GNED 1300 – 1: **Disability and Deformity**

A narrative and syllabus

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**Introduction**

Athleticism and beauty define an extreme of the human condition. Disability and deformity represent perhaps the polar opposite of athleticism and beauty. Some stare longingly at a tanned body displaying an obvious six-pack of abdominal muscles. We watch with envy the primped model swishing her long fine tresses as a part of a well-designed shampoo commercial. Most avert their eyes when a person, with a long ago burned face missing an upper lip, comes to the register to pay for goods. Would you accept the credit card from the nubbed hands of a noseless citizen crippled from leprosy? Humans determine their interactions with other humans too often on the basis of physical appearance. With so many values today determined by the charismatic charm of physical grace and endowment, how do we recognize the inner strength of a person with true character who in fact may be classified as ugly in appearance? I will argue that through an understanding of society’s characterization of disability and deformity, it is possible to define the human social condition of a population. Which is more grotesque, the disabled and deformed or the vilification of same by the normal population?

This course is indirectly focused on the human spirit. It is amazing at what the human spirit can overcome: loss of limb, loss of sight, loss of health, and the profound infirmities of aging. The course will also consider what fear can do to the way humans live their lives. How can one appreciate the fear and sense of terror parents may feel when they realize their newborn child has a cleft lip and palate or perhaps Down’s syndrome? Can you imagine your sense of fear when you awake in a hospital bed without a left leg that was amputated just four hours ago after a late evening car crash at Shook and Hildebrand? How does the human spirit deal with this fear?

Disability, disfigurement, and deformity all present such a morbid reality. The point is that they are reality... a reality that produces fear and an affront to the human spirit. How do you talk to a deaf person; how do you shake the hand of a limbless person; or do you offer to push the wheelchair of a paraplegic stranger? What accommodations should a biology instructor make in the teaching lab for a person with cerebral palsy or spina bifida? These are real everyday issues. But these are the easy issues. How do you deal with someone with mental depression or Crohn’s disease, something that may not have an immediate outward physical manifestation? Disability and deformity have a great deal to do with defining the human character by exploring the extremes of that character.

**Major Goals of this Seminar**

1) What is the norm for human physical size and appearance? The first goal of the course is essentially to explore several venues of aesthetics. The study of beauty will accomplish two objectives for us. 1) We will try to define why people who are not of the norm find disfavor with so many and 2) by this exploration we can develop a technique of study as a seminar class. To accomplish this first goal we will consider concepts such as Eigenface, koinophilia
and the Vitruvian Man. There are no formal texts for this information; in essence we will write our own book using the Internet, which in turn becomes an exercise in information literacy.

2) Our second goal is to consider the concept of “hegemony of physical appearance and being.” Borrowing from Wikipedia on human physical appearance: “Some differences in human appearance are genetic, others are the result of age or disease, and many are the result of personal adornment.” To this list one could add differences due to disfigurement because of accident or physical harm. With this definition of differences in personal appearance in mind, we will explore the idea of hegemony; and perhaps, our start will be at an unconventional place: Issei, Nisei, Sansei and Executive Order 9066 of February 1942. This discussion will lead us to Mary Mallon, also known as Typhoid Mary.

From this point we will launch into a discussion of leprosy using two reference works: *The Colony* and *No Footprints in the Sand.* The United States maintained for some time two leper colonies: Kalalapapa, Molokai, Hawaii and Carville, Louisiana. There is a genetic predisposition for *Mycobacterium leprae* and it is a disease that can cause severe disfigurement and disability. There are many directions that a seminar discussion could go with this topic; and, here we are at a juncture. We can look at a description of the problem or we can pursue personal narratives by people with the problem… an interesting dilemma.

3) The third goal of the course is to consider the public perception of “not-normal people” through the eyes of the 2009 book titled *The Ugly Laws: Disability in Public.* The City of San Francisco passed Order 783 on July 9, 1867 that stated in Section 3 the following:

“Any person who is diseased, maimed, mutilated, or in any way deformed so as to be an unsightly or disgusting object, or an improper person to be allowed in or on the streets, highways, thoroughfares or public places in the City or County of San Francisco, shall not therein or thereon expose himself or herself to public view.”

What causes a population of people to support and pass Ugly Laws? Perhaps a modern corollary would be why are people so surprised by Susan Boyle’s singing? In a way this goal combines goals one and two: aesthetics and hegemony. If one is not deemed pleasing, then, at best, that person is ignored by the populace. Thus we move into a study of human nature.

4) The fourth goal of the course is to explore a social experiment which is embodied by the Americans with Disabilities Act of 1990 and its amendment of 2008. This thread of the course begins with Otto von Bismarck, who as Chancellor of Germany brought into being in 1889 a National Disability Insurance program. He also created other “modern” social legislation dealing with old age, accident, and health insurance. At this point we go to war. Warring countries ask much of their citizens, including incurring both physical and psychological wounds. Through a combination of guilt/responsibility for wounded war veterans and civil rights/fair play for minority citizens, the United States is exploring some interesting social water with recent ADA legislation and Supreme Court decisions: from Bismarck to Bush in a manner of speaking. As was the case for goal one, there is not specific text for this section of the course. We will start with the Internet and dive deeper.
The four goals of this course can be summarized as single expressions: aesthetics, hegemony, ugly, and ADA. What is the practical articulation of these goals as a seminar course?

**Of Ideals and Ideas.**

Of Note: The First-Year Seminar Program at Trinity is completing its first 25 years. What is a seminar? Wikipedia provides an appropriate description.

The word *seminar* is derived from the Latin word *seminarium*, meaning "seed plot."

*Seminar* is generally a form of academic instruction, either at an academic institution or offered by a commercial or professional organization. It has the function of bringing together small groups for recurring meetings, focusing each time on some particular subject, in which everyone present is requested to actively participate. This is often accomplished through an ongoing Socratic dialogue with a seminar leader or instructor, or through a more formal presentation of research. Normally, participants must not be beginners in the field under discussion (at US universities, seminar classes are generally reserved for upper-class students, although at UK and Australian universities seminars are often used for all years). The idea behind the seminar system is to familiarize students more extensively with the methodology of their chosen subject and also to allow them to interact with examples of the practical problems that always occur during research work. It is essentially a place where assigned readings are discussed, questions can be raised and debates can be conducted. It is relatively informal, at least compared to the lecture system of academic instruction.

Why did the faculty consider a seminar program necessary for all First-Year students? The current faculty approved curricular statement concerning the First-Year Seminar is found below.

The specific requirements for reading, writing, and oral communication must be consistent with the following statement adopted by the General Faculty:

"Major primary works in any of the fields traditionally included in the liberal arts and sciences are assigned for study and discussion in the seminars, which serve both to induct the students into a University-wide intellectual discussion of substantive issues, and to enhance their speaking, writing and bibliographic skills."

Hence, in addition to reading seminal works, each instructor’s requirements for writing and oral communication should constitute a sizeable proportion of the overall course requirements. For example, requiring several small papers (1-2 pages) and a major seminar paper would be quite acceptable. Of course, active oral participation would be expected in any seminar. First Year Seminars should have additional requirements. For example, a few short presentations and one formal presentation would be quite acceptable. Generally, it should be necessary for students to use the library extensively to develop and hone research skills.

Of the various policies for the course adopted by the faculty, I have always favored the one of March 19, 1999.

1) **Goals**: a) To develop ability to weigh evidence, critically evaluate ideas and arguments, and make reasonable judgments; b) To develop ability to generate ideas, create arguments, and think independently; c) To develop research and writing skills; and d) To develop discussion skills.

2) **Assessment guidelines**: a) At least 20 pages of evaluated written work; b) At least one evaluated presentation as well as active participation in informal discussion; c) Required attendance; policy discussed in syllabus; and d) Writing and oral component each must count for at least 30% of grade.
The ideal undergirding the seminar course is for the student to develop approaches (methodology) to formulate quality arguments in the form of discourse both verbal and written. And in this particular section of First-Year Seminar we will attain this ideal by exploring the ideas surrounding disability and deformity. And as I have indicated earlier I trust as we do this we discover something deeper about the sense of the human character.

**Grading for this course is very simple.**

1) 50% of the grade will come from writing (short writing assignments will be announced a week or more in advance of the due date and longer assignments will have two weeks or more notices).

2) 40% of the grade will come from oral presentation and participation in discussions (your oral work may come as a result of a group assignment or individual assignment... you will generally have at least one week to prepare for an oral presentation).

3) 10% of the grade will come from various short assignments (often these are in the form of abstracts of work underway). I am also requiring that you keep a research log.

**Office Hours and Contact:**

CLS 153, X7243, rbleston@trinity.edu

Tuesday and Thursday 1:00 to 3:30 pm; and by appointment.

I strongly encourage you to contact me or the peer tutor, Lauren Holmgren, while working on assignments. These contacts can come as office visits, email, or even Skype. However, don't expect a rapid response in the 24 hours before an assignment is due. Speaking of the peer tutor, a major innovation of the First-Year Seminar program was and is the use of peer tutors. Peer tutors are individuals who demonstrated clarity of thought and quality of assignment when they took the course in a previous semester. I am fortunate that Ms. Holmgren had my course in the fall of 2006 and has served as my peer tutor twice before. She will graduate this May and will enter medical school in the fall. Lauren has my confidence.

In terms of your conduct in the course, the Trinity University Honor Code will be followed. Generally assignments are done individually. I encourage you to discuss your ideas with classmates and have others read your written work for comment before turning it in; however, the work presented must be your own. You must give appropriate attribution for work used in developing your arguments. Take extreme care in developing bibliographies and cited references. You will at several points in the course work within a group structure. I will clearly indicate whether I expect a group report and/or individual comments about an assignment. I encourage you to bring a wireless equipped laptop to class; however, please use the computer in support of the course. Attendance is required. Deadlines are deadlines. Late work is accepted at my discretion. Generally I prefer written assignments in digital format (submit by email) and as either .doc or .docx files.

Disclaimer: This is the first time I have led a seminar with this topic. The texts are new to me as is much of the associated literature. My timing of the various components will be defined and refined as we go along. An approximate schedule (with tentative assignments) follows.
**Part One: Aesthetics**  
Jan 13 to Jan 29 (seven class periods with Jan 18 being MLK day)

Develop an essay that defines what normal means within the body of the idea of aesthetics. Is it possible to define what normal is using numerical methods?

**Part Two: Hegemony**  
Feb 1 to Feb 26 (twelve class periods with Ms. Holmgren leading the seminar on Feb 10 and 12)

Develop two essays: one from the perspective of the majority and the other from the perspective of the minority. Some group work will be involved, as well, involving oral presentation.

**Part Three: Ugly**  
Mar 1 to Mar 26 (nine class periods with Spring Break Mar 15 – 19)

A critical discussion of Susan Schweik’s work. We will probably work in pairs in terms of discussing chapters. An essay will cap this reading and discussion. Is it possible to legislate what ugly is? Can disableness or ugliness be sufficient to be declared a public nuisance?

**Part Four: ADA**  
Mar 29 to Apr 23 (eleven class periods with Apr 2 being Good Friday)

How does Bismarck’s motivation for public regulation of disability compare to US motivation for public regulation of disability? Everyone will give a formal oral presentation for this section. Our goal will be to define a broad topic with everyone contributing to the exploration of that topic with specific examples. A formal compendium should result from our collective effort (in other words, a collection of focused essays).

**Part Five: Summary**  
Apr 26 to Apr 30 (three class periods)

This week will be used to support a final and major term paper. The focus for the final work will be determined by where we think we have come during the semester.

**Part Six: Conclusion**  
Apr 30 – Course Evals; May 3 – Reading Day; May 11 - Final

It is doubtful that we will have a final; however, the date may serve as a deadline for the very last essay/final paper. That eventuality will be defined sometime in mid April.

Tally (subject to some variation): six essays of varying length; one formal discussion; and one formal presentation. A research notebook, a possible compendium, and active participation in class discussions accompany the more formal activities listed.
Websites of Interest for GNED 1300-01 - Spring 2010

1) [http://www.smithsonianmag.com/history-archaeology/10023711.html](http://www.smithsonianmag.com/history-archaeology/10023711.html)

   From the Feb 2007 Smithsonian magazine, an article describing the creation of facemasks for disfigured WWI soldiers.

2) [http://www.stanford.edu/group/parasites/ParaSites2005/Leprosy/index.htm](http://www.stanford.edu/group/parasites/ParaSites2005/Leprosy/index.htm)

   From a course in parasitology at Stanford, an information rich resource on Hansen’s disease that deals with the biology and public health issues of Leprosy.


   A very general piece, not well-edited or referenced, but it does give a good organizational starting point on physical appearance. It raises some critical issues associated with physical appearance including body image, Eigenface, and erotic capital.


   An interesting starting point concerning hegemony and it does cite Susan Schweik.

5) [http://homepage.psy.utexas.edu/homepage/group/LangloisLAB/morph2faces.html](http://homepage.psy.utexas.edu/homepage/group/LangloisLAB/morph2faces.html)

   What is koinophilia? This is a social development research lab website from UT Austin that shows facial averaging examples. It is fun to walk through and something we could do if we wanted. Perhaps we should arrange a field trip or invite the professor down here?

6) [http://www.pbs.org/wgbh/nova/typhoid/](http://www.pbs.org/wgbh/nova/typhoid/)

   Who was “The Most Dangerous Woman in America?” Mary Mallon was the subject of a PBS Nova special (Oct. 12, 2004). I am arranging for the purchase of the DVD.

7) [http://www.youtube.com/watch?v=UYAKQvEmc2w&feature=related](http://www.youtube.com/watch?v=UYAKQvEmc2w&feature=related) and [http://www.youtube.com/watch?v=g4Wa--rrdZM&NR=1](http://www.youtube.com/watch?v=g4Wa--rrdZM&NR=1)

   The two-part 16-minute video reviews the events leading to the Americans with Disabilities Act of 1990 (ADA) as led by Senator Edward Kennedy. It has an interview with Kennedy.


   An interesting presentation of ADA is found at this Wikipedia site. One might ask how accurate the information is and is it biased? It lists the five parts of the ADA legislation and provides some very useful links, especially for government ADA documents and court cases. You should spend some time here.
**Texts for the Seminar Course:**


The following book is not required but it does explore disability in a most unusual way. I was disturbed when I read it; but, it did introduce me to a genre of subject material for which I had no experience (homosexual experiences).


Kenny Fries was born with a congenital problem: “deformities of the lower extremities.” He has no fibulae and is also missing several toes and some leg muscle. He wears very special shoes in order to walk. He is about three inches shorter than the rest of his body suggests. Fries juxtaposes his struggle for survival of the fittest with Darwin and Russell’s history of evolution. So far so good and quite novel and interesting. But Fries is openly gay and writes about his sexual experiences in conjunction with his physical maladies. So it is a very personal narrative of a gay man with a severe physical disability who views himself within the concept of the survival of the fittest. It is not required reading for this course.