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Learning Activity 1: Defining Healthy People & Environments **Disease, Disability, & Immortality: Hope & Hype Module** *by Katayoun Chamany & Adrienne Asch Updated July 2017*

The World Health Organization defined health in 1946 as the “state of complete, physical, mental, social well-being and not merely the absence of disease or infirmity. One year prior, Vannevar Bush, Director of the United States (US) Office of Scientific Research and Development, proposed the establishment of a structure and funding mechanism (National Science Foundation) to support basic science and biomedical research in an effort to boost economic and social capital.

The rewards of such exploration both for the Nation and the individual are great. Scientific progress is one essential key to our security as a nation, to our better health, to more jobs, to a higher standard of living, and to our cultural progress. (Bush, 1945)

In the aftermath of WWII countries convened in Paris in 1948 to draft the Universal Declaration of Human Rights and included health as a right, and later, during the 1970s, health was addressed in the International Covenant of Economic, Social, and Cultural Rights (ICESCR). During this period, social justice activists agreed that health equity is achieved when each person has the opportunity to attain their full health potential and is not disadvantaged from achieving this potential due to social position or other socially determined circumstances. This concern was taken up by the emergence of the social model for disability wherein those living with disability were viewed as an oppressed group. The model in the United Kingdom distinguishes the impairments that people have from the oppression they experience, and defines “disability” as the social oppression, not the form of impairment. Whereas the social approach to defining disability in the United States stops short of this distinction, and instead views those that ‘live with disability’ as members of a minority group.

These views led to a number of initiatives to support healthy people and healthy environments, including more recently, *Healthy People 2020* led by the Centers of Disease Control and the Sustainability Development Goals adopted by United Nation (UN) member states. Additionally, several covenants, put forth by the UN in its role as a quasi-governmental body, have sought to reduce health disparities for the most vulnerable, including women and children. However, the [Convention of the Rights of Persons with Disabilities](#) has not been ratified by the US. With respect to disability rights in the US, the passage of the Americans with Disabilities Act (ADA) in 1990 and other laws are designed to provide benefits in the form of financial support, work opportunities, and home healthcare to those who live with disability. In the UK, the distinction between (biological) impairment and (social) disability resulted in protections and rights emerging through the equal opportunities and race relations laws.

Returning to an earlier definition proposed by George Canguilhem in 1943, in which health is defined as the ability to adapt to one’s environment, we are reminded that health is a dynamic state of being. All humans at some point in their lives, experience disability, either through injury or age-associated degeneration. How then can society promote health?

Some may argue that we should invest in the development of diagnostics, preventions, and treatments targeting the person using the biomedical model of health. Others argue that a more immediate and useful approach would be to invest in the development of adaptive technologies, design, and social policies that

target our environments. While still others argue that we should use a combination of the biomedical and the social models to support healthy communities and the development of healthy environments that address the natural variation in the human population.

The following resources offer a glimpse of political engagement regarding investment in these models, their focus on either social or economic capital, and the possibility that an investment in stem cell research focused on cure will further discriminate those that live with disease and/or disability.

At the completion of this activity you will be able to:

- Recognize the difference between the biomedical and social models of health and the ways that the medical advocacy and the disability rights movements align with these models
- Consider the historical context that led to an investment in biomedical research for “cures” and generate a set of comments and questions regarding its impact on society
- Generate questions about the types of disease and disability that could be best addressed by either the biomedical or social model of health
- Explain how autonomy, agency, exploitation, and labor are involved in disability rights and justice.
- Explain why states are investing in stem cell research using public monies
- Distinguish between different sectors, public and private, and identify ways in which they are interdependent.
- Recognize the influence that advances in basic science, law, business, human rights, and medicine can have on one another and how this informs an address of social problems.
- Provide two lines of evidence, or reasoning, to support or dismantle the funding of stem cell research
- Provide two lines of evidence, or reasoning, to support the development of policies and structures that allow for democratic deliberation regarding the allocation of state or federal funds for different kinds of research and social support

To ground the activity you will read the letter exchange between President Franklin D. Roosevelt and Vannevar Bush that led to release of the *Science: The Endless Frontier* report. As further context, the article authored by Stein suggests that society’s preoccupation with the eugenics movement in the 1930s and 40s contributed to the president’s choice to hide his disability acquired through polio infection. The chapter on public health resource allocation provides a contemporary view on social values. The *Lancet* editorial circles back to the history of defining health while the two TEDx talk excerpts (0-6:00min; 19:00-21:00min) point to the future.

1. **Letters and Summary of Report:** Bush, V. 1945. *Science: The Endless Frontier*. [Link](#)
2. **Article:** Stein, S. Spring 2004. The president’s two bodies: Stagings and restagings of FDR and The New Deal politic. *American Art*. 18(1):32-57. [Link](#)
3. **Book Chapter:** Garland, M., & Stull, J.2003. Module 9: Public Health and Health Systems Reform: Access Priority Setting and Allocation of Resources. In B. Jennings, et al. (Eds.), *Ethics and Public Health. Model Curriculum* (pp. 241-251.) Association of the Schools of Public Health, The Health Resources and Service Administration and the Hastings Institute. [Link](#)
4. **Editorial:** Anonymous. 2009. What is health? The ability to adapt. *The Lancet*. 373(9666):781. [Link](#)
5. **TedX Video:** Benajmin, R. Jan 2015. From Park Bench to Lab Bench- What Kind of Future Are We Designing? TedXBaltimore. [Link](#) (time stamps 0-6:00min and 19:00-21:00min)

Additionally, you may be assigned to review all the resources below, or your class may be split in half and those with a last name beginning with A-M will read the even-numbered resources while those with last names beginning with N- Z will read the odd-numbered resources. Read the resources assigned and generate a list of comments and questions for discussion. Some questions to consider as you review the resources follow:

1. What kind of document, product, or publication is this?
2. When was this published or showcased and where? Who is the author/creator? What is their bias?
3. Who is the audience? What is its purpose?
4. What do you know? What is the take away message?
5. Which model (s), biomedical and/or social, does the resource support and/or challenge?
6. What do you need to know? What questions does it prompt you to ask?
7. What was the most surprising, interesting, or shocking aspect of your piece?
8. Where does our knowledge of disability come from?
9. What information might we need to understand how people live with disabilities?
10. Do people attribute problems to their physical and behavioral characteristics, to the social environment, or to the interaction of body and environment?

Part 1: Disability, Diversity, Discrimination, & Justice

1. **Article:** Scotch, R. K., & Schriener, K. 1997. The Americans with Disabilities Act: Social Contract or Special Privilege?: Disability as human variation: Implications for policy. *Annals of the American Academy of Political and Social Science*. 549 (1):148-159. [Link](#)
2. **Blog Post:** Linton, S. 1998. "Reassigning Meaning" In *Claiming Disability. Knowledge and Identity*. New York University Press. 8-17 as seen on the *Disability History Museum*. [Link](#)
3. **Blog Post:** Baynton, D. 2001. "Language Matters: Handicapping an Affliction" In Radio Series titled *Beyond Affliction* on NPR by Laurie Block, on the *Disability History Museum*. (1 p) [Link](#)
4. **Article:** Wilson, J. 2003. Evolving metaphors of disease in postgenomic science: Stigmatizing disability. *Rhetoric Review*. 22(2):197-202. [Link](#)
5. **Feature:** Johnson, H. Feb 16, 2003. Unspeakable Conversations. *New York Times Magazine*. ~10p. [Link](#)
6. **Research Article:** Hahn, H. & Belt, T. 2004. Disability identity and attitudes toward cure in a sample of disabled activists. *Journal of Health and Social Behavior*.45:453--464. [Link](#)
7. **Historical Feature:** Brignell, V. Dec 10, 2010. The Eugenics Movement Britain wants to Forget. *New Statesman*. [Link](#) (audio available at website; 2 ½ pages)
8. **Historical Feature:** Brignell, V. Dec 10, 2010. When America Believed in Eugenics. *New Statesman*. [Link](#) (audio available at website; 3 1/2 pages)
9. **News:** Adams, R. 2011. Bring Down the Barriers--Seen and Unseen. *The Chronicle of Higher Education*. [Link](#)
10. **News:** Davis, L. 2011. Why is Disability Missing from the Discourse on Diversity? *The Chronicle of Higher Education*. [Link](#)
11. **News:** Rich, M, April 6, 2011. Disabled, but Looking for Work. *New York Times*: B1. [Link](#)
12. **Blog Post:** AbilityOne.gov History. [Link](#). *Wagner-O'Day Act passed by FDR in 1938*
13. **Article:** Quackenbush, N. 2011. Speaking of-and as-stigma: Performativity and Parkinson's in the rhetoric of Michael J. Fox. *Disability Studies Quarterly*. 31 (3): (~10 pages) [Link](#)
14. **Opinion:** Nee'man, A. Dec 30, 2015. Screening sperm donors for autism? As an autistic person I know that's the road to eugenics. *The Guardian*. [Link](#) (2 pages)

Part 2: Resource Allocation for Biomedical & Social Models of Health

1. **Video:** Klein, Bob. Aug 20, 2015. Progress Report on the Milestones to Cures. Americans for Cures. [Video Link](#) (18:33 min)
2. **News:** Siders, J. et al. Jan 9, 2015. California Budget Plan Stays Largely Same for Health, Social Services. *Sacbee.com* [Link](#)
3. **News:** Low, C. Jan 12, 2016. Cutting Disabled People's Benefit Will Make it Harder for Them to Find Work. *The Guardian*. [Link](#)
4. **News:** Pear, R. July 22, 2015. Disability Benefits Face Cuts in 2016, Trustees Say. *New York Times*: A15. [Link](#)
5. **News:** Georgia Institute of Technology. Feb 18, 2015. State Funding Boosts Stem Cell Research in California, Other States. *ScienceDaily.com*. [Link](#)
6. **News:** Gugliotta, G. Nov 9, 2015. Why Many States Now Have Stem Cell Research Programs. Kaiser Health News. *Governing.com*. [Link](#)