

Preface to "Beyond Quality of Life: Exploring Disability and Bioethics."

When invited to design the first course about disability for the Master of Bioethics (MBE) program at the University of Pennsylvania, we thought about the program's diverse and intellectually curious students—physicians, nurses, therapists, attorneys, a judge, and medical, dental, law, and graduate liberal arts students. Most of them wanted to think more carefully about ethical dilemmas they encountered, or might, in their professional lives. We wished to take a more capacious look at ethical issues affecting the lived experiences of people with disabilities than bioethics as a discourse and a practice typically does. To do so, we hoped to complicate conventional medical and cultural narratives about bodies regarded as disabled, and we anticipated having our own understanding of disability complicated by the variety of our students' experiences and multidisciplinary perspectives. We hoped that by beginning with the body and the personal and cultural meanings we make of it, our students would develop a broader understanding of disability to bring to their ethical and philosophical thinking and to their encounters with people with disabilities and their families. We also provided opportunities to scrutinize the institutional, environmental (broadly defined), legal, and ethical structures that open the world to some bodies and not others. While we would revise aspects of this course if we teach it again, we were gratified that students' evaluations credited it for introducing ways of thinking they hadn't encountered in other bioethics classes.

Our own varied disciplinary backgrounds and relationships to disability informed our syllabus and our aspirations for our work with our students.

While teaching this course, Carol Schilling was an Associate Fellow in the former Penn Center for Bioethics. She currently teaches cross-disciplinary courses in medical humanities, bioethics, disability, and health and social justice in the Health Studies program of Haverford College. She has also taught humanities and disability courses in medical school. Her graduate work in literary studies was followed by a Fellowship in Medical Ethics at Harvard Medical School and post-graduate studies in medical humanities, bioethics, and disability ethics. Her experience with disability in her family informs her teaching and writing.

Teresa Blankmeyer Burke is an Associate Professor of Philosophy at Gallaudet University. Her primary research interests are ethics, philosophy of disability, bioethics, and Deaf studies. Dr.

Burke's interest in disability stems from her experiences trying to make sense of the world as a hard-of-hearing child. In addition to working with the signing Deaf community and hard-of-hearing populations, Dr. Burke has also worked with autistic children and as a leadership trainer for People First, a disability self-advocacy organization supporting people with developmental and intellectual disabilities.

BIOE 590.001 Topics in Philosophy

Fall 2008

Beyond Quality of Life: Exploring Disability and Bioethics

Carol Schilling

Teresa Blankmeyer Burke

Office Hours: We will regularly be in the Bioethics Center on Monday afternoons, but can be available other days as well. It is always best to arrange appointments in advance via email.

Course Description

This course conducts an inquiry into bioethical responses to human variations that become categorized as disability. The interdisciplinary project of disability studies will provide a fresh theoretical and practical lens through which to view bioethics, its philosophical framework, and the library of cases that are argued within that frame. For the most part, bioethics discussions about disability have been limited to quality of life analyses, especially regarding decisions about the beginning and the end of life. Disability studies scholarship has, however, taken a more comprehensive look at ethical issues affecting the lived experiences of people with disabilities, including both clinical and broader social ethical concerns. The disability perspective on bioethics also exposes the ways that headline-making instances of what is framed as the right to die, as well as the less visible surrogacy and best interest decisions made daily, are centrally about how disability is understood. At its core, what's at stake in this inquiry is who is welcome and graciously accommodated in the human community.

Readings will range from theoretical texts to narratives by the disabled and their families that enable us to work at the intersections of bioethics, disability studies, and the medical humanities. We will pause to ask what conditions constitute disability and who decides (deafness, paralysis, chronic illness, pain, cognitive differences. . .), what additional frameworks for bioethics (narrative ethics, care ethics, rehabilitation ethics, feminist ethics, the humanities,

the social sciences) can contribute to discussions of bioethics and disability, and what the creative arts can teach about disability. As disability theorists and the World Health Organization propose an inclusive conceptualization of disability as a condition of the human life cycle, rather than an unanticipated, alienating, individual event, and as the number of disabled citizens increases, the need to bring disability studies and bioethics into conversation becomes increasingly urgent.

SCHEDULE OF WEEKLY TOPICS and READINGS

Week 1

Sept 8

Introduction: Speaking of Disability

Language and Meanings

N. Mairs, "On Being a Cripple" (Bb)

S. Linton, "Reassigning Meaning" (in *Disability Studies Reader* DSR)

Medical and Social Models of Disability

T. Shakespeare, "The Social Model of Disability" (DSR)

I. Basnett, "Health Care Professionals and Their Attitudes toward and Decisions Affecting Disabled People" (Bb)

Definitions and Demographics (for reference on Bb)

WHO, "Towards a Common Language for Functioning, Disability and Health"

www.who.int/classifications/icf/site/beginners.bg.pdf

CDC, "Nat'l Center for Health Statistics: New Report on Disability Available from NCHS"

<http://www.cdc.gov/nchs/pressroom/97facts/disable.htm>

Kaye, Kang, & LaPlante, "Disability Statistics Abstract:

Wheelchair Use in the United States"

<http://dsc.ucsf.edu/publication.php>

Americans with Disabilities Act <http://www.eeoc.gov/ada/>

RRTC of Cornell Univ, "2006 Disability Status Report, United States" www.DisabilityStatistics.org--45

Week 2

Sept 15

Disability Studies in Bioethics

Review of Principlism & Views of Biomedical Model from a Disability Perspective

Theoretical and Disciplinary Grounding of Bioethics

G. E. Pence, summary of principlism and other approaches: "Ethical Theories and Medical Ethics: An Historical Overview" from

Classic Cases in Medical Ethics (Bb)

T. Chambers, "Centering Bioethics" (Bb)

Disability Perspectives on Bioethics

M. Kuczewski, et al, "Disability: An Agenda for Bioethics" (Bb)

S. Tremain, "The Biopolitics of Bioethics and Disability" (Bb)

R. Amundson & S. Tresky, "Bioethics and Disability Rights: Conflicting Values and Perspectives" (Bb)

Contested Views of Quality of Life

S. Goering, "'You Say You're Happy, but...': Contested Quality of Life Judgments in Bioethics and Disability Studies" (Bb)

T. M. Gill & A R. Feinstein, "A Critical Appraisal of the Quality of Quality-of-Life Measurements" (Bb)

Week 3

Sept 22

Disability in History and Culture: Bioethics and Marginalization

L. Davis, "Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century" (DSR)

Anita Silvers, "'Defective Agents': Equality, Difference and the Tyranny of the Normal" (Bb)

J. Charlton, "The Dimensions of Disability Oppression" (DSR)

M. Klages, "The Semiotics of Blindness" from *Woeful Afflictions* (Bb)

S. Snyder & D. Mitchell, "Preface" to *Cultural Locations of Disability* (Bb)

DNA archives on eugenics and Nazi programs of extermination

<http://www.eugenicsarchive.org>

<http://www.dnai.org>

Week 4

Sept 29

The Disabled Body as a Site of Artistic Production: Implications for Bioethics

Performances

AXIS dance videos

http://www.axisdance.org/performance_repertory.php

"Talking Back" S. Snyder, director (selections from the film in class)

Lynn Manning, performance artist. Class visit

Commentaries

T. Davies "Mobility: AXIS Dancers Push the Boundaries of Access" (Bb)

H. Rose, "Approaching a Politics of Difference through Performance" (Bb)

Week 5

Oct 6

Deaf Issues, Part I: Debating Cochlear Implants & Challenging the Medical Model

“Sound and Fury” (Josh Aronson, Producer)

R. Crouch, “Letting the deaf Be Deaf” (Bb)

B. Tucker, “Deaf Culture, Cochlear Implants, and Elective Disability” (Bb)

C. Padden & T. Humphries, “Deaf People: A Different Center” (DSR)

L. Komesaroff, “Media Representation and Cochlear Implantation” from
Surgical Consent: Bioethics and Cochlear Implantation (Bb)

Overview of Bioethics and the Deaf Community (for reference on Bb)

T. B. Burke, “Bioethics and the Deaf Community” from *Signs and Voices*

Week 6

Oct 13

Deaf Issues, Part II: Genetic Technology and Reproducing Deafness

J. Glover, “Disability and Genetic Choice” (Bb from *Choosing Children: Genes, Disability and Design*)

J. Harris, “Disability and Super-Ability” (Bb from *Enhancing Evolution*)

L. Mundy, “A World of their Own” (Bb)

M. Sandel, “Designer Children, Designer Parents” (Bb from *The Case Against Perfection*)

M. Little, “The Morality of Abortion” from *A Companion to Practical Ethics* (Bb)

Oct 20

Colloquium Series Lecture

Yuval Levin, “Bioethics and Politics” 4:30 (replaces a class meeting)

Week 7

Oct 27

Living with Disability

Narratives of the Everyday

A. Dubus, from *Broken Vessels* (Bb)

G. T. Couser, “Disability, Life Narrative, and Representation” (DSR)

Ambiguous Loss

P. Boss, sel. from *Ambiguous Loss* (Bb)

S. Wendell, “Unhealthy Disabled: Treating Chronic Illnesses as Disabilities” (Bb)

Implications for Requests to Die: The Cases of Elizabeth Bouvia and Larry McAfee

G. E. Pence, "Requests to Die: Elizabeth Bouvia and Larry McAfee"
from *Classic Cases in Medical Ethics* (Bb)

M. Shildrick, "Deciding on Death: Conventions and Contestations in the
of Disability" (Bb)

Week 8

Nov 3

Disability and Social Justice, Part I: Assumptions in Bioethics

A. Silvers, D. Wasserman, M. Mahowald, "Introduction" to *Disability,
Difference and Discrimination: Perspectives on Justice and Public Policy*(DDD)

A. Silvers, "Formal Justice" (DDD)

Week 9

Nov 10

Disability and Social Justice, Part II: Issues in Bioethics

Narrative

H. B. Johnson, "Unspeakable Conversations" (Bb)

Theories

L. Becker, "Reciprocity, Justice and Disability" (Bb)

M. Mahowald, "A Feminist Standpoint" (DDD)

Week 10

Nov 17

Disability in the Family, Part I: Caregiving as a Challenge to Autonomy

Narratives

C. Levine, "The Loneliness of the Long-Term Caregiver" (Bb)

M. D. Cohen, sel. from *Dirty Details* (Bb)

Theories and Policies

E. Kittay, sel. from *Love's Labor* (Bb)

C. Levine & T. Murray, sel. from *The Cultures of Caregiving* (Bb)

D. Levine & C. Zuckerman, "The Trouble with Families: Toward an Ethic
of Accommodation" (Bb)

Definitions and Demographics (for Reference on Bb)

NAC-AARP, "Caregiving in the US" Executive Summary and Final
Report (Bb)

Levine, C. et al., "Young Adult Caregivers: A First Look at an Unstudied
Population" (Bb)

Articles on the Health Status of Family Caregivers (Bb)

Week 11

Nov 24

Disability in the Family, Part II: Best Interests with Implications for Ethics Committees and Social Policies

Narratives

R. Galli, *Rescuing Jeffrey*

“Pillow Angel” (Bb and on-line discussions tba)

Commentaries

H. Lindemann & J. Nelson, “The Romance of the Family” (Bb)

B. S. Wilfond, “The Ashley Case: The Public Response and Policy Implications” (Bb) continued . . .

S. M. Liao, et al, “The Ashley Treatment: Best Interests, Convenience, and Parental Decision-Making” (Bb)

A.J. Tarzian, “Disability and Slippery Slopes” (Bb)

Week 12

Dec 1

Colloquium Series Lecture 4:00 reception, 4:30 lecture

Eva Feder Kittay on Cognitive Disability

(replaces a class meeting: **required attendance**)

SCHEDULE OF RESEARCH AND WRITING PROJECTS

Project One

Due Week of Oct 20 (no class meeting)

Bibliography on a topic of your choice that pertains to disability and bioethics. Be sure to email us what your intended topic is before Oct 20. Each Bibliography will be posted on Bb as a resource to benefit the whole class. You may work collaboratively on these Bibliographies.

Project Two

Due Nov 3

Prospectus for your Course Essay due via email.

Project Three

Due Dec 12

Course **Essay** due via email

We will give you a Brief that explains each of these Projects in detail.

BOOKS you can purchase in preferred editions at the PENN BOOK CENTER, 34th and Sansom Streets:

- Davis, Lennard J. *The Disability Studies Reader*, 2nd ed. 2006

- Silvers, Wasserman, & Mahowald. *Disability, Difference Discrimination: Perspectives on Justice in Bioethics and Public Policy*. 1998
- Galli, Richard. *Rescuing Jeffrey*. 1999

ACADEMIC INTEGRITY

All your work for this course needs to accord with Penn's Code of Academic Integrity. All work, whether graded or not, must be your own. When you cite sources, correctly use either the MLA, APA, or Chicago Manual documentation format. If you consult with others—colleagues in or out of class, friends, family—follow the academic practice of recognizing their contributions to your thinking or your writing in a note of acknowledgment at the end of your work.

COURSE REQUIREMENTS:

- Preparing the readings and other class assignments, such as reporting on a reading or contributing to a Bb discussion, when they are due.
- Handing in the three course Projects when they are due.
- Attendance and Participation:
We request that you plan your schedules through December 1 to enable you to attend all 12 of our class meetings. Your presence and participation in our class discussions are central to a seminar course like ours, in which you accept the responsibility to yourself and your colleagues to attend each class and to arrive on time and prepared. To fulfill this responsibility, we request that you miss no more than 20% of our class meetings and that you email us an alert if you do need to be absent. We understand that a sudden emergency or an important competing responsibility can keep you away from class, and we don't need to know or to judge the reason for an absence. Although you won't receive a grade for participation, we will reserve the right to increase your final grade by at least 1/3 for truly exceptional contributions to our class meetings or to Bb discussions and to decrease it by at least the same amount for seriously inadequate participation. We will also do our best to work with you to keep everyone on track, and we ask that you let us know if anything ever inhibits your participation.

NOTE: The University and your instructors for this class are committed to providing equal educational opportunities for our students. Students who think they may need accommodations in this course because of the impact of a disability should meet with one of us privately by the second week of the semester. Students should also contact Penn's Office of Student Disabilities Services (www.vpul.upenn.edu/lrc/sds) as soon as possible to verify their eligibility for reasonable accommodations and, thereby, prevent disruptions to the process of learning.