



DISABILITY AND BIOETHICS

Ethics: Autonomy & Health (Spring 2014)

Laura Guidry-Grimes



FIRST-PERSON PERSPECTIVES

- ▶ [Aimee Mullins on TEDTalks](#)
- ▶ What are some ways in which stereotypes or misperception of disability can negatively affect disabled individuals' identities and opportunities for autonomous agency?
- ▶ What are some of the small-scale and large-scale barriers to well-being that impaired individuals generally face in today's society?



WHAT IS ABLEISM?

- ▶ **Ableism**: discrimination against, disregard for, or oppression against those who are viewed as disabled or physically/mentally “abnormal”
 - ▶ Relies on assumption that impairment is a defect, rather than a dimension of difference
 - ▶ Related to **able-bodied and able-minded biases**
- ▶ **Erroneous assumptions behind ableism***:
 - 1) Chronic illness or disability precludes possibility of happiness, well-being
 - 2) If a disabled person experiences isolation, powerlessness, poverty, unemployment, or low social status, these are inevitable consequences of biological limitation

DISABILITY & IMPAIRMENT

- ▶ **Impairment**: “associated with a particular medical condition, which may (or may not) lead to a disability, with a disability being associated with various social and political restrictions” (Smith 18)
 - ▶ Can be associated with talents, benefits
- ▶ **Union of the Physically Impaired Against Segregation**:
 - ▶ “Disability is the loss or limitation of opportunities to take part in the normal life of community on an equal level with others due to physical and social barriers” (qtd. in Smith 19)
- ▶ **World Health Organization**
 - ▶ “an identifiable variation of human functions” with three dimensions: “impairments, activity limitations and participation restrictions” (qtd. in Ells 599)



MODELS OF DISABILITY*

	<i>Interpretation</i>	<i>Understanding of Disability/Disorder</i>
<i>Medical/Biological Models</i>	full-essentialist individual deficiency interpretation (FEID)	Disability is caused by fixed medical characteristics that inevitably prelude a life of deficiency and 'abnormality'.
	part-essentialist individual deficiency interpretation (PEID)	Whilst disability is caused by the above medical characteristics, these can be partially alleviated by changes in the social environment, so as to enable some degree of 'normal living'.
<i>Social Models</i>	politics of disablement interpretation (POD)	Disability is caused by social practices that systematically exclude impaired people from the activities of 'normal citizenship'.
	social construction of disablement interpretation (SCOD)	Disability is caused by the way impairments are defined and associated with characteristics that are necessarily assumed to have a negative impact on personal identity, development, and fulfillment.

TENSION BETWEEN BIOETHICISTS AND DISABILITY ADVOCATES

▶ **Overlapping concerns**

- ▶ **Critiques of medical paternalism**
- ▶ **Empowering patients and expanding conceptions of autonomy**
- ▶ **Calls for social justice, improved access to care**

▶ **Divergence**

- ▶ **Questioning patient choice re: impairment**
- ▶ **In dominant bioethical literature, failures to acknowledge that poor quality of life is not inherent in disabilities “but instead could result from the social arrangements facing people living with such conditions” (Asch 299)**



DECISION-MAKING WHEN DISABLED

- ▶ **Free, voluntary, informed decision-making should be respected, but...**
- ▶ **In case of prospective disability: Cannot easily imagine oneself or others as disabled when life plans and expectations have revolved around assumption of able-bodied condition**
- ▶ **In case of chronic or permanent disability: “have experienced constant discrimination, denials of information about life possibilities, inability to obtain legally available services and supports, and often abandonment by family and friends” (Asch 312)**
- ▶ **How can a physician or clinical ethicist respond to these issues when (e.g.) a patient with a disability wants treatment withdrawn?**



DECISION-MAKING WHEN DISABLED

- ▶ **Conflicting ideological strands among disability advocates:**
 - ▶ Emphasize **similarities** between disabled and non-disabled
 - ▶ → advocate for equal treatment (e.g., in favor of PAS)
 - ▶ → stress autonomous capacities of disabled, advocate for more choices
 - ▶ Emphasize **division in social arrangements** for disabled and non-disabled
 - ▶ → advocate for equal recognition and societal reforms (e.g., against PAS until reforms in place)
 - ▶ → stress threats to autonomous decision-making, advocate for decreased barriers and vulnerability



AUTONOMY EMBODIED & SOCIALLY EMBEDDED

- ▶ Experiences of the self tied to the body, what can be achieved physically (and mentally) through this body
- ▶ “Where professionals ‘tend to define independence in terms of self-care activities,’ people with disabilities tend to define it ‘as an ability to be in control of and make decisions about one’s life’” (Ells 602)
- ▶ Embodiment, interdependence, and interconnectedness as significant to the self
 - ▶ For all people, but especially evident in cases of disability



AUTONOMOUS CAPACITY WHEN DISABLED

- ▶ **'Autonomy' implies having authority AND control**
 - ▶ Inability to act on decisions → false impression that the individual does not have the authority to make decisions
 - ▶ Lack of control sometimes attributable to impairment, usually attributable to lack of social arrangements
 - ▶ “Control is something to be negotiated with other valued features of one’s life” (Ells 607)
- ▶ Respecting autonomy involves **opening up possibilities, broadening how we perceive autonomous decisions, improving access and minimizing barriers**



DISCUSSION QUESTIONS

- ▶ **Consider the case of Elizabeth Bouvia. Do you think her wish to starve herself to death while sedated should be respected by her physicians?**
- ▶ **What are some problems with the extreme versions of the medical/biological model and the social model of disability?**
- ▶ **Do you think that oppressive able-bodied norms and social arrangements threaten the autonomy and authentic identity of disabled persons?**
 - ▶ **How should awareness of ableism shape hospital policies or practices?**
- ▶ **Based on your readings so far this semester, do you agree that there is a deep tension between bioethicists and disability advocates?**



ADDITIONAL MATERIALS

- ▶ Smith, Steven R. "Social Justice and Disability: Competing Interpretations of the Medical and Social Models". *Arguing about Disability: Philosophical Perspectives*. Eds. Kristjana Kristiansen, Simo Vehmas, and Tom Shakespeare. New York: Routledge, 2009. 15-29.
- ▶ "What Is Ableism? Five Things about Ableism You Should Know." *Feminists with Disabilities*:
<http://disabledfeminists.com/2010/11/19/what-is-ableism-five-things-about-ableism-you-should-know>





QUESTIONS? COMMENTS?

