

**January 2019 (1-11-2019)**

**HCB 511 Bioethics, Disability & Community  
Room 067**

**Meeting Dates:**

Week One

Jan. 8 (Tuesday) Alex Wagner, SG Post

Jan. 9 (Wednesday) Robyn McKeefrey

Jan. 10 (Thursday) Robyn McKeefrey

Week Two

January 15 (Tuesday) Linda Bily

January 16 (Wednesday) Alex Wagner

January 17 (Thursday) Linda Bily

Week Three

January 22 (Tuesday) Alex Wagner

January 23 (Wednesday) SG Post

January 24 (Thursday) SG Post

**Class Time:** 5:15 to 9:00pm

**Co-instructors:**

Stephen G Post, PhD (instructor or record)

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## **Background**

The acrimonious conflict between the bioethics and disability movements is well recognized. Disability advocates have long been critical of the eliminatory mindset of prenatal testing and selective abortion. But there are many other areas of significance where bioethics runs against the grain of disability advocates and affected individuals, including exclusionary hypercognitive theories of “personhood” and moral status,” diminished reproductive rights, resistance to life-extending medical interventions, narrow and dismissive perspectives on quality of life and well-being, the affirmation of non-disabled values such as independence and autonomy, utilitarian theories of justice and rationing according to “social worth,” and a general medical model of disability as dysfunction. Questions about human rights at the beginning and at the end of life, and about the allocation of scarce resources such as organs to the sick, have turned on evaluations of ability and disability.

While bioethics makes frequent use of ‘disability’ in philosophical inquiry and debate, only recently have the voices of people with disabilities and their family members, and the perspectives of disability rights, appeared in its journals and university curricula. People with disabilities challenge judgments about quality of life with physical and cognitive impairments, and contribute to our understanding to issues of access to treatments and supports.

## **Course Objectives**

1. Student 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. Student, through exploration of the long history of eugenic thought and practice, as well as the identification of alternative traditions of mutual regard, will gain an appreciation for disabled people and their allies as potential agents of change.
3. Student will be able to explain and contest the marginal position of individuals with disabilities in discussions of moral responsibility and citizenship.

## **Readings**

There is one major text for this course that you should **order immediately and read in its entirety by January 8**. This is Alicia Ouellette’s *Bioethics and Disability: Toward a Disability-Conscious Bioethics* (Cambridge University Press, 2013). This is an excellent book for our course because it covers the disagreements between disability advocates and bioethicists with great clarity. It also proceeds nicely by section on the general 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 this book now you will have a lot of strong background in place before we actually start the course.

A second text, much briefer, is Jean Vanier, *Becoming Human* (New York: Paulist Press, 1998).

**Assignment One: On January 8 come to class with a thoughtful 5-page double-spaced reflection on the tensions between disability advocates and bioethicists, and some possible resolutions, as put forward by Alicia Ouellette in her book.**

## Course Calendar and Topics

### Week One

#### **January 8, 6pm (Tuesday) Introduction to the Course and Models of Disabilities**

Faculty: Alex Wagner, SG Post

We will explore models of disability as tools for defining impairment and, ultimately, for providing a basis upon which government and society can devise strategies for meeting the needs of disabled people.

We will also clarify the historic tensions between disability advocates and the bioethics movement. Go to [www.NotDeadYet.org](http://www.NotDeadYet.org) and examine their strong ethical stances against assisted suicide, euthanasia, futility, and various others issues that come up in bioethics debates. Read with care and prepare for discussion.

We will begin with a discussion of Ouellette, pages 1 – 71 (page 67 does a nice job of summarizing various tensions), and then turn to the reading listed below:

#### *Readings*

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*, Vol. 7(4), 283–294.

Gilson, S. F., & Depoy, E. (2000). Multiculturalism and disability: A critical perspective. *Disability & Society*, Vol. 15(2), 207-218.

Mackelprang, R. W. (2010). Disability controversies: Past, present, and future. *Journal of Social Work in Disability & Rehabilitation*, Vol. 9, 87–98.

[Bioethics and Disability text, chapters 1 & 2](#)

**January 9, 5:30 pm (Wednesday) The Eugenics Movement and Modern Day Eugenics: Designer Babies**

Faculty: Robyn McKeefrey

After an introduction to various definitions and models of disability, we will consider the histories of eugenic segregation and sterilization – an important context for the emergence of oppositional political bodies of disabled people. These perspectives have often been formed in opposition to the dominant worldview of professional fields such as medicine, rehabilitation and psychology. Key philosophical approaches challenge us to conceive of disability differently and consider different approaches against and for the conception of designer babies.

*Readings*

- Hubbard, R. (1997). Abortion and disability: Who should and who should not inhabit the world. In L. Davis (Ed.), *The disability studies reader* (pp. 187-200). New York, NY: Routledge.
- Janvier, A., & Watkins, A. (2013). Medical interventions for children with trisomy 13 and trisomy 18: What is the value of a short disabled life? *Acta Paediatrica*, Vol. 102(12), 1112-1117.
- Kuczewski, M.G. (2001). Disability: An agenda for bioethics. *American Journal of Bioethics*, Vol. 1(3), 36-44.
- O'Brien, G.V. (2011). Eugenics, genetics, and the minority group model of disabilities: Implications for social work advocacy. *Social Work*, 56(4), 347-354.
- Savulescu, J., & Kahane, G. (2009). The moral obligation to create children with the best chance of the best life. *Bioethics*, Vol. 23(5), 274-290.
- Soniewicka, M. (2015). Failures of Imagination: Disability and the Ethics of Selective Reproduction. *Bioethics*, Vol. 29(8), 557-563.
- Sparrow, R. (2015). Imposing genetic diversity. *The American Journal of Bioethics*, Vol. 15(6), 2-10.

[Bioethics and Disability text, chapter 3.](#)

**January 10, 5:30 pm (Thursday) Sexuality and Reproductive Justice for Women with Disabilities**

Faculty: Robyn McKeefrey

Women with intellectual and developmental disabilities have long been violated by the instruments of eugenics such as: physical and communication barriers to obstetrical and gynecological services; forced abortion, overuse of long-acting contraceptives; and the loss of child custody. We will explore these and other instruments which continue as barriers to sexual health and reproductive justice.

*Readings*

- Block, P. (2000). Sexuality, fertility, and danger: Twentieth-century images of women with cognitive disabilities. *Sexuality and Disability*, Vol. 18(4), 239-254.
- Dotson, L. A., Stinson, J., & Christian, L. (2003). People tell me I can't have sex: Women with

- disabilities share their personal perspectives on health care, sexuality, and reproductive rights. *Women & Therapy*, Vol. 26(3-4), 195-209.
- Pham, H. H., & Lerner, B. H. (2001). In the patient's best interest? Revisiting sexual autonomy and sterilization of the developmentally disabled. *Western Journal of Medicine*, Vol. 175(4), 280-283.
- Richards, D., Miodrag, N., & Watson, S. L. (2006). Sexuality and developmental disability: Obstacles to healthy sexuality throughout the lifespan. *Developmental Disabilities Bulletin*, Vol. 34, 137-155.
- Silvers, A., Francis, L. P., & Badesch, B. (2016). Reproductive rights and access to reproductive services for women with disabilities.
- Tilley, E., Walmsley, J., Earle, S., & Atkinson, D. (2012). 'The silence is roaring': sterilization, reproductive rights and women with intellectual disabilities. *Disability & Society*, Vol. 27(3), 413-426.

[Bioethics and Disability text, chapter 5.](#)

**Assignment Two: Come to class on January 15 with a thoughtful 5-page double-spaced reflection on the some of the key issues covered in Week One.**

## Week Two

**January 15, 5:30 pm (Tuesday) Introduction to the ADA: From Theory to Reality**

Faculty: Linda Bily

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 will define your perception of the ADA and address the issues in real time.

### *Readings*

#### Required

[www.ADAbasics.org](http://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.

## Recommended

Hoff, David. *Access for All: A Resource Manual for Meeting the Needs of One-Stop with Disabilities*. Manual. Boston: Institute for Community Inclusion, n.d. 2001

### **January 16, 6 pm (Wednesday) Disabilities and the Role of Ethics and the Impact of Bias**

Faculty: Alex Wagner

Are you aware of your personal prejudices, inherent, learned and societal? Is your understanding of disabilities accurate?

#### *Readings*

#### Required

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.

McDonald, Anne. "Crossley, Rosemary and McDonald, Anne.

Nancy Mairs, "Plunging In."

Alicia Ouellette, Alicia. "The Struggle: Disability Rights versus Bioethics." In *Bioethics and Disability*, 12-46.

Robert F. Murphy, "The Damaged Self."

### **January 17, 5:30 pm (Thursday) Who Will Care for the Children?**

Faculty: 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 rights, of the child and parents? What happens when gender dysphoria is a contributing factor?

#### *Readings*

#### Required

Dad, Ashley's Mom and. "The Ashley Treatment: Towards a Better Quality of Life for Pillow Angels." 2 January 2007. *Pillow Angel*. <[www.pillowangel.org](http://www.pillowangel.org)>.

Lawsuit: ADA's "gender dysphoria" exclusion is discriminatory  
<http://www.rootedinrights.org/lawsuit-adas-gender-dysphoria-exclusion-is-discriminatory/>

McDermott, John William. "Growth Attenuation In The Profoundly Developmentally Disabled: A Therapeutic Option or a Socioeconomic Convenience?" *Seton Hall Legislative Journal* (2008).

AAIDD. *Unjustifiable Non-Therapy: A response to Gunther & Diekma (2006), and to the issue of growth attenuation for young people on the basis of disability from the Board of Directors of the American Association on Intellectual and Developmental Disabilities*. Washington DC: AAIDD Board of Directors, 2012.

Peace, William. "Dueling Editorials: Singer Versus Smith and Scary Revelations." 16 March

2012. *Bad Cripple*. <badcripple.blogspot.com>.  
Puberty-Blocking Hormone Therapy for Adolescents with Gender Identity Disorder: A  
Descriptive Clinical Study  
<http://www.tandfonline.com/doi/abs/10.1080/19359705.2011.530574>

*Bioethics and Disability* text, chapter 4

### Recommended

Access to HC for Transgendered Persons: Results of a Needs Assessment in Boston  
[http://www.tandfonline.com/doi/abs/10.1300/J485v08n02\\_08](http://www.tandfonline.com/doi/abs/10.1300/J485v08n02_08)

Nyden, Paul J. "W. Va. considers future of sterilization law." *Charleston Gazette* 21 July 2012.  
Providing Cross-Gender Hormonal Therapy for Transgender Patients  
<http://www.lgbthealtheducation.org/wp-content/uploads/Providing-Cross-Gender-Hormone-Therapy-to-Transgender-Patients.pdf>

**Assignment Three: Come to class on January 22 with a thoughtful 5-page double-spaced reflection on the some of the key issues covered in Week Two.**

### Week Three

**January 22, 6 pm (Tuesday) a) Down Syndrome**  
Faculty: Alex Wagner & Stephen Post

... We will focus on the positive option of true inclusion (mutuality, common humanity, inclusivity) in the context of L'Arche and the life work of Jean Vanier, Templeton Prize Winner. What is the nature of mutuality in this context? (SGP and JV have been friends for 25 years.)

#### *Videos Before Class*

<https://www.youtube.com/watch?v=vDnfdHQu-rg> *L'Arche Intro*

#### *Videos In Class*

<https://www.youtube.com/watch?v=XWrru31ZPzo> *Templeton Prize*

#### *Readings*

Jean Vanier, *Becoming Human* (New York: Paulist Press, 1998).

*Bioethics and Disability* text, chapter 6

**January 22, 6 pm (Tuesday) b) The Brooke Ellison Story**

We will watch *The Brooke Ellison Story* in class and talk about medical treatment and withdrawal in people with quadriplegia.

**January 23, 6 pm (Wednesday) Age-Related Cognitive Changes (ARCC)**

Faculty: Alex Wagner & Stephen Post

We will focus on the problem of “hypercognitive values” and bias against deeply forgetful people. We will focus on continuity of selfhood and its implications, and on many additional concerns and issues...

*Readings*

Frank, J. “Semiotic Use of the Word “Home” Among People with Alzheimer’s Disease: A Plea for Selfhood?.” Edited by G.D. Rowles & H. Chaudhury, 2005, pp. 171-197.

Bartlett, R., Windemuth-Wolfson, L., Oliver, K., & Dening, T. (2017). “Suffering with dementia: The other side of “living well”.” *International Psychogeriatric Association*, 29(2), doi:10.1017/s104161021600199x

Read what you can from the website [www.musicandmemory.org](http://www.musicandmemory.org).

SG Post, “Is Grandma Still There?” A Pastoral and Ethical Reflections on Soul and Continuing Self Identity in Deeply Forgetful People,” *Journal of Pastoral Care & Counseling*, Vol. 70, No. 2, 2016, pp. 148-153.

SG Post, “Hope in Caring for the Deeply Forgetful: Enduring Selfhood and Being Open to Surprises,” *Bulletin of the Menninger Clinic*, Vol. 77, No. 4, 2013, pp. 349-368.

*Bioethics and Disability* text, chapter 7

**January 24, 6 pm (Thursday) The Bioethicists Gone Wrong?**

Faculty: Stephen Post

*Readings*

*Bioethics and Disability* text, chapters 7 & 8

**Assignment Four: Hand in a thoughtful 5-page double-spaced reflection on the some of the key issues covered in Week Three by January 27.**

**Grading**

**Attendance and participation 20%**

**Module Assignments 20% x 4 = 80%**

**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.