

June 2022 Summer One

HCB 511 Bioethics, Disability & Community

Class Time: 5:30 - 8:55 pm

Location: Department of Family, Population and Preventive Medicine Seminar Room
066/06

The course is meeting in person, but for certain sessions our guest faculty will be chiming in to our assembled group via Zoom. SGP will be present at all sessions.

Instructor:

Stephen G Post, PhD (instructor of record)

Professor, Center for Medical Humanities, Compassionate Care & Bioethics

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Guest Faculty:

Michelle Ballan PhD MSW

Professor & Associate Dean for Research, School of Social Welfare

Professor, Center for Medical Humanities, Compassionate Care & Bioethics

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Linda Bily, MA

Faculty Associate, Center for Medical Humanities, Compassionate Care & Bioethics

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Brooke Ellison PhD MPP

Associate Professor, Program in Health and Rehabilitation Sciences

SB School of Health Technology and Management

Center for Medical Humanities, Compassionate Care & Bioethics

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Eva Feder Kittay, PhD

Distinguished Professor Emeritus of Philosophy

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Background

In this course we will examine, among other themes, the deep and long-standing tensions between disability advocacy and bioethics. Why this tension? Disability advocates and affected individuals have struggled against exclusionary pressures. For example, Enlightenment rationalist theories of “personhood” have led to diminished “moral consideration” and respect. This is clear from the history of eugenic theories of human progress going back to Francis Galton, and especially dominant at Cold Spring Harbor a century ago. While selective abortion is

generally considered an ethically acceptable practice based on parental autonomy, many disability advocates view this as an assault on “differently abled” people by those who fail to value them. People with disabilities have been sterilized either nonvoluntarily or involuntarily. In addition to diminished reproductive rights, there is the denial of life-extending medical interventions, dismissive perspectives on quality of life, the dominance of non-disabled values such as independence, utilitarian theories of justice according to “social worth” that leave them with “leftovers” or with no access to life-saving treatment as in the case of early dialysis and the Seattle “God committees.” In general, utilitarian bioethics are a stark contrast to the “ethics of care” of a philosopher such as Eva Kittay, one of the major voices in reframing bioethics so as to set aside utilitarian abuse and harshness, as well represented by Peter Singer of Princeton. There are many perspectives and approaches to a course in this area, and we include a variety of voices.

Course Objectives

1. Students will be able to explain in detail how the biomedical practices of analyzing bodily differences contribute to collective understanding of individuals with disabilities as well as various disability communities.
2. Students, through exploration of the long history of eugenic thought and practice, as well as the identification of alternative traditions of equal regard, will gain an appreciation for disabled people and their allies as potential agents of change.
3. Students will be able to explain and contest the marginal position of individuals with disabilities in discussions of moral consideration.

Readings

The voice of a mother

A first text is Eva Kittay’s *Learning from My Daughter: The Value and Care of Disabled Mind* (Cambridge University Press, 2019). Professor Kittay is the foremost feminist ethicist of care in the United States and in the world. She is now Distinguished SUNY Professor Emeritus after a fabulous career at Stony Brook University in the Department of Philosophy. This is arguably the finest book ever written by a philosopher of care. It is not overly technical, and is especially deep because it builds around the author’s powerful transformative narrative as mother to her daughter Sesha. If you can get a start with this now, great. **Dr. Kittay** will join us for the first two sessions of the course, scheduled for May 31 and June 2.

The voice of a person with quadriplegia

Brooke Ellison is one of the most distinguished faculty members at Stony Brook. She was hit by a car on Nicolls Road in 1990 at the age of 11 while walking home from her first day of junior high school. Paralyzed from the neck down, she graduated from Ward Melville High School in 1996 and went on to become the first person with quadriplegia to graduate from Harvard (cognitive neuroscience). She went on to win a masters degree in public policy from the Kennedy School of Government and her PhD from Stony Brook University (2015). Some of you have probably viewed *The Brooke Ellison Story*, a blockbuster TV movie about her life. Please view this before June. With this background, we will have the benefit of **Dr. Ellison** teaching two sessions of the course on June 21 and June 23. We will be reading Brooke’s remarkable new book, which is a reflective narrative entitled *Look Both Ways* (2021). Proudly, Dr. Ellison holds

an appointment in the Stony Brook Med Center for Medical Humanities, Compassionate Care, and Bioethics.

The Law-Ethics Assessment

Please order and immediately get started with Alicia Ouellette's *Bioethics and Disability: Toward a Disability-Conscious Bioethics* (Cambridge University Press, 2011, paperback). This is the finest book available at this interface because it covers in depth the disagreements between disability advocates and bioethicists with philosophical and legal clarity. It also proceeds through sections on the topics of

- Infancy
- Childhood (including Ashley X)
- The Reproductive Years
- The Adult Years
- The End of Life

The book wraps up with a great section "Toward a Disability-Conscious Bioethics." By reading at least the first half of this book now (aka "pre-course") you will have a lot of background in place before we actually get started meeting.

Faculty

In addition to Professor Kittay and Ellison, we will have for one session Professor Michelle Ballan is perhaps the leading expert on disability studies representing social work, and she also hold her bioethics MA degree. Linda Bily will join us to take up *Ashley's Case*. Dr. Post will facilitate all sessions, and at the end of June will lead a session on his book *Dignity for Deeply Forgetful People: How Caregivers Can Meet the Challenges of Alzheimer's Disease* (Hopkins, 2022), a free copy of which will be given to each student.

Pre-Course Assignment

May 10-28

Alicia Ouellette's *Bioethics and Disability: Toward a Disability-Conscious Bioethics* (Cambridge University Press, 2013), **Chapters 1-5 only**

www.NotDeadYet.org

NOT DEAD YET is a national grassroots disability rights organization that opposes legalization of assisted suicide and euthanasia as deadly forms of discrimination. See www.NotDeadYet.org and examine their strong ethical stances against assisted suicide, euthanasia, futility, and various others issues that come up in bioethics debates. This will clarify the historic tensions between disability rights and the bioethics movement

T-4: The elimination of "useless eaters" and "life unworthy of life." Read Leo Alexander, "Medical Science under Dictatorship," *NEJM* Vol. 241 (2), 1929, pp. 39-47.

Course Sessions and Schedule

Thursday May 26 (ZOOM): Discussion of Pre-Course Assignment & Course Introduction (SGPost)

We will begin with a discussion of Ouellette summarizing various points of tension between the disabilities and bioethics movements. We will touch on this tension with reference to pioneering disability leader Adrienne Asch (1946-2013), who was part of the “imperiled neonates” project at the Hastings Center in 1985-88. We will also touch upon Dr. Leo Alexander (co-author of the Nuremberg Code) and his famous article “Medicine Science under Dictatorship” in the *NEJM*.

Readings: We will draw on the pre-course assignment

Tuesday May 31: In Person Session with Eva Kittay Zooming into 066 & 067 (Eva Kittay)

Importantly, Professor Kittay does not want to teach didactically. She wants us to have read her book with diligence and joy, and then ask her whatever questions we want. I hope that each student will come with a couple of questions in mind.

Readings

Eva Kittay, *Learning from My Daughter*. Parts I & II.

Thursday June 2: The Ethics of Care (Eva Kittay)

Professor Kittay to field questions from students about *Learning from My Daughter*. Part III.

Tuesday June 7: An Introduction to Models of Disabilities (Michelle S. Ballan, PhD MSW MA)

Are you mindfully aware of your personal prejudices, inherent, learned and societal? Is your understanding of disabilities accurate? Where do these biases come from? How can you overcome them? Is this problem reflected in the recent COVID-19 scenario?

Readings

Bunbury, S. (2019). Unconscious bias and the medical model: How the social model may hold the key to transformative thinking about disability discrimination. *International Journal of Discrimination and the Law*, 19(1), 26-47.

Beaudry, J.S. (2016). Beyond (models of) disability? *Journal of Medicine and Philosophy*, 41, 210-228. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4886464/pdf/jhv063.pdf>

Buntinx, W. H. E., & Schalock, R. L. (2010). Models of disability, quality of life, and individualized supports: Implications for professional practice in intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 7(4), 283–294.

- Dunn, D.S. (2019). Outsider privileges can lead to insider disadvantages: Some psychosocial aspects of ableism. *Journal of Social Issues*, 75(3), 665-682.
- Gilson, S. F., & Depoy, E. (2000). Multiculturalism and disability: A critical perspective. *Disability & Society*, 15(2), 207-218.
- Dunn, D.S. (2019). Outsider privileges can lead to insider disadvantages: Some psychosocial aspects of ableism. *Journal of Social Issues*, 75(3), 665-682.
- Mackelprang, R. W. (2010). Disability controversies: Past, present, and future. *Journal of Social Work in Disability & Rehabilitation*, 9, 87-98.

Thursday June 9: The End of Life

(SGPost)

Bioethics and Disability, chapter 6, 7 & 8

Tuesday June 14: Who Will Care for the Children? Ashley's Case

(Linda Bily)

There is a slippery slope when addressing the physical, emotional and psychosocial needs of children with a disability. Who defines the needs, or right, of the child and the parents?

Readings

- Dad, Ashley's Mom and. "The Ashley Treatment: Towards a Better Quality of Life for Pillow Angels." 2 January 2007. *Pillow Angel*.
- Directors, AAIDD Board of. "Unjustifiable Non-Therapy: A response to Gunther & Diekma and to the issue of growth attenuation for young people on the basis of disability." *AAIDD* (2012).
- Epstein, Julia and Rosenbaum, Stephen. "Revisiting Ashley X: An Essay on Disabled Bodily Integrity, Sexuality, Dignity, and Family Caregiving." *Touro Law Review* 135.1 (2019): 101-138.
- Gunther, Daniel and Diekema, Douglas. "Attenuating Growth in Children with Profound Developmental Disability." *Arch Pediatr Adolesc Med* 160.10 (2006): 1013-1017.
- Kirschner, K, Brashler, R and Savage, T. "Ashley X." *American Journal of Physical Medicine and Rehabilitation* (2007): 1023-1029.
- Kittay, Eva. "Forever Small: The Strange Case of Ashley X." *Hypatia* (2011): 610-620.
- McDermott, John. "Growth Attenuation in the Profoundly Developmentally Disabled: A Therapeutic Option or a Socioeconomic Convenience?" *Seton Hall Legislative Journal* (2008).

Thursday June 16: Introduction to the ADA: From Theory to Reality

(Linda Bily)

Guest Faculty: Valerie Lewis, ADA Compliance Officer for Suffolk County and disability advocate (blind herself), with whom Linda Bily has worked for ten years plus. (7 - 8 PM)

Students will explore the five unique areas addressed by the Americans with Disabilities Act and Amendments, the organizations responsible for enforcement and the practical aspects of this legislation. An interactive field study normally follows. What will define your perception of the ADA and address the issues in these challenging times?

www.ADAbasics.org

This online course covers ADA basics and provides CEU credit. Please complete before our first session.

Couser, G. Thomas. "Disability, Life Narrative, and Representation." Davis, Lennard J. editor. *The Disability Studies Reader*. New York: Routledge, 2006. 399-401.

"Culture and Resistance: The Hunter College Disability Studies Project, "Definition of Disability Studies"." Albrecht, Gary L. editor. *Encyclopedia of Disability*. Thousand Oaks, California: Sage Publications, 2011. 488-490.

Garland Thomson, Rosemarie. "Seeing the Disabled." Longmore, Paul K and Umansky, Lauri. *The New Disability History*. New York: New York University Press, 2001. 335-374.

Mairs, Nancy. "Plunging In." Mairs, Nancy. *Waist-High in the World*. Boston: Beacon Press Books, 1996. 3-18.

McDonald, Anne. "Annie's Coming Out." Crossley, Rosemary and McDonald, Anne. *Annie's Coming Out*. n.d.

Murphy, Robert. "The Damaged Self." Murphy, Robert. *The Body Silent*. New York: W.W. Norton and Company, 1990. 85-111.

Ringwood, Victoria. "The Struggle: Disability Rights versus Bioethics." Ouellette, Alicia. *Bioethics and Disability*. Cambridge: Cambridge University Press, 2011. 12-46.

Tuesday June 21: Brooke Ellison I: The Brooke Ellison Story
(Brooke Ellison)

Please watch *The Brooke Ellison Story* **before class**. In class we can discuss with Brooke. Come with questions. We can take the last half hour and discuss the classic bioethics article by Patterson et al. (below), which raises in a very powerful way the significant tensions ethically between a disability perspective that might wish to allow an effected individual time to adjust (even a couple of years) before taking their autonomy seriously. There is probably no easy answer to this tension, but it is worth serious conversation.

Readings

David R. Patterson, et al., “When Life Support is Questioned Early in the Care of Patients with Cervical-Level Quadriplegia,” *NEJM* Vol. 328 (7), 1993, pp. 506-509.

Brooke Ellison, “The Patient as Professor: How My Life as a Person with Quadriplegia Shaped my Thinking as an Ethicist,” *Perspectives in Biology and Medicine*, Vol. 62(no. 2), Spring 2019, pp. 342-351.

Thursday June 23: Brooke Ellison II: Brooke Ellison’s book *Look Both Ways*
(Brooke Ellison)

Written nearly 30 years following a life-changing, paralyzing accident, *Look Both Ways* is a deep and personal exploration of the lessons learned by virtue of living with an extensive physical disability. In this book, Ellison looks internally, reflecting the emotional struggles required to incorporate disability into one's identity, and externally, discussing the skills necessary to adapt to and move forward in life when it is radically altered. *Look Both Ways* provides complex insights into living life with disability, but also into living life for everyone. (This paragraph was written by Brooke for our class.

Tuesday June 28: Deeply Forgetful People (copies provided)
(SGPost)

Assignment: This course is reading and seminar intensive: At the end of the course, have completed a 10-page succinct and polished paper on the general tension between disability advocates and bioethics, approaching the topic as thoughtfully as you can. The paper does not require outside research. Indeed, given the volume of readings, just focus on what we have assigned. We will be selecting top papers that can be places on the Center website.

PAPER DUE THURSDAY JULY 7

Grading

Attendance and participation 30%

Paper 70%

From Official Stony Brook University Policy:

Statements required to appear in all syllabi on the Stony Brook campus:

Americans with Disabilities Act:

If you have a physical, psychological, medical or learning disability that may impact your course work, please contact Disability Support Services, ECC (Educational Communications Center) Building, room 128, (631) 632-6748. They will determine with you what accommodations, if any, are necessary and appropriate.

Academic Integrity:

Each student must pursue his or her academic goals honestly and be personally accountable for all submitted work. Representing another person's work as your own is always wrong. Faculty are required to report and suspected instances of academic dishonesty to the Academic Judiciary. Faculty in the Health Sciences Center (Schools of Health Technology & Management, Nursing, Social Welfare, Dental Medicine) and School of Medicine are required to follow their school-specific procedures. For more comprehensive information on academic integrity, including categories of academic dishonesty, please refer to the academic judiciary website at <http://www.stonybrook.edu/uaa/academicjudiciary/>

Critical Incident Management:

Stony Brook University expects students to respect the rights, privileges, and property of other people. Faculty are required to report to the Office of Judicial Affairs any disruptive behavior that interrupts their ability to teach, compromises the safety of the learning environment, or inhibits students' ability to learn. Faculty in the HSC Schools and School of Medicine are required to follow their school-specific procedures.