information on the various types of academic dishonesty please refer to the Academic Integrity Policy, located at <http://www.mcmaster.ca/academicintegrity>

The following illustrates only three forms of academic dishonesty:

1. Plagiarism, e.g. the submission of work that is not one's own or for which other credit has been obtained.
2. Improper collaboration in group work.
3. Copying or using unauthorized aids in tests and examinations.

The instructor and university reserve the right to modify elements of the course during the term. The university may change the dates and deadlines for any or all courses in extreme circumstances. If either type of modification becomes necessary, reasonable notice and communication with the students will be given with explanation and the opportunity to comment on changes. It is the responsibility of the student to check their McMaster email and course websites weekly during the term and to note any changes.